Copyright is owned by the Author of the thesis. Permission is given for a copy to be downloaded by an individual for the purpose of research and private study only. The thesis may not be reproduced elsewhere without the permission of the Author.

It “Made a Huge Difference when he had a Dry Bed in the Morning”: Impacts of Dementia-Related Incontinence on Informal Carers Sleep, Health, and Quality of Life

A thesis presented in partial fulfilment of the requirements for the degree of

Master of Science

In

Health Psychology

At Massey University, Palmerston North, New Zealand

Jaime Fearn

2022

Abstract

Incontinence is increasingly recognised as a symptom of dementia and is more common at night, having repercussions for the sleep status of people with dementia and their informal carers. This is important as sleep disruptions can exacerbate some of the waking symptoms of dementia, as well as affect the carers capacity to care, influencing their health, wellbeing, and quality of life. Despite this, the person-centred experience of informal carers managing dementia-related incontinence and the subsequent impacts is largely underrepresented. Thematic analysis was used on continence-related comments within responses from 526 carers participating in a confidential sleep survey. Further narrative assessment was used on relevant follow-up interview data provided by a pool of 20 carers recruited from the initial survey. Basic and global themes concerning continence in relation to the sleeping and waking lives of informal carers and those they support will be presented, alongside overarching narratives of sleep and caregiving. These include content concerning the progressive changes to toileting needs and sleep disruptions with ageing and dementia-related decline; incontinence and its management creating a significant issue for sleeping and waking life; and how incontinence ultimately impacts carers quality of life and ability to cope. This thesis illustrates how incontinence can have a profound impact on sleep and wellbeing within dementia care, having the potential to jeopardise the overall informal care situation. Findings will inform future research on continence, sleep, and ageing within dementia care, as well as strategies for supporting those affected by dementia. In particular, the findings will be used to inform the co-production of a core outcome set within a wider research programme that comprises appropriate quality indicators for people living with dementia, their caregivers, and whānau, so that good continence care can be measured in future complex interventions, and carers have better access to education and support which enables them to continue their role safely and effectively.

Acknowledgements

Firstly, I’d like to thank my wonderful supervisor Dr Rosie Gibson for allowing me the opportunity to come on board and become part of this incredible research project and learning opportunity. You were always right there with support, encouragement, and guidance; and your depth of knowledge and experience in the field was a constant source of reassurance and inspiration for me. Thank you for sharing your ‘baby’ with me, and for introducing me to the wider research team - such an amazing bunch of people adding so much to the field of dementia, sleep, incontinence, and ageing research.

To my amazing Mum (Granny) and Grandad, thank you for all the many and various ways you support me, and for always bringing me back down to earth with your realistic and sensical minds. Mum, you will always be my go-to for wise and honest advice and guidance. Words really don’t even begin to describe how grateful I am for everything. Thank you and I love you both.

To my ride or die Angelique, we met at the very beginning of our study journeys all those years ago. So much has changed in that time, but one thing that never will is how much I love and appreciate you, and how much I *need* our daily phone calls. I could never do life without you. Thank you for always being there and for reminding me that I can and will get through this. We got this.

To my darling Shaun, thank you for your constant love, understanding, encouragement, and support; for always believing in me and building me up when I need it most; for taking the kids out so I could focus on study; and for all the reassuring hugs and kisses along the way. I see you; I respect you, and I love you. Always and forever.

To my beautiful daughter Bella, who up until this point in her life has only ever known me as a student. I promise I will be finished studying one day and it will all be worth it. Thank you for understanding how important study is to me, and for always believing in me. Remember nothing worth having comes easy, you have to put the hard work in. Never stop reaching for your dreams and

always believe in yourself the way I believe in you. Thank you for being you, and for teaching me so much about myself. I love you to the moon and back.

Lastly, but certainly not least, to the participants who openly and courageously shared their stories and experiences with us, thank you from the bottom of my heart. This research would not be possible without you, and I hope by you sharing your experiences that future education and support can become available to other informal carers in similar situations. I hope I was able to capture the true essence of your experiences and honour your unique journeys. Thank you again for making this project possible.

Table of Contents

Table of Tables

Table of Appendices

Glossary

Term	**Definition**
Care recipient	An individual receiving care from a caregiver
Continence	The name for what is commonly referred to as toileting
Dementia	The overarching term for a series of physical, behavioural, and cognitive symptoms related to the deterioration of normal brain functioning
Faecal Incontinence	The involuntary loss of solid or liquid faeces
Formal Carer	An individual who cares for others within an organisation or health care institution
HRC	The Health Research Council of New Zealand is a crown owned agency that guides and funds health-related research in New Zealand
Informal/Family Carer	Unpaid relatives or friends, often close family members providing in-home caregiving support
Urinary Incontinence	The involuntary loss of urine
WHO	The World Health Organization (WHO) is a specialised agency of the United Nations responsible for global public health

Chapter One: Introduction

Myself as Researcher

I am a mother, partner, daughter, and granddaughter, who has lived with several chronic health conditions since 2010 when I experienced a life-altering health event which changed my life, and more specifically the direction of my career towards the field of health psychology. Since then, I have had my own daughter, and we now share a home with my partner and his two children. I have worked as a community support worker for several years, and through this I have gained first hand insight into the challenges faced by people living in the community with serious illness.

I was also involved in caring for my grandmother who lived with several life-limiting health conditions which meant she needed support from multiple sources including family (myself, my mother, my aunty and my two cousins), caregivers, district health nurses, doctors, and specialists. Throughout this time, we as a family experienced significant stress, disappointment, fear and above all else, heartache, which stemmed from watching our loved one struggle to live each day while experiencing physical pain alongside the loss of her pride and independence. These experiences have all helped to shape my understanding of what it’s like to live with life-limiting health conditions, and they have also highlighted the importance of the collaboration that’s needed to effectively support someone living with serious illness in the community.

Maintaining Health and Wellbeing

Maintaining good health and wellbeing throughout the course of our lifespan has been associated with higher rates of life satisfaction, and better overall quality of life (Jadhav et al., 2021). Thus, the importance of bringing to light and creating awareness around some of the pertinent social, behavioural, and environmental factors that directly impact individual and community health is critical for empowering individuals and communities to think and behave in ways which are supportive of health promotion for all (McMurray & Clendon, 2014).

Maintaining and even improving aspects of our health is of particular importance as we age, whereby our body begins to physically deteriorate, which is caused by changes to the bones, muscles, skin, cells, and blood vessels (Prerost, 2019). The brain is also significantly affected by deterioration related to physical atrophy and reduced neural activity, resulting in sensory and memory loss, as well as the loss of perception and spatial awareness (Prerost, 2019). These normal degenerative consequences of ageing can be further exacerbated by certain health conditions and diseases, such as dementia. The detrimental and progressive symptoms of dementia increase the rate of deterioration within the brain, adding another layer of physical and cognitive impairment for the individual affected. Moreover, dementia-related brain deterioration often occurs in individuals who have already started to experience some of the natural consequences of aging by the time they become impacted by this disease, making the impacts of dementia even more challenging, not only for the affected individual, but for their caregivers, family, and wider support systems (Prerost, 2019).

Dementia: An Overview

Dementia is a prominent health issue which has seen a huge rise in the number of cases globally due to the rapidly increasing age of the population, including an overall higher number of older adults as compared to other age brackets (Alzheimer's New Zealand, 2020). Dementia is the overarching term for a series of physical and cognitive symptoms related to the deterioration of normal brain functioning (Neurological Foundation, 2019). According to the World Health Organisation (WHO) "Dementia is an umbrella term for several diseases affecting memory, other cognitive abilities and behaviour that interfere significantly with a person's ability to maintain their activities of daily living" (WHO, 2022, para. 1). There are many types of dementia, with Alzheimer's Disease being the most common. Dementia is not a normal part of ageing, even though age is one of the strongest risk factors for developing the disease (WHO, 2022).

Globally, dementia affects approximately 55 million people (WHO, 2022). In New Zealand there are presently around 70,000 people living with dementia, with that number expected to more than double over the next 20 years (Krishnamurthi et al., 2022). Although WHO uses the word ‘disease’ to describe dementia, it is probably more accurate to describe it as a series of symptoms and behaviours that occur due to the impairment of neurological functioning within the brain (Innes et al., 2020).

Obtaining a diagnosis of what was previously termed dementia but is now clinically referred to as major or mild neurocognitive disorder can be a rather complicated and lengthily process (American Psychiatric Association, 2013). The new term for dementia ‘neurocognition’ can be loosely translated as ‘brain’ and ‘thinking’. This more fitting term was chosen due to the neurological disruptions that occur in the brain which cause subsequent changes to the processes involved in thinking and memory (Dementia Australia, 2022), as well as social and behavioural changes that occur as the disease progresses (Alzheimer’s New Zealand, 2022). Given the demographic and language used within the majority of literature and data the term ‘dementia’ will be used to describe this condition throughout this thesis.

Due to the number of older adults currently making up a significant portion of New Zealand’s population, dementia has become a significant public health issue that requires serious attention (Alzheimer’s New Zealand, 2020). There are many forms of the disease, with Alzheimer’s Disease being the most prominent form of dementia seen in New Zealand, followed by Vascular Dementia (The Neurological Foundation, 2019). People can also have a mixture of dementia causes and symptoms, including other common types such as frontotemporal dementia and dementia with Lewy Bodies, to name a few (Ministry of Health, 2021).

Although not part of the normal ageing process, dementia is a progressive condition which is more likely to develop later in life, particularly after the age of 65, hence the increasing occurrence of the disease alongside an ageing population (Alzheimer’s NZ, 2022). People experience dementia symptoms in different ways and to varying degrees (Alzheimer's NZ, 2022), and dementia does not discriminate across ethnicity or socioeconomic status (WHO, 2021). Some of the key areas affected by dementia include cognition, memory, emotions, sleep, behaviour, and personality (Alzheimer's NZ, 2022).

It is common for individuals with dementia to experience memory loss, loss of reasoning skills, impaired language skills, and an overall reduction in the ability to perform usual everyday living activities (Ministry of Health, 2021). The impacts of this condition are far reaching, as there are implications beyond the individual, including changes to family life, relationships, social settings, and extending to almost all other areas of society (Ministry of Health, 2021).

Carers Sleep, Health, and Wellbeing

The positive association between good health and wellbeing, and quality sleep has been thoroughly researched within the fields of health and psychology. It is now well understood that sleep is an essential human necessity which directly impacts an individual's health, wellbeing, emotional state, and overall quality of life (Jadhav et al., 2021). It is also well known that less than optimal sleep is associated with the development of many illnesses and diseases, or in the very least lack of sleep poses an increased risk of developing various forms of illness and disease (Peterson et al., 2018).

Despite the amount of research on sleep and health, a large proportion of what is known is based on sleep duration, that is, the amount of sleep achieved, rather than the quality of that sleep and the subsequent associations with health and wellbeing. This is surprising considering the consensus that quality sleep is important for optimal human functioning. In fact, quality sleep can be described as an essential ingredient for repairing the body and the mind; and there is also growing awareness that lack of quality sleep can significantly compromise one's overall health and wellbeing (Lee & Lawson, 2021).

Lack of quality restorative sleep is a significant issue for the people who choose to care for their friends or relatives with dementia, allowing them to remain in their own homes for longer.

These people are known as informal or family carers. Informal/family carers are unpaid friends or relatives, often close family members and most commonly a spouse (Gibson et al., 2020). Changes to sleep timing and sleep quality occurs in response to sleep disturbances associated with the demands of caring, leading to a reduction in the amount and quality of sleep carers are able to achieve each night (Gibson et al., 2020).

The Impacts of Managing Incontinence

Incontinence is known as a health condition that impacts home-dwelling adults with dementia as well as their informal carers and wider support systems (Talley et al., 2021). Due to the nature of dementia symptoms which stem from cognitive decline, people with dementia have been identified as more likely to have issues managing their continence, which has been found to be extremely daunting and create feelings of shame and embarrassment, as well as negatively influence their self-esteem and sense of dignity (Payne, 2020). Issues with continence are also more common at night, which can impact sleep and increase some of the waking symptoms of dementia (Gibson et al., 2020).

Further concern for caregivers involves the significant deprivation of quality and restorative sleep that is caused by frequent sleep disruptions due to managing incontinence around the clock. The importance of achieving adequate quality sleep will be discussed later on in this section, including the significance of quality sleep for optimal health, wellbeing, and quality of life (Lee & Lawson, 2021), as will the impacts of managing dementia-related incontinence which adds further stress to an already overwhelmed and sleep deprived informal carer (Payne, 2020).

Jerez-Roig et al. (2019), suggest that incontinence is among the biggest predicting factor of functional decline among people living with dementia, even more so than hospitalisation. People living with dementia often indicate a preference to being able to stay in their own home, and it has also been shown to provide them with a sense of connection and familiarity, which positively influences their wellbeing and overall quality of life (Smith et al., 2021). Supporting people living with dementia to remain in their own homes for as long as possible is one of the main aims of informal carers. To do this, they require proper education and support so that they can not only care for their care recipient, but also have the capacity to maintain their own health and wellbeing.

Carers in formal settings such as residential aged care facilities would typically have more training, experiences, and resources helping care recipients manage continence and/or incontinence, however, for informal carers this aspect of care can be unfamiliar and unnerving, particularly if they have never been exposed to incontinence before (Payne, 2020). Often, informal carers have no training, and minimal support in terms of managing continence and/or incontinence and will only get advice from District Health Nurses or other nurses at their local general practice or hospital. This can be incredibly stressful for carers, who may find that dealing with incontinence goes beyond what they can comfortably manage and cope with (Payne, 2020).

New Zealand research by Schluter et al. (2016), revealed that urinary incontinence is an independent risk factor for admittance into residential aged care. The researcher's conducted a study that involved risk assessment testing of 44,460 individuals aged 65 years and above living in their own homes. Of this number, 32, 285 were eligible to participate in the study, with the average age of participants being 82 years old. The results of particular interest were that individuals who identified as having incontinence issues living with non-relatives had a much higher rate of admission to aged residential care and subsequent death, as compared to individuals living with family members (Schluter et al., 2016). These results add further evidence that informal carers are invaluable in supporting people to live well with dementia in their own homes, and that sleep disturbances combined with managing incontinence has the potential to cause significant stress for carers, which can negatively affect their health, wellbeing, and overall quality of life, and also has the potential to jeopardise the overall caregiving situation.

Despite the significant impact that managing dementia-related incontinence has on the sleep, health, wellbeing, and overall quality of life of informal carers, incontinence management is still one area that remains largely under researched within an in-home dementia care setting. This could partially be contributed to the social stigma surrounding sensitive topics such as incontinence as they may bring about feelings of shame and embarrassment. As such, this thesis aims to explore how carers experience the impacts of managing incontinence in the setting of in-home informal dementia care, and how managing dementia-related incontinence affects them in terms of their sleep, health, wellbeing, and overall quality of life.

Chapter Two: Literature Review

Literature Review Introduction

This chapter will begin by briefly exploring some of the key understandings of dementia throughout history and up until the present day. It will then introduce the concept of ‘living well with dementia’ and outline the important components of sleep and the importance of quality sleep for optimal health and wellbeing, particularly in the setting of informal caregiving. The challenges involved in managing continence and incontinence within dementia care will be presented, including how areas of the carers’ health, wellbeing and quality of life may be affected. Ageing and sleep will also be discussed, including how dementia care has the potential to significantly impact sleep which compounds issues the carer may have in regard to their health, wellbeing, and overall quality of life. The wider sleep study that pre-empted this thesis will also be discussed, including some of the pertinent findings from the completed studies thus far (Gibson & Gander, 2021; Gibson et al., 2020). This chapter will also explain the role that stress plays within the caregiver role, and the importance of education and support for caregivers. Moreover, some of the social stigmas and barriers involved in carers seeking out and engaging in such support will be discussed, as a way to provide context and to broaden the understandings of some of the wider social issues at play.

The ways in which carers sleep, health, and wellbeing is impacted by the overall caregiver situation will also be presented, including how sleep disturbances, and managing dementia-related incontinence poses unique challenges which are significantly under researched, despite likely jeopardising the sleeping and waking health of carers and those they support, which eventually erodes their ability to cope and has implications for the overall caregiving situation.

Lastly, the concept and importance of ‘caring for the carer’ will be presented alongside how these research findings enrich the pool of knowledge on health, sleep, ageing, and caregiving in the setting of dementia; and ultimately how this research can contribute to richer understandings, and the development of educational tools and support for carers and those they support.

Dementia: Understandings Throughout History

The way dementia is understood today is quite different to how it has been conceptualised throughout history. In the 18th century for example, dementia was thought to be a reversable cognitive aliment alongside delusions and hallucinations that could affect individuals of any age (Vatanabe et al., 2019). Later on in the 18th century dementia was first classed as one of five different types of mental disorders by French physician Philippe Pinel (1745-1826). Pinel was also the first to connect age with the symptoms of dementia, coming up with the term 'démence senile' (Vatanabe et al., 2019).

By the 19th century, dementia was understood to be a disease of organic origin, that is, a disease which was exclusively defined by biochemical and physiological changes within the body; rather than that of a non-organic disease classified as affecting other areas of human functioning, such as psychological, social, and behavioural functioning (Bratfos, 1990). During this time in history, dementia was also understood as being an illness of insanity, with medical professionals believing that dementia was the final and fatal stage of the disease progression (Vatanabe et al., 2019).

By the 20th century, understandings of dementia had progressed to being that of a cognitive disorder, with German Berrios (1940) coining the phrase 'cognitive paradigm' which significantly narrowed the clinical diagnosis of dementia to involving cognitive processes only, with memory being the main indicator for the disease's presence (Vatanabe et al., 2019). Shortly after this time Alzheimer's disease was first identified by German neurologist Alois Alzheimer in a 51-year-old female who suffered from cognitive issues such as memory loss, delirium, disorientation, and anxiety, which caused her to be increasingly limited in terms of partaking in her usual daily activities (Vatanabe et al., 2019). After the woman's death, Alois Alzheimer was able to identify changes in the structures of her brain that were linked to her cognitive ailments, thus marking the remarkable discovery of Alzheimer's disease, which went on to inspire immense changes in the ways the various forms of dementia were understood (Vatanabe et al., 2019).

Dementia Today

Fast forward to the 21st century, and the way we understand dementia today is increasingly multifaceted. An online study, known as the Delphi study, was designed to gain insight into how health professionals conceptualise dementia in today's current society. The online study involved asking medical professionals such as psychologists, psychiatrists, geriatricians, neuroscientists, nurses, and dementia advocates across Australia, the United Kingdom (UK), and the United States (USA) about their knowledge on the essential understandings and concepts of dementia and its associated care requirements (Annear et al., 2015).

Results from the Delphi study indicated that the most important understandings of the condition centred around caring for the person affected by dementia and their caregivers and other close family members (Annear et al., 2015). Interestingly, today's diverse conceptualisation of dementia allows for more potential improvements for those affected by the condition, particularly in terms of existing social and behavioural factors that may be modified to better support people living with dementia in the community.

Today's clinical understandings of dementia include the belief that it is a progressive degenerative disease impacting the individual in terms of both cognitive and behavioural functioning, which affects the daily life and activities of the individual affected (Vatanabe et al., 2019). Moreover, dementia is commonly understood as being associated with loss, that is, loss of self, identity, functioning, and cognition; as well as the loss of brain cells at the neuroscientific level, and eventually the loss of life (Zimmerman, 2020). According to Alzheimer's New Zealand (2022), dementia is considered a multifaceted health condition that impacts many areas of daily life and functioning, including mental, emotional, and physical functioning, and even extending further than the affected individual to also being impactful to close family and friends, as well as the wider community. The neurocognitive loss that results from this disease can be understood both in terms of western biomedical sciences as well as through societal discourses (Zimmerman, 2020). Combined, these factors help shape the ways in which dementia is interpreted and even experienced by people living with the disease, along with those that care for them and their extended support systems.

Dementia is also a prominent issue affecting New Zealand's indigenous population, Māori, with 1,928 Māori reported as living with the condition in 2011, and more than double that number expected by the year 2026 (Dudley et al., 2019). Mate wareware is the Māori term that has been developed by Māori to help describe dementia. Mate can be translated as meaning sick or unwell and wareware as forgotten or to forget (Dudley et al., 2019). Unfortunately, there is still limited research on the condition and how it impacts and is experienced by Māori, which means that what is known about the disease is largely based on Western biomedical views and theories which fail to consider a Māori perspective (Dudley, et al., 2019).

'Living Well' with Dementia

Due to the negative impact dementia can have, and because there is no known cure or treatment available for the disease, individuals with dementia often require a high level of care to maintain their optimal health, wellbeing, and functioning (WHO, 2021). There are many areas impacted by this cognitive disease, with care needs differing depending on the type of dementia, the degree of cognitive impairment, other co-existing health conditions, functional issues, and neuropsychiatric symptoms (Curnow et al., 2021).

The main goals of caring for someone with any form of dementia include optimising and maintaining their health and wellbeing; ensuring they stay as physically active and mentally strong as possible; and maintaining their independence, dignity, and overall quality of life; which can be achieved in part by supporting them to live safely in their own homes for as long as possible (WHO, 2021).

Before the other aspects of living well with dementia are presented, it would be pertinent to discuss what is generally meant by the term ‘living well’. According to this nicely described definition by Rahman (2014), living well involves:

> “a positive and sustainable state that allows individuals, groups, or nations to thrive and flourish. This means that at the level of an individual, wellbeing refers to psychological, physical, and social states that are distinctively positive. Positive psychological states are exemplified by emotions such as happiness and contentment, attitudes such as generosity and empathy, and mental processes such as cognitive capabilities, interest, and motivation. Positive physical states are characterised by vitality and physical capabilities, while positive social states include satisfying social bonds and loving relationships. Our definition of wellbeing also encompasses human resilience - the ability to survive and thrive in the face of the setbacks inherent in the process of living” (Rahman, 2014, pg. 13).

This definition nicely sums up what is meant by living well, and to expand on this definition in the context of dementia, living well often involves the ability of those affected to remain in their own homes for as long as they can (WHO, 2021). Staying in their own home may be particularly important because it provides people with dementia a sense of safety and security, which comes from being in comfortable and familiar surroundings. This is important for those living with this disease due to the cognitive symptoms that cause memory loss and confusion, which makes new and unfamiliar spaces not only difficult to adapt to and cope with, but also contributes to stress for the person with dementia as well as their carer and wider support systems (Bonner, 2005).

Another aspect of living well with dementia involves staying socially connected to friends and family, as well as staying active in the local community through activities and outings (WHO, 2021). This is important because those affected by dementia along with their carers have an increased risk of experiencing social isolation, which involves feelings of loneliness and loss; as well as having limited meaningful relationships and a felt sense of not belonging (Sun et al., 2021).

Conversely, caring for a family member or friend with dementia has also been shown to strengthen relationships and create more close and meaningful connections among family members, which provides a nice alternative to the often-negative descriptions of the relationships between family carers and their friends or relatives living with dementia (Clarke et al., 2011).

Defining Sleep

According to Grandner (2019), sleep can be defined as:

> "a naturally recurring and reversible biobehavioural state characterised by relative immobility, perceptual disengagement, and subdued consciousness. As a predictable and easily reversible phenomenon, sleep is distinct from states of anaesthesia and coma, which typically involve the absence or suppression of neural activity. Additionally, proper sleep involves a dynamic interaction between voluntary decisions and involuntary biological activities. Turning off the lights, reducing noise, and laying down are voluntary behaviours, but the result is an involuntary increase in the hormone melatonin and a series of shifts in the activity patterns of the brain throughout the night. Sleep ultimately depends on this collaboration between behaviour and biology, and a deficit in either will disrupt sleep" (Grandner, 2019, p. 3).

There are two main stages involved in sleep architecture: Rapid Eye Movement (REM) and Non-Rapid Eye Movement (NREM), with the latter stage involving three sub-stages known as N1, N2, and N3 (Manzoli et al., 2018). Sleep occurs in cycles whereby it moves through the four stages during the course of the night, and usually there are approximately four to six cycles of REM and NREM during an average night's sleep (Sleep Foundation, 2022). As the latter stages progress sleep becomes deeper and causes a decrease in blood pressure and heartrate (Manzoli et al., 2018).

The first stage of sleep that occurs when we first fall asleep is N1. During this stage of NREM the body and mind are relaxing and are slowing down preparing for deeper sleep. This stage only usually lasts one to five minutes and an individual can be easily roused during this phase (Sleep

Foundation, 2022). Following on from this stage is N2, which is a deeper state of sleep than that which occurs during N1; eye movement stops, and heartrate, respiration, and brain activity slow down, and the person is generally more difficult to wake up. The N2 stage of sleep usually lasts between 10 to 25 minutes (Sleep Foundation, 2022). The last stage of NREM is N3, which is the deepest state of sleep. During this sleep phase the body is much more relaxed, and heart and respiration rates decrease even further. This stage of sleep is also known as slow-wave sleep or delta wave sleep, due to the particular brain patterns that occur. This sleep stage is also known as the most critical stage for growth, repair, and restoration of the body and mind, and is also known as the stage where inspiration and creativity flourish and memories are stored (Sleep Foundation, 2022).

REM sleep is a different type of sleep whereby brain activity is almost as high as when we are awake. This stage of sleep is thought to be responsible for consolidating emotions and long-term memories (Saylor, 2014). REM sleep begins approximately 60 to 90 minutes after falling asleep, and during this stage is when brain development and dreaming occurs (Sleep Foundation, 2022).

Sleep can be conceptualized as a behaviour directly affecting health as it has interactions on a neurobiological level which impact our cognitive and emotional state, as well as our immune and digestive systems. Because of this interplay, individual health can be improved by making changes to sleep (Grandner, 2019). The three-process model of sleep as described by Grandner (2019) involves three key components that are vital for sleep to occur, these are: sleep need, sleep ability, and sleep opportunity. Sleep need involves the human requirement for sleep so that we can maintain optimal functioning at a biological level, and it also includes the amount of sleep an individual requires based on their unique biology and genetics. Sleep ability is the number of hours of sleep we achieve each night, and unlike sleep need this amount can vary based on our lifestyle, and thus can be modified through our behaviour. Sleep opportunity involves the time an individual allocates for sleep, and unlike sleep need and sleep ability, sleep opportunity is voluntary and is highly influenced by psychological, physical, social, and environmental factors (Grandner, 2019).

Quality Sleep

Simply achieving the right amount of sleep is not enough to maintain optimal health and wellbeing; rather we need quality sleep that is reparative and restorative and effectively prepares us for optimal functioning the following day (Grandner, 2019). Quality sleep is a multifaceted term that comprises more than just the actual amount in hours of uninterrupted sleep we get, but also includes Buysse's (2014) dimensions of sleep health which are satisfaction, alertness, timing, efficiency, and duration, as well as how we experience and interpret sleep

Furthermore, developing illness and disease, including both physical and mental, has been linked with a deprivation of quality, restful sleep, which is even more prevalent among family carers of people with dementia due to the role's demands and subsequent stress which can lead to further health issues (Sittler & Wilz, 2019). As discussed above, the later and deeper stages of sleep are when rest and restoration of the body and the brain occurs. Due to the challenges and associated stress within the dementia caregiving role, and the subsequent sleep disturbances that occur, informal carers are getting minimal amounts of this vitally important quality sleep that helps them maintain their overall health and wellbeing (Blinka et al., 2022).

Sleep, Ageing, and Cognitive Decline

As with other important aspects of life, sleep is affected by age, with changes to sleep occurring in both the short-term and long-term throughout the course of our lifespan (Morgan, 2017). The physiological mechanisms involved in sleep alter due to changes within the body, specifically the nervous system as we age. These changes are internal and happen across the lifespan regardless of the environment; whereas the environmental or psychosocial changes that also take place in response to external factors have also been recognised as negatively affecting sleep, for example sleep disruptions caused by stress, illness, disease, bereavement, housing changes, becoming a grandparent, and retirement has the potential to significantly impact sleep (Morgan, 2017).

The specific physiological changes that happen as we age take place in the brain, which is the control centre for the body's nervous system. (Ramduny et al., 2022). Some of the key structural changes that take place include deterioration of the brain's white and grey matter, which causes cognitive decline and affects performance and functioning (Ramduny et al., 2022). Some researchers have suggested that this cognitive decline may actually be exacerbated by sleep disturbances. Ramduny et al. (2022) undertook research to explore this very idea and produced mixed findings. On the one hand, they saw a positive association between poor sleep quality, broken sleep, and brain deterioration in older adults, but their findings were somewhat inconsistent, and their cross-sectional study design was limited. On the other hand, their research did provide evidence that there appears to be modifiable changes one can make to their behaviours surrounding sleep that may slow the brain's natural age-related deterioration and reduce the chance of developing neurocognitive diseases such as dementia (Ramduny et al., 2022).

Getting adequate quality sleep is even more important as we age, and particularly if we have coexisting health conditions (Zhang et al., 2022). A recent study involving older adults aimed to explore the corresponding factors and associations between sleep quality and wellbeing. Results from the study confirmed a positive association with quality sleep and better overall health and wellbeing. It also found that social support acted as a mediator for wellbeing by increasing the amount of quality sleep in older adults; while negative emotions decreased the amount of quality sleep and were also associated with lower overall wellbeing among older adults (Zhang et al., 2022).

Research by Liao et al. (2022) explored the associations between quality sleep and amount of sleep alongside cognitive and emotional functioning among older adults in China. Their study involved 150 participants aged over 65 years who were recruited via public hospital admittance between early 2019 and early 2021 (Liao et al., 2022). The research utilized psychological measures such as the Mini-Mental State Examination (MMSE) to determine cognition; the Pittsburgh Sleep Quality Index (PSQI) to determine sleep quality; the Hamilton anxiety scale (HAMA) to measure anxiety; the Hamilton depression scale (HAMD) to establish depressive symptoms; and the Montreal Cognitive Assessment (MoCA) to determine cognitive functioning (Liao et al., 2022).

The findings from the above-described study were a positive correlation between poor sleep quality and sleep timing, and poor health and wellbeing. One point of particular interest was the link between poor sleep quality and cognitive decline. In fact, the researchers found that cognitive decline was almost four times higher in participants who reported sleep disturbances when compared to participants who didn’t have disrupted sleep (Liao et al., 2022).

A similar study carried out in Korea also used the PSQI to assess quality sleep among older participants (Kim & Cha, 2022). This study involved 229 informal carers caring for a family member with some form of dementia. The research utilized the Patient Health Questionaire-9 and the European Quality of Life Five-Dimension Index (EQ-5D) and compared these findings with the participants level of perceived stress to assess whether or not a correlation existed. The results confirmed a positive relationship between these two factors, and it also showed a strong link between quality sleep and better overall health and wellbeing, including a reduction in depressive symptoms among carers (Kim & Cha, 2022). The study recommendations included the development of a quality sleep intervention that protected the health and wellbeing of caregivers of people with dementia by improving their sleep quality and minimising their symptoms of depression (Kim & Cha, 2022).

In a review by Frohnhofen et al. (2017), they discuss a more serious consequence of sleep deprivation, which involves classifying it as a substantial risk factor for developing dementia due to neuronal structural changes within the brain that occur when sleep is significantly disturbed. The authors suggest that a significant amount (15%) of dementia causes can be linked to sleep disturbances, which they point out as being somewhat beneficial in terms of the potential to modify some of the behaviours surrounding sleep as a way to reduce this particular risk factor (Frohnhofen et al., 2017).

Australian researchers' Peterson et al. (2018) talk about this very notion and provide examples of certain behaviours that are considered powerful in reducing the likelihood of developing obesity, diabetes, and other diseases impacted by sleep disturbances. Some of the health promoting behaviours include implementing changes such as regulating one's lifestyle and establishing a consistently stable routine, which have both been linked with better overall health and wellbeing (Peterson et al., 2018). Further to this, improved subjective sleep quality among older adults in Australia has also been attributed to consistent lifestyle regulation (Peterson et al., 2018).

At the cellular level, quality sleep helps brain cells repair and re-connect via a process known as neuronal DNA repair (Mourrain & Wang, 2019). The cells within the brain do not die like other cells in the human body do; rather they stay with us during the course of our lifespan and go through significant rupture and repair processes (Mourrain & Wang, 2019). Quality sleep is essential for these fundamental cellular processes within the brain to ensure that any neurons (brain cells) that get damaged during waking life are repaired in order to maintain optimal brain functioning (Mourrain & Wang, 2019). Therefore, for people affected by dementia quality sleep is even more important so that they are better positioned to retain their cognitive functioning.

The Importance of Quality Sleep within Dementia Care

As mentioned above, quality sleep is such a crucial component of sleep, especially for people with dementia and their caregivers. Further reasons why sleep is so vital in dementia care is partly due to how reduced sleep quality can notably increase the daytime symptoms of dementia, as well as the detrimental effects to the health and wellbeing of informal carers, which leads to stress, coping issues, and even impinging on the safety and overall wellbeing of the care recipient (Gibson et al., 2020).

Lee and Lawson's study, which explored the associations between sleep health and wellbeing among 441 adults, re-iterates the importance of sleep by reaffirming its strong correlation with better overall health and wellbeing. More specifically, in-line with what Gibson et al. (2020) found, Lee and Lawson (2021) also identified that the more problems carers reported in terms of sleep quality, the more stress and chronic health issues they suffered in waking life (Lee & Lawson, 2021).

The caregiving role has been identified as being challenging and stressful, add to it significant sleep deprivation and this likely supersedes the carers capacity to perform their role effectively and safely; and may even start to severely impact their own health and wellbeing. Byun et al. (2016) believe just this; that sleep disruptions can negatively impact caregiver health and wellbeing, and yet they found a lack of recognition in relevant research that looks into this very association. Thus, to gain a better understanding, Byun et al., (2016), carried out a systematic review of literature that explored how caregivers sleep is being impacted by caring for an ill family member. Their review showed that almost all caregivers, regardless of the care setting, reported a lack of quality sleep, which was even more prominent among caregivers of people with dementia-related conditions. The authors were also not surprised to find that poor sleep quality was linked with daytime sleepiness and what they described as ‘brain fog’, which in turn impinged on daytime activities and had ramifications for the safety of care recipients (Byun et al., 2016).

An American study involving 80 caregivers who looked after a family member with some form of dementia discusses this very notion. The study, by Simpson and Carter (2015), aimed to better understand the relationship between carer sleep quality and the living arrangements of carers. Interestingly, the results showed no significant association between quality sleep and whether the caregiver lived with their family member full-time or not, showing that sleep is impacted in various settings of dementia care, and doesn’t only impact carers who live full-time with their friend or relative with dementia. This finding also highlights just how challenging the role of caregiving itself can be, and also points to the need for better caregiver support that’s inclusive of all caregivers regardless of whether they live with their care-recipient or not, as the stress and sleep disruptions they experience appear significant regardless of their living arrangements (Simpson & Carter, 2015).

New Zealand research has been undertaken by researchers exploring the impacts of dementia care on the sleep health status of family carers. One study used focus groups to gain insight into this phenomenon and found that sleep was greatly affected by the associated responsibilities of caring for people with dementia within an informal care situation. More specifically, dementia-related behaviours which caused confusion, also known as ‘sundowning’ were among the greatest dementia-related sleep disturbances expressed by family carers (Gibson et al., 2014). This particular study by Gibson et al. (2014) also identified strategies the carers’ utilised in various settings as a way to cope with the disruptions to their sleep and try to improve the quality of their sleep. Some of the strategies associated with their environment included: sleeping in separate beds or rooms; having comforting noises such as televisions or radios; and modifying the amount of light in the room (Gibson et al., 2014). Strategies related to safety included the risk of falls, particularly for those awakening at night to toilet, as well as concerns over falling again if they had experienced previous falls. Strategies employed to mitigate these risks included: using night lights or having torches at the bedside; using bed pans for night-time toileting; using a bell to ask for assistance; ensuring doors and windows are shut and locked; and gaining insight into effective support strategies (Gibson et al., 2014). The other strategy used by carers was to develop a set routine for daytime and bedtime, however this strategy was not very reliable due to the very nature of dementia symptoms (Gibson et al., 2014).

A dyadic case study approach was used in another New Zealand study which involved 30 participants made up of 15 pairs of carers and their care recipients (Gibson et al., 2017). The study explored the use of non-pharmacological interventions and their subsequent impact on dementia-related sleep problems. The interventions used exercise and education on sleep health as well as bright light therapy (Gibson et al., 2017). The study found that participants with stable higher level dementia symptoms and significant sleep disruptions showed some positive effects to the non-pharmacological interventions (Gibson et al., 2017). Further, the findings from the study were unique as they illustrated the effectiveness of non-pharmacological interventions in a community home-based setting. Despite the relevance of continence issues among people with dementia, this element of care was not actively included in the study, in fact it is has not been included in any other studies in New Zealand to date.

Informal Carers

Due to the level of impairment ultimately caused by dementia, it can be significantly stressful and even detrimental to the health and wellbeing of informal carers (Drennan et al., 2011). Depending on the severity of dementia symptoms, as well as the health and well-being status of the informal carer, the care associated with caring for someone with dementia can impact carers in terms of their physical health, their mental and emotional wellbeing, their sleep, and their overall quality of life (Gibson et al., 2020).

One of the ways in which society can support people living with dementia, is by properly supporting those who care for them, so that they can continue caring for their care recipients in the comfort of their own homes, whilst also caring for themselves at the same time. Research suggests that this very factor is transformative in terms of positively influencing the lives of those living with dementia (Gibson et al., 2020; Cross et al., 2018).

The Consequences of Caring

The number of informal carers is increasing exponentially due to the rising global prevalence of dementia (Cross et al., 2018). Despite this, there is currently still limited research on the lived experiences of informal carers, and how the role of caring for someone with dementia specifically impacts them, particularly in terms of their own health, and overall quality of life. This lack of understanding suggests the need to gain a deeper understanding of the impacts of the informal carer’s role, so that the effects of these impacts may be mitigated by ensuring the right type of education and support is available to informal carers (Gibson et al., 2020). Developing greater awareness around the lived experiences of carers in the setting of informal dementia-care could help inform effective support, which may help reduce stress and alleviate some of the other detrimental impacts of the role, allowing informal carers to maintain their own health and wellbeing more effectively, whilst continuing to care for their friend or family member with dementia. Identifying the best methods to support informal carers may not only reduce stress and help them cope, but it could also reduce the likelihood of them seeking out institutional care for the person they are supporting (Cross et al., 2018).

The Alzheimer's Association suggests that informal carers are the most valuable and effective support for people living with dementia, particularly in terms of maintaining the persons quality of life (Farina et al., 2017). However, caring for someone with dementia can be exceptionally daunting, and the high workload involved has implications for impacting waking stress, as well as sleep disturbances and overall fatigue (Cross et al., 2018). It can also be particularly stressful during the early stages of dementia, in terms of carers adjusting to the news that their friend or relative has this condition, which can bring about a wide range of emotions and be extremely difficult to adjust to and accept (Alzheimer's NZ, 2022). This further supports the need to ensure that informal carers are provided with the knowledge and support they need, not only to maintain their own health and wellbeing, but so that they are properly equipped to provide care to the person they are supporting, allowing them both to remain in their own environments safely for as long as possible.

Stress and the Caregiving Role

Because the caregiving role can be so demanding, carers frequently experience high rates of stress and emotional distress (Drennan et al., 2011). Caregivers in the setting of dementia care seem to experience greater levels of stress as compared with caregivers in alternative settings, which, according to the insights from the American Caregiving Transitions Study could party be attributed to the higher number of hours dementia carers worked when compared with carers who worked in non-dementia care roles (Sheehan et al., 2021).

The Caregiving Transitions Study was a follow-on study from the Geographical and Racial Differences in Stroke (REasons) longitudinal study involving more than 30,000 Americans of

Caucasian and African American ethnicities. During the baseline interview for this study potential participants were asked whether they provided on-going care to a family member with long-lasting health conditions or illnesses. This pre-interview recruited 251 carers with almost half (47%) providing in-home care for relatives living with dementia. The study's inclusion criteria were carers who had been in their role for longer than one year and in that time had looked after their care recipient for at least five hours per week (Sheehan et al., 2021). The Caregiving Transitions Study utilized several subjective measures which gained insight into the overall stress and mental strain of the caregiving role, which have been used successfully in previous studies to ascertain wellbeing and morality among caregivers (Sheehan et al., 2021). Although this study was based on the experiences of caregivers with various relationships to care recipients, as well as carers who did not necessarily provide full-time or live-in care, it still highlighted the significant stress experienced by caregivers, especially caregivers of people living with dementia; and it also reiterated the need for better support for carers in dementia care. Moreover, despite the potential significant impacts associated with sleep disturbances and managing dementia-related continence/incontinence, the above-described research did not consider either of these areas within its research on caregiver experiences and stress within dementia care.

A cross-sectional study that looked at the various factors relating to in-home caregiver stress found that caregivers caring for family members in a rural setting experienced significant psychological stress, which was considered as the most impactful aspect of their role and influenced their ability to remain in the role long-term (Krutter et al., 2020). The same study also suggests that caregivers require a professional level of daily support to keep them from experiencing emotional distress and depressive symptoms, which was mainly attributed with no longer enjoying their usual daily leisure activities as well as social isolation (Krutter et al., 2020).

Another American study exclusively involving participants that identified as African American, looked at the relationship between the role of caregiving in the setting of dementia (specifically Alzheimer’s Disease) and stress. The study hypothesised that stress brought about by the caregiver role impacted the health and wellbeing of carers and exacerbated some of their pre-existing health conditions. The researchers first measured objective levels of stress among family caregivers by collecting saliva samples to test the participants cortisol levels. They then measured subjective levels of stress by utilizing the Zarit Burden Interview Scale, which involves a series of 22 questions that participants are asked to answer in terms of how their role of caregiving impacts them personally (Cothran et al., 2022). The study revealed that sleep disruptions and depressive symptoms were the most experienced symptoms of caregiver stress, and it also highlighted the links between personal characteristics of caregivers and stress rates, determinants of health, and health outcomes (Cothran et al., 2022).

Drennan et al. (2011) found that informal carers of people with dementia reported significantly higher levels of stress and more depressive symptoms compared with carers of people without dementia-related conditions, which again points out the importance of effectively supporting informal carers who dedicate themselves to caring for those living with dementia. Research carried out by Sheehan et al. (2021), explored the differences between dementia and non-dementia caregivers in terms of their stress levels and overall health and wellbeing. The study revealed that caregivers of people with dementia reported higher levels of stress and more depressive symptoms as compared to caregivers in non-dementia settings (Sheehan et al., 2021).

Because dementia is most prevalent in older age, informal carers are often already experiencing some of the natural effects of ageing themselves and are also more likely to already be managing their own health issues and age-related challenges. This can in part be contributed to informal carers sharing the same lifestyles and health concerns as the person with dementia, particularly carers who are spouses and those who live with the person they are supporting (Wang et al., 2014).

Farina et al. (2017) carried out a systematic review that aimed to explore the impact of caring for people with dementia in terms of their quality of life. The review used a narrative synthesis method with thematic headings to outline the results. The themes identified included: demographics, carer-patient relationship, dementia characteristics, demands of caring, carer health, carer emotional wellbeing, support received, carer independence, carer self-efficacy, and future. This research revealed that the most positive correlation was between better carer mental and physical health, and carer quality of life. Included in this was the finding that poor sleep quality among carers was negatively associated with quality of life. Conversely, the area found to impact carer quality of life the least was demographics. These findings are rather positive, in that the areas which show the most impact are areas that have the potential to be modified and improved upon. This can be achieved, in part, by understanding the impact involved in the caring role, and by looking at ways to provide carers with the best knowledge and support so they are able to perform their role effectively and safely, with minimal impact to their health and wellbeing.

The above literature re-iterates the importance of developing proper support for caregivers, so that they are equipped to remain in their roles for longer safely and with the knowledge that they are able to access support when they need it. There is also a clear need to examine further the lived experiences of informal carers in the context of dementia care so as to ascertain exactly how they experience the different aspects of their role, and how their experiences can help shape future supports.

The findings from Farina et al. (2017) review further highlight the significant challenges involved in the role of caregiving, especially in the setting of dementia care, and particularly in terms of the impacts to the carers sleep, health, wellbeing, and overall quality of life. Moreover, this research also supports the need to further explore the best ways to educate and support caregivers, the community and wider society, so that some of the detrimental effects of the role can be reduced, and so that caregivers feel supported and empowered to continue caring for their family members with dementia in their own homes, which ultimately benefits them, their care recipient's and their local community, and the healthcare system.

Maintaining Health and Continence Practices

A big part of maintaining our independence as we age is our capacity to look after all aspects of our daily life, particularly in terms of our health and our own personal care and hygiene practices. Like other areas of bodily function, ageing affects our organs responsible for optimal health and overall functioning (Payne, 2020). The organs responsible for expelling liquid and solid waste from our bodies, our kidneys, are particularly impacted by the natural effects of ageing (Payne, 2020). Continence, more commonly known as toileting, is one of those areas that when impacted can significantly affect an individual's independence, sense of dignity, and overall quality of life (Talley et al., 2021). When people lose control of bodily functioning in this area it is known as incontinence. Urinary incontinence is "the involuntary loss of urine, and faecal incontinence is the involuntary loss of solid or liquid faeces" (Burholt et al., 2020, p.2).

The Impact of Managing Dementia-Related Incontinence

One way to understand why there is still such a gap in research on the challenges involved in dementia-related caregiving, is by exploring some of the social factors that may prevent carers from seeking support for managing aspects of care that are perceived as taboo. Drennan et al. (2011) illustrated the social stigma around caregivers discussing continence and incontinence issues within his qualitative research. The results from the study revealed that carers were very protective and overly concerned with preserving the dignity and personal identity of their family members, and thus preferred to cope with issues such as urinary incontinence alone and in silence, rather than seek out advice or support from medical professionals (Drennan et al., 2011). This finding suggests the need to address the social and societal factors related to dementia, such as: normalising seeking help and support; reducing stigma around toileting and incontinence; and raising awareness around the key impacts of supporting a care recipient with dementia.

In a similar vein, research by Rose et al. (2015), suggests that sleep disturbances caused by incontinence in people with dementia is often the main reason for seeking out institutional care; which further illustrates just how challenging the role can be, and also further highlights the need to address this area of health to ensure all is that can be done is being done to help support those affected by dementia, as well as those who care for them.

The importance of developing awareness and good support for informal caregivers, particularly with regards to managing incontinence, is vital in the setting of dementia care. Rose et al. (2015) suggest that superior quality support for carers would likely reduce the likelihood of seeking out formal care options for their care recipient, and it would also ensure that the carers own health and wellbeing needs are being met alongside their care recipient.

Further to the above, identifying issues that may impact upon the informal carer's quality of sleep and overall health and wellbeing is vital. Previous research suggests that one rather overlooked health issue in this area is incontinence, and the implications for carers who help manage this symptom. According to the Australian and New Zealand Continence Journal (2009), carers reported some of the lowest rates of overall wellbeing, with a significantly decreased rate for carers who worked with people with incontinence issues. Physical and emotional health was also mentioned, with fatigue, and loss of energy and motivation the main concerns among carers. Furthermore, although continence has been shown to impact on carer stress, sleep is often not included, yet research suggests it is a key factor in carer health and wellbeing.

Cassells and Watt (2003) looked to explore the impact of managing incontinence on informal carers health and wellbeing. Their study revealed that incontinence is a common health issue primarily affecting the aging population, and in turn impacting the health and wellbeing of spouses who care for them. Further, the research suggests that the role of caregiving is already significantly challenging enough, with incontinence adding yet another dimension of stress for carers (Cassells & Watt, 2003).

Rose et al. (2015) discuss the implications for caregivers of people with dementia who also have incontinence issues, suggesting that they often report feeling overwhelmed, and the stress associated with managing incontinence often leads them to seek out alternative care options for the person they support. One interesting point they made is that incontinence is not a typical progression of ageing, or of dementia, but despite this, carers tend to assume that it is, and therefore they don't always seek out advice or intervene appropriately. This often results in carers turning to pharmaceutical interventions instead of incontinence products or behavioural interventions often with poor results (Rose et al., 2015). These research findings further confirm the urgent need to raise awareness, educate, and normalise caregivers seeking support, so that they can continue their role effectively whilst also maintaining their own health and wellbeing in the process.

Aldridge and Dening (2021) also looked at the impact of incontinence in the context of dementia. Their study found that there are interventions which can alleviate the impacts of incontinence, allowing for the person with dementia and their caregiver to enjoy better quality of life. Identification, assessment, and management were identified as the key vital components of managing incontinence. Etters et al. (2008), suggest that the best kind of interventions are ones involving various external services, and ones specifically tailored to the individual with dementia and their caregiver. The outcome of quality intervention plans would involve better overall quality of life and decreased stress for caregivers, as well as the ability and desire to continue caring for the person they support in their own home, rather than seeking out formal care options (Etters et al., 2008). To date, the relationship between the key areas of continence and sleep are seldom considered in the informal caring/coping literature.

Research Aims

Both continence and sleep are vital areas involved in maintaining health and wellbeing, particularly in the context of informal dementia care, however, despite this these two aspects are often left out of dementia-related research. Furthermore, the valuable role undertaken by informal carers and the associated impacts to their health, sleep, and quality of life remain significantly under researched, and there is currently limited research which explores the person-centred experiences of informal carers in the setting of in-home dementia care in New Zealand. Having this knowledge and understandings is important not only because of the rapidly increasing incidence of dementia alongside the rising age of the population, but also because the findings from this study can help guide future interventions and education that can support carers in managing continence and incontinence. The result of which allowing them to continue in their roles safely and effectively, and in doing so enabling people with dementia to remain living in their own homes for longer, which has been shown to positively influence their overall quality of life and also reduce the number of people living in aged residential care facilities (Schluter et al., 2016).

This research is a development from two larger Health Research Council (HRC) funded research projects concerning continence and sleep led by Professor Vanessa Burholt and Dr Rosie Gibson respectively. These projects all share the aim of exploring the current health practices around continence and incontinence care within a community setting in New Zealand. This thesis hopes to build upon this research by exploring how managing dementia-related incontinence impacts the sleep, health, wellbeing, and quality of life of informal carers working across both urban and rural community settings within New Zealand.

This will be achieved through a qualitative approach to pre-existing written and oral data collected within a broader set of research concerning sleep, ageing, and dementia (Gibson & Gander, 2021; Gibson et al., 2020). Moreover, this thesis aims to provide a voice to the informal carers who expressed their challenges around managing dementia-related incontinence in the original study, despite there being no prompts relating to incontinence throughout the original data collection. This highlights the significance of the carers' experiences of managing dementia-related incontinence, and this research aims to represent and honour this adjunct content that appears pertinent to carers.

The specific research questions include: “How does managing dementia-related incontinence impact informal carers in terms of their sleep, health, and wellbeing?” and “How does managing dementia-related incontinence affect informal carers overall quality of life, ability to cope, and their capacity to care?”

Chapter Three: Methodology

This study was conducted with the understanding that there is a close interrelation between the research methods, methodology, epistemology, and the theoretical perspectives, in that each informs the other, and each is necessary for the other to answer the research questions effectively (Crotty, 1998). In terms of the methodological approach, and the epistemological and theoretical perspectives that underpin this approach, the present study utilised a hermeneutic phenomenological approach which is grounded by the assumption that an integrated relationship exists between the human mind and the environment; and by uncovering and revealing the meaning of interpersonal experiences we can acquire a deeper understanding of ourselves and our experiences (Howell, 2013). Phenomenology is a difficult concept to define and outline in one all-encompassing explanation. At its core, phenomenology comprises the philosophy around what it is to be human; including what it means to think about the knowledge we have (Qutoshi, 2018). Researchers utilise this philosophy by engaging in interpretation, and by aiming to establish the meaning embedded in the lived experiences of various human phenomena, allowing for deeper understanding and awareness around the experiences of different individuals' and groups within our society (Qutoshi, 2018).

There are a few different perspectives in the field of phenomenology, dating back to the days of Aristotle; but the founder of phenomenology was Edmund Husserl (1859-1938), who viewed phenomenology as a way of interpreting the human world by way of phenomenological reduction (or bracketing), which involves detailing, interpreting, and expressing lived human experiences in context (Qutoshi, 2018). Heidegger, a student of Husserl, viewed things in a more in-depth manner, further expanding upon Husserl's theory to develop interpretive-hermeneutic phenomenology (Qutoshi, 2018). Understanding the underpinnings of hermeneutic phenomenology is not considered in terms of cognitive processing; rather it involves understanding the consciousness interplay between an experience, the individual articulating said experience, and the individual (or researcher) aiming to interpret and describe that individual's experience within the realm of a specified or intended context (Ginev, 2014; Qutoshi, 2018).

Using a hermeneutic phenomenological approach allows the researcher to stay as close to the data as possible, letting the very essence of that data to shine through. This was a crucial element of the present research, as it permitted the findings to be as genuinely representative of the participants' lived experiences as possible, giving an authentic representation of their unique journeys of caring for their care recipients with dementia. The phenomenological approach was used successfully in a similar setting in research by Byers and France (2008), whose results corresponded with Watson's theory of human science and human care, which is a theoretical framework underpinned by phenomenological assumptions that helps guide this type of research.

Another similar study carried out closer to home was an Australian study that used a hermeneutic phenomenological approach to understand the lived experiences of nursing students in a palliative care setting (Ranse et al., 2018). The study looked to explore the experiences of looking after a patient who was dying, as well as supporting their family through an extremely difficult life experience (Ranse et al., 2018). The study was carried out among third year nursing students, and similarly to the present study, the underpinning methodological assumptions were chosen to allow insight into the real-world lived experiences of participants in the context of caring and providing end of life care (Ranse et al., 2018).

Chapter Four: Methods

Data collection

The present study utilised previously collected data from a nationwide confidential sleep survey of informal carers in the setting of dementia care, along with the 20 subsequent semi-structured interviews (see Appendix A) (Gibson & Gander, 2021; Gibson et al., 2020). The present study branches off from the wider Health Research Council (HRC) incontinence study (Improving Continence Management for People with Dementia in the Community - 21/117) as well as the HRC emerging researcher study (The Role of Sleep and Healthy Ageing and Living well with Dementia – 18/621) that is focused on understanding the experiences of sleep and ageing within informal in-home dementia care.

The sleep and healthy ageing and living well with dementia research used thematic analysis to describe the open-ended comments sections of the sleep and health survey completed by informal caregivers in the setting of in-home dementia care. The next stage of the research involved 20 follow-up interviews ensuing the initial survey, whereby post-care the participants were asked further questions (see Appendix B) relating to their sleep, health, and wellbeing: as well as questions about their general experiences within the informal caregiver role. The original sleep study found that caregivers suffered from significant sleep issues in all five areas of sleep health, including: sleep timing, sleep duration, sleep satisfaction, quality of sleep, and sleep efficiency. All of which had various short and long-term implications for their mental and physical health, as well as their overall quality of life and capacity to care (Gibson & Gander, 2021; Gibson et al., 2020). Thus far, the original study has looked at the experiences of carers in terms of their sleep status, whereas the present study aims to explore the carers specific experiences of managing dementia-related continence and incontinence in terms of how it affects their health, sleep, and quality of life. Thus, this thesis aligns with the aims of the continence project by representing carers dementia-related incontinence care experiences in an informal care setting. More specifically, this thesis explores the experiences, strategies, impacts and consequences of promoting continence and managing incontinence for people living with dementia in the community.

Participation of the sleep survey was anonymous, except for those who indicated their interest in being contacted in the future to provide more in-depth information about their care experiences through the latter interview process. Completion and return of the sleep survey inferred informed consent (Gibson et al., 2020). The New Zealand Health and Disability Ethics Committee approved the ethical conduct of the research (16/CEN/101) (see Appendix C).

The interview data was collected separately by Dr Rosie Gibson of the Sleep/Wake Research Centre at Massey University approximately two years after the initial sleep survey. The semi-structured interviews took place both in person (N=13) and over the phone (N=7), with the interviews ranging from 28 to 77 minutes in duration. Both written and verbal informed consent along with consent to record the interviews was provided by each participant (see Appendix D). The key differences regarding the approaches across the two data sets are mostly attributed to the timing of data collection and the subsequent change of care setting, which changed the carers perspectives from current to retrospective in terms of their experiences during and after informal in-home dementia care. Other notable differences were that the sleep survey was completed in written form, whereas the interviews were carried out face to face between the carer and the researcher, making the sleep survey more anonymous.

Participants

The participants of the sleep study who completed the initial survey included 526 informal carers, who at the time were cohabiting and caring for a family member or friend with dementia in their own homes. This number represents just over a ten percent (11%) response rate out of the total number of surveys distributed (Gibson & Gander, 2021). Approximately two years later 20 participants were recruited to participate in the follow-up interviews after indicating their willingness to take part in further research involving their experiences post-care – following their care recipient's transition into formal care. Selection criteria involved participants whose care recipient had since transitioned into formal care between them completing the sleep survey and the commencement of the interviews. Participants were located across the North Island of New Zealand in both urban and rural areas so as to be as representative of the population as possible. Most (13) of the semi-structured interviews were carried out in person in the carers' homes, while the remaining seven who lived rurally had their interviews conducted over the phone. Of the 20 carers interviewed, 13 mentioned continence and/or incontinence and thus only their data was included in the present study. The carers and care recipients have been given pseudonyms in order to protect their identities.

Data analysis: Written comments

Reflexive thematic analysis (TA) was utilised as an overarching approach for interpreting and describing the sleep survey data. Braun and Clarke (2019), outline the important recommendations for using reflexive TA in qualitative research; and in line with their guidelines this approach was chosen to help identify and develop thematic patterns within this dataset. The reflexive way of approaching TA is far more reflective that that of the initial TA, as this newly revised approach considers the researcher's own personal views, beliefs, and life experiences in terms of the perspectives they bring and how they influence data interpretation and form conclusions from the data based on their own lived experiences (Braun & Clarke, 2019).

The already collated comments from four sections of the sleep survey pertaining to sleep, heath, the general care situation, and any additional comments, were imported as separate Microsoft Word files into the coding software NVivo 12. The questionnaire specifically asked carers for comments relating to the following: your caregiving situation; your own sleep or the sleep of the person you support; your physical or mental health; and any additional comments if required.

Of the 526 participants, 94 referred to continence and/or incontinence, thus their data was included in the present study (Gibson et al., 2020; Gibson et al., 2021). The first stage of the data analysis involved familiarisation. This was achieved by reading through all the comments several times and identifying and highlighting anything that related to continence and/or incontinence. Once identified and highlighted, the data was then coded into semantic (descriptive) codes. Initially there were 32 semantic codes created, including nine from the general care comments; five from the health comments;18 from the sleep comments; and all references from the additional comments section fitted into the existing codes.

The number of references to continence and/or incontinence varied between the four comments sections, with the sleep section containing the most references (83); while there were 22 references made under the general care section, and eight references under both the health and additional comments sections. After the initial semantic codes were produced, a further analysis of the data was carried out to construct latent (interpretive) codes. This phase of the analysis involved merging similar content, and further defining and re-naming the codes so that they aligned better with the data. The outcome of this stage resulted in 12 latent top-level codes, and 18 latent sub-level codes.

Further defining and revising these codes occurred by re-grouping them and looking across the entire dataset to gain appropriate context. This was key to ensuring the codes accurately reflected the participants’ experiences.

Data analysis: Interviews

For the interviews, narrative analysis was used as a framework for interpreting and portraying some of the inexplicitly expressed motivations, feelings, and behaviours of carers in the context of informal dementia care (Herman & Vervaeck, 2019). This approach was based on the underlying theoretical assumptions and understandings of narrative psychology (Bold, 2011; Wong & Breheny, 2018), and was used to guide the researcher’s interpretation of the interview data, helping form the narratives of the participants’ lived experiences in the setting of in-home informal dementia care. Herman and Vervaeck (2019) suggest that narrative analysis allows researchers to uncover some of the social and cultural concepts of reality that inform human experiences, thus this method allows for the interpretation of the social and cultural aspects embedded in the narratives of individuals who share their personal lived experiences.

Models of narrative analysis have been used in many different settings, in order to explore various areas of human experiences based on psychological, sociological, and anthropological elements to name a few (Cortazzi, 2014). Narratives are a central aspect of human life and have been used throughout history to explain social and cultural opinions of the human experience in the world and of what it means to be human (Herman & Vervaeck, 2019). Narrative analysis is an extremely intentional and reflective research approach which considers the experiences, views, and beliefs of the researcher (Murray, 2008). This was a key factor that helped inform the use of this approach in the present study's interview data analysis, along with proof of its successful use within a similar study involving informal carers in New Zealand. This research by Breheny et al. (2022), used narrative analysis in order to understand the caregiving identities embedded in the interview transcripts among informal carers in the setting of dementia care.

The follow-on project included the transcripts from the 20 follow-up interviews based on the carers' experiences post-care. By this time, the care recipients had all either moved into formal care facilities or had since passed away. This lapse in time and change in care situation allowed for diversity between the carers perspectives and provided insight into the carers' experiences of being in the thick of their caring role as well as their experiences post-care. Carers were in various stages of grieving, but all were able to articulate their own experiences of caring for their friend or family member with dementia.

When the interviews took place, all the carers had ceased providing support within the home environment. Eleven of the care recipients were residing in formal care, and the remaining nine had subsequently passed away.

As with the sleep survey comments, the interview data was imported into the NVivo 12 coding software as 20 separate Microsoft Word files, and then all content relating to continence and/or incontinence was coded semantically. The initial data analysis involved listening to the audio recordings, which were around 55 minutes in length on average. The initial phase of analysis also included reading through the interview transcripts several times and highlighting any content relating to continence and/or incontinence. This initial phase produced 33 semantic codes: including 25 top-level codes and nine sub-level codes. After these initial codes were created, a further analysis was then carried out, which similarly to what was described above for the survey comments data, involved refining and merging similar codes and content, and re-defining the codes to ensure they were accurately representative of the data. As a result, the final number of latent top-level codes created was 14, with 19 latent sub-level codes created.

Further analysis was then undertaken, whereby the codes were organised into similar groups producing key overarching themes and eventually narratives. Initially, there were nine broad themes created, which were then further refined into the final three overarching narratives.

The construction of the themes and overarching narratives was a reflective and collaborative process comprising input from the other key researchers involved in the incontinence study (R. Gibson & V. Burholt). Other contributions were made by members from the sleep and continence HRC project, and were provided via in person workshops and virtual Zoom meetings. This collaborative process allowed for the discussion, revision, and re-defining of themes and narratives, which was guided by reflexive TA and narrative analysis to ensure that they effectively represented the data. These research methods were key to interpreting and describing the lived experiences of informal carers in the context of urban and rural in-home dementia care in New Zealand.

Chapter Five: Results

Of the 526 participants who competed the sleep survey, almost all (87%) were spouses, while the remaining were another family member or a friend of the person with dementia. The survey response rate was relatively low (almost 11% of those who were sent the survey) and of that the vast majority (92%) identified as being of New Zealand/European ethnicity, and a large proportion (75%) were women. Most of the participants (80%) were aged 65 years and over, with the oldest being 96, and the youngest being 23 years old (Gibson et al., 2020; Gibson et al., 2021).

The data from both the sleep survey comments and the interviews showed complementary findings, particularly in terms of the negative impact that managing continence and incontinence had on the sleep and overall wellbeing of informal carers. These key themes from the survey data are predominantly summarised in table one, and then further developed within the narrative analysis of the interview data.

Sleep Survey Themes

Three key global themes were created from the survey data, and within these global themes six main organising themes and 17 basic themes were developed, supported by direct quotes from the data. The three global themes illustrate the experiences of informal carers caring for their care recipients with dementia in their own homes. The three global themes are: Sleep becomes progressively disrupted due to toileting needs; Managing incontinence for supporting sleep and waking life; and Incontinence impacts carers quality of life and ability to cope. These findings include personal examples of carers negotiating continence, sleep, health, and wellbeing within the role of dementia-care, including eventually managing dementia-related incontinence, and the subsequent impacts to carers sleep, overall health and wellbeing, and quality of life. Table 1 below illustrates each of the key themes constructed from the sleep survey comments data, along with the corresponding sub-themes, description of each theme, and supporting quotes from the data. This table was created to outline how the themes all fit together; as well as to provide a deeper understanding of the data in context. The table of themes also allows the reader to easily follow the progression of dementia-care through the eyes of informal carers.

Table 1.

Summary of themes created from the sleep survey comments

Organising themes	Theme description	Supporting quotes
Sleep becomes progressively disrupted due to toileting needs		
1. A familiarity of negotiating toileting with sleep across the lifespan		
1.1. Carers are used to having disrupted sleep	Carers are familiar with sleep disruptions and feel they can still function properly on the sleep they achieve each night	*'My sleep pattern is the same as it was 50 yrs ago - I manage on an average of 6 hours actual sleep or less - but always broken - it doesn't concern me'* (68-year-old female caring for her 74-year-old spouse with Alzheimer's Disease)
1.2. Carers get up during the night to use the toilet	Carers sleep well despite waking to use the toilet at night, getting up is not an issue as they get back to sleep easily	*'Apart from 1 or 2 trips to the toilet I sleep very well myself'* (75-year-old female caring for her 82-year-old spouse with Alzheimer's Disease) *'My sleep. Awake 2 or 3 times but get to sleep after going to toilet'* (85-year-old male caring for his 85-year-old spouse with Alzheimer's Disease)
1.3. Gradual changes noticed in PWD's toileting needs	Carers notice and expect gradual increases in night-time and early morning toileting for PWD as they age and decline with dementia	*'Sleep fairly well and I have cat naps throughout the day. Have to get up to the toilet 2 or 3 times a night'* (81-year-old male caring for his 73-year-old spouse with emerging dementia) *'We are in our 80s - expect patterns to change'* (83-year-old female caring for her 86-year-old spouse with an undisclosed form of dementia)

1.4. Medical conditions exacerbate PWD’s night-time toileting needs	PWD’s co-existing medical conditions increase night-time toileting needs, causing sleep disruptions	*‘He used to sleep well, quickly falling asleep, getting up 1 - 2 for the toilet during the night and going right back to sleep, waking feeling fit in the mornings. Prostate cancer has changed this, some nights he is up every 30 mins and can’t find his way back to bed’ (*75-year-old male caring for his 83-year-old spouse with undisclosed form of dementia)
2. Night-time toileting needs contribute to sleep disruptions		
2.1. Carers own night-time toileting needs begin to impact sleep	As the carer ages, they are needing to use the toilet more frequently at night	*‘My own sleep would be better if I didn’t have to get up 4 - 6 times for bathroom’* (88-year-old male caring for his 88-year-old spouse with an undisclosed form of dementia)
2.2. PWD’s night-time toileting needs begin to impact both their own and carers sleep	Carers sleep is occasionally disrupted, but they still feel they get enough sleep. PWD is still able to use toilet unassisted during the night, although often has trouble getting back to sleep	*‘When he wakes, I listen that he has found the toilet. Then when he comes back to bed, I ask him to turn the light off so I don’t have to get up. Sometimes he just likes to cuddle and talk’ (*84-year-old male caring for his spouse with dementia)
2.3. PWD’s night-time toileting needs significantly impact carers sleep	Carers sleep is regularly disrupted, carers find it hard to get back to sleep and feel tired during the day most days. PWD is still able to use the toilet unassisted	*‘He gets up every two hours to toilet. I wake and turn light on for him. He doesn’t feel tired, I do’* (71-year-old female caring for her 76-year-old spouse with an undisclosed form of dementia)
2.4. Carers pre-existing sleep problems exacerbated by toileting needs associated with age and dementia care	Carers sleep has never been that good, and now sleep disturbances have increased due to PWD’s dementia symptoms and increased night-time toileting. These sleep disruptions occur in addition to carers own night-time toileting needs	*‘My sleep has always been erratic but worsened due to my husband’s rapidly deteriorating condition. His sleep is also erratic as he doesn’t comprehend night or day and often wakes me for reassurance. He gets up regularly to go to the toilet as do I’ (*71-year-old female caring for her

		82-year-old spouse with an undisclosed form of dementia)
Managing incontinence for supporting sleep and waking life		
3. Incontinence presented a great problem for sleep		
3.1. PWD’s incontinence causes sleep disturbances for carer	Carers sleep is disrupted due to managing incontinence, carer often schedules night-time toilet visits for PWD to avoid accidents	*‘Incontinence presented most problems with sleep’* (74-year-old female caring for her 71-year-old spouse with an undisclosed form of dementia) *‘Lack of sleep effects everything’* (79-year-old male caring for his 77-year-old spouse with an undisclosed form of dementia)
3.2. Carers sleep quality is undermined	Carer sleeps on high alert, and has broken sleep due to waiting to assist care recipient with incontinence during the night	*‘The quality of sleep is also undermined because I always have an ear out for her’* (54-year-old female caring for her 85-year-old mother with Alzheimer’s Disease)
4. Carers use strategies to relieve the impact incontinence has on sleep		
4.1. Carers utilize their own night-time toileting needs as an opportunity to assist PWD with their night-time toileting needs	Carers are used to getting up to the toilet themselves at night with minimal sleep disturbances, so they maximize this time by also assisting PWD with their night-time toileting	*‘I usually need to get up for a pee in the small hours so it’s no problem to help [PWD] up and onto the commode at this time and give her a change if necessary’* (83-year-old caring for his 87-year-old spouse with Dementia with Lewy Bodies)
4.2. Carers utilize medication to manage the impact incontinence has on sleep	Carers sleep becomes significantly impacted. PWD starts taking medication, which manages their incontinence and reduces the number of sleep disturbances for both them and carer	*‘Sleep was intermittent and disruptive, however with medication normalcy returned’* (74-year-old female caring for her 71-year-old spouse with an undisclosed form of dementia)

		‘PWD sleeps well now because he is on Quetiapine 75mg night. He has been on Quetiapine for about 2 years’ (69-year-old female caring for her 86-year-old spouse with Vascular dementia)
Incontinence impacts carers’ quality of life and ability to cope		
5. Incontinence impacts carers’ mental, emotional, and physical wellbeing		
5.1. Carers experience significant stress	Carers are often tearful, feel frustrated, and wish they had more support. Managing PWD’s catheter also creates additional stress, particularly when accidents occur	*‘Sometimes get very stressed, especially having to deal with double incontinence. I have taken my husband to the incontinence clinic at the hosp 3 times, I wish I had more help in this area’* (66-year-old female caring for her 73-year-old spouse with Alzheimer’s Disease) *‘As my husband now has a catheter (S,P.C) which causes him concern. I find this also quite stressful for myself’* (81-year-old female caring for her 85-year-old spouse with Alzheimer’s Disease)
5.2. Managing incontinence adds to carers workload	Carers clean up accidents, do extra laundry, frequently change clothing and bedding. Carers feel frustrated with the additional workload and physical toll	*‘Washing almost every day due to incontinence of my wife get very frustrated’* (87-year-old male caring for his 86-year-old spouse with an undiagnosed form of dementia). *‘He is incontinent of urine which means washing bedding on most days and sometimes changing trousers during the day’* (70-year-old female caring for her 70-year-old spouse with frontotemporal dementia)

5.3. Carers concerned about coping with incontinence as they age themselves	Incontinence adds another level of care and carers are worried about coping long term. Carers quality of life is impacted. Carers are aging themselves and are already struggling to cope mentally and physically	*'I really don't know how I can cope. I'm 87 next month and just feel I cannot keep on doing all the washing and cooking and coping'* (86-year-old male caring for his 88-year-old spouse with an unknown form or dementia)
6. Incontinence drives care referral		
6.1. Incontinence tips the coping scales and leads carers to consider formal care options	Carers are sleep deprived and struggling to cope now that PWD is incontinent. Lack of money restricts options	*'My wife is now becoming incontinent, and I am struggling to care for her. She SHOULD be in a home, but I cannot afford to pay for it'* (86-year-old male caring for his 88-year-old spouse with an unknown form of dementia)
6.2. Carers are unable to cope now that PWD is completely incontinent	Carers are struggling to cope with managing incontinence, incontinence is seen as a hospital-level symptom of dementia and is a deciding factor, and often the reason for moving PWD into formal care	*'A year later she is now hospital level care. We knew she would have to go in somewhere eventually as I'm not a nurse and she would need professional care - that time has come - she is completely incontinent'* (55-year-old female caring for her 80-year-old mother with dementia with Lewy Bodies)

Sleep Becomes Progressively Disrupted Due to Toileting Needs

The first theme: *Sleep becomes progressively disrupted due to toileting needs,* refers to how toileting needs impact sleep during the later stages of life and throughout the trajectory of the dementia-care role. A familiarity of negotiating toileting with sleep across the lifespan was clear. This included pre-dementia care, to early onset of dementia symptoms, and right through to the later stages of informal dementia care. Some carers described having issues with sleep prior to their care recipient's dementia diagnosis, and these carers discussed a familiarity of surviving and thriving on the amount of sleep they achieved each night.

Other carers talked about noticing changes in their own toileting habits, particularly an increase in night-time toileting, which they interpreted as being a natural and expected consequence of aging. In the early stages of dementia-care, carers were generally nonchalant about their own and their care recipient's changes in toileting needs and seemed to adapt and cope well to these changes. The following quote illustrates this very concept: "In general, I sleep well but do need to wake to relieve myself and usually go back to sleep" (84-year-old female who cared for her 87-year-old spouse with an undisclosed form of dementia). Some carers also spoke about the pre-existing medical conditions of their care recipient with dementia, and how thy attributed to and seemed to exacerbate their care recipient's night-time toileting needs, which also influenced the amount of sleep they and their care recipient were able to achieve each night.

As their care recipient's disease progressed, and their dementia symptoms became more impactful, carers described noticing incremental changes to the frequency of night-time toileting, which started to really impinge on their sleep, and on the sleep of their care recipient; particularly in terms of the duration and quality of the sleep they experienced each night. The second sub-theme: night-time toileting needs contribute to sleep disruptions was created to illustrate the way night-time toileting needs increased throughout the care role, and alongside ageing and worsening dementia symptoms, which caused sleep disruptions which worsened due to night-time toileting of both the carer and care recipient. This quote provides an example: “My lack of quality sleep is due to the number of times my wife gets up to go to the toilet and getting up early "I’m up everyone is up" no chance of a lie in wife unsteady on feet so lights are on” (72-year-old male caring for his 79-year-old spouse with mixed dementia).

Carers also talked about their own pre-existing sleep problems, and how these were exacerbated by the continually increasing toileting needs of both them and their care recipient due to aging and the development and worsening of dementia symptoms. Some of the pre-existing issues described by carers as influencing sleep disruptions included: being a light sleeper; taking medication which interfered with sleep; and having health issues such as asthma, artritis and other pain-related conditions. The following quote represents this finding well: “My sleep has always been erratic but worsened due to my husband’s rapidly deteriorating condition. His sleep is also erratic as he doesn’t comprehend night or day and often wakes me for reassurance. He gets up regularly to go to the toilet as do I” (87-year-old female caring for her 92-year-old spouse with mixed dementia).

Managing Incontinence for Supporting Sleep and Waking Life

As the disease progressed and managing continence morphed into managing incontinence, carers described significant disruptions to their sleep, particularly with regards to the quality of sleep they achieved each night. Some carers discussed the influences on sleep quality as being attributed to sleeping on high alert, which meant that they were often in a light sleep or on what they referred to as ‘standby mode’, which meant they were ready to spring into action at any moment as required. The theme ‘incontinence presented a great problem for sleep’ was constructed to represent how the carers sleep, including quality sleep, was significantly disrupted by the practices involved in manging incontinence. This excerpt provides an example of this theme: “The impact on my sleep in not just actual interruptions when mum goes to the toilet - which is sometimes every hour but mostly 3 - 4 times a night. The quality of sleep is also undermined because I always have an ear out for her, so I never drop into a deep sleep. Being on the edge of wakefulness is debilitating and is a hard pattern to break, even when mum is away on respite” (54-year-old female caring for her 85-year-old mother with Alzheimer’s Disease).

As incontinence issues continued and worsened, carers began to develop management strategies to help mitigate the impact that managing incontinence had on their sleep. These themes are summarised under the theme: ‘carers use strategies to relieve the impact incontinence has on sleep’. Some of the ways carers achieved this was by waking the person with dementia during the night, often at the same time as they needed to use the toilet, which worked to maximise their time and at the same time usually prevented additional sleep disruptions. This strategy also worked to minimise accidents, which if they occurred would negatively impact the carers workload and stress levels. On the other hand, this strategy also served to protect the dignity and comfort of their care recipient, by allowing them some authority and independence over their own toileting. An example of this is shown in the following quote: “To manage we go [to the toilet] x 2 per night” (79-year-old male caring for his 79-year-old spouse with mixed dementia).

Another way incontinence was managed is included in the above-described theme (carers use strategies to relieve the impact incontinence has on sleep) and includes how carers experienced less sleep disruptions when the person with dementia started medication that helped to manage their symptoms, allowing their own and their carers sleep patterns to return to a more normal schedule. The following quote illustrates this: “Sleep was intermittent and disruptive, however with medication normalcy returned” (74-year-old female caring for her 71-year-old spouse with an undisclosed form of dementia).

Incontinence Impacts Carers Quality of Life and Ability to Cope

This final global theme constructed concerns the impact of managing incontinence in dementia care, and how informal carers experienced this situation in terms of their mental, emotional, and physical health and wellbeing. Aside from sleep, a key theme constructed from the data was around how ‘incontinence impacts carers’ mental, emotional, and physical wellbeing’. This theme represents how when incontinence became a significant issue, carer’s experienced relentless frustration and emotional distress, along with stress, feelings of isolation, and the feeling of being generally unsupported in their role. This theme is represented in the following quote: “I just got very, very tired of dealing with repetitiveness and incontinence and having to stay calm so as not to upset him. Cried a lot when on my own” (69-year-old female caring for her 77-year-old spouse with Alzheimer’s Disease).

Carers also described the impact of having extra washing such as bedding and clothes due to toileting accidents, which they described as both adding to their already heavy workload, and negatively impacting them both mentally and emotionally. This was described to add to the physical toll they experienced, which they attributed to the extra work of washing clothes and bedding and cleaning up any toileting accidents caused by incontinence. This extra workload caused a huge amount of stress for carers, particularly because they were experiencing some of the consequences of ageing themselves, and so physical work was becoming much harder to manage anyway. This is described in this excerpt: “Washing almost every day due to incontinence of wife get very frustrated” (87-year-old male caring for his 86-year-old spouse with an undiagnosed form of dementia).

For many, factors involved in managing incontinence exceeded their capabilities and caused them to seek out formal care options for their care recipient. The theme “Incontinence drives care referral” outlines how this decision is largely the result of long-term sleep deprivation due to managing dementia-related incontinence and other dementia-related symptoms; and due to a significantly reduced capacity to cope as the carers age and their own health and functioning begins to deteriorate, as described by this wife below who supported her husband with incontinence. The following quote sums up the desperation experienced by some of the carer's: "Is becoming dire. He is incontinent most of the time" (69-year-old female caring for her 75-year-old spouse with Alzheimer's Disease).

Sleep Survey Results Summary

In summary, the findings from the sleep survey showed how managing dementia-related incontinence impacted the lives of informal carers in terms of vital areas such as health, wellbeing, sleep, and the overall quality of their day-to-day lives. What became evident was the progressive nature of toileting changes alongside ageing and the developing and worsening of dementia symptoms, which impacted the carers' ability to cope and their capacity to care. Further findings supported associations between caregiving and reduced health, wellbeing, and overall quality of life, which was mostly attributed to the exceptional demands and stress associated with sleep deprivation, which was influenced by the mental, emotional, and physical toll involved in managing dementia-related incontinence. The findings from the sleep survey data provided a solid foundation for the more involved narrative work with the interview data, which will be described in detail below.

Interview Narratives

For the interview data, 14 out of the 20 carers who participated were female; 11 female carers cared for their husbands; six male carers cared for their wives; one female carer cared for her mother; one female carer cared for her grandfather; and one female carer cared for her long-term friend. Thirteen of the 20 interviewees mentioned continence and/or incontinence and therefore their data was included in the present study. Table 2 below outlines the carers' and care recipients' demographic details.

Table 2.

Carer and care recipient demographics

ID no.	Carer	Care recipient	Place of interview	Region	Age	Length of care	Dementia type
1	Sonia	Martin	Home	urban	68	6	Mixed
2	Steven	Karen	Home	urban	83	3	Alzheimer's
3	Sue	Brent	Home	urban	79	4	Prob. Alzheimer's
7	Nathalie	William	Home	urban	64	3.5	Vascular
8	Pamela	Tony	Home	urban	75	5	Vascular
9	Grace	Edward	Home	urban	69	3.5	Vascular
11	Olivia	Holly	Phone	urban	73	3.5	Alzheimer's
13	John	Linda	Home	urban	83	3.7	Vascular
14	Emma	Matthew	Phone	rural	66	3	Frontotemporal
15	Jacob	Ivy	Phone	rural	87	3	Unknown
16	Daniel	Lucy	Phone	rural	73	5	Alzheimer's
17	Hannah	Charles	Phone	rural	76	8	Alzheimer's
18	Harry	Molly	Phone	rural	81	2.7	Unknown

One of the key interview narratives aligned with one of the main themes that came from the sleep survey, namely, ‘sleep becomes progressively disrupted due to toileting needs’; with the three final key narratives created including: “That made a huge difference when he had a dry bed in the morning’’; “It was just a nightmare”; and “We still have emotional problems, you know?” These three narratives were termed using direct quotes from the interview data, as they accurately reflect the experiences of the participants in the setting of post in-home care of a family member or relative with dementia.

More than half of the carers interviewed (65%) brought up issues pertaining to managing continence and/or incontinence throughout their informal dementia-care role. Not only did they bring up these issues, but they did so despite not being asked any specific questions relating to continence or incontinence throughout their interviews. As with the findings produced from the sleep survey comments, the interview data illustrated how the impacts of managing dementia-related incontinence significantly impacted the carer’s ability to cope, and subsequently for many of them resulted in them making the difficult decision to move their care recipient into formal care.

The similarities between the survey comments data and the interview data were evident throughout the carers’ discussions around the progression of sleep disruptions, particularly in terms of increasing toileting needs alongside the progression of dementia symptoms, and ageing, which collaboratively negatively impacted the sleep of both the carer and their care recipient. Further to this, there were three overarching narratives established, which were titled using direct quotes from the data that nicely summed up each of the narratives. The three narratives are entitled: “That made a huge difference when he had a dry bed in the morning”; “It was just a nightmare”; and “We still have emotional problems, you know?”

“That Made a Huge Difference when he had a Dry Bed in the Morning”

This first interview narrative represents how managing dementia-related incontinence impacts the carer’s emotional and physical wellbeing; and how it has further implications for both them and their care recipient in terms of their overall quality of life and life satisfaction. This narrative also illustrates the carers experiences of managing incontinence alongside getting enough quality sleep to function properly during the day, and to fulfil their role as a caregiver. Across the data set, carers described how dealing with incontinence negatively impacted their sleep, which was largely associated with the stress and worry that came with managing night-time accidents. In that same vein, carers spoke about the additional mental toll that managing incontinence added to an already extremely challenging and stressful role.

This first excerpt was taken from an interview with an 81-year-old man named Harry, who cared for his wife Molly with an unknown type of dementia for nearly three years. Harry’s excerpt was chosen to illustrate the significant mental toll involved in manging incontinence alongside frequent sleep disturbances. Harry had just been talking to the interviewer about how he had always been a pretty good sleeper prior to becoming an informal carer.

INT: Did that change much over, well, obviously it changed a little bit with age, but with your wife’s dementia did that change for you, or was your sleep disrupted?

HARRY: Certainly, it did because I had to be very careful. In those days I had to get something to put over the sheets and that, because she would wet herself during the night (even though I put those pull-ups on her). Quite often she would, like if I didn’t try and get in the habit of sort of waking about every hour and a half and basically try to wake her up and then drag her to the toilet to go to the toilet, then yes, you could end up with a bit of a mess in the morning. So yes, that interfered with your sleep quite a bit because every time you sort of just got into a light sleep, you'd wake up and think 'Right I've got to get up and get her to the toilet'. That was four or five times over the period overnight, so that was quite a worry.

INT: Was that her main issue with sleeping, was the toileting?

HARRY: Yes, yes I'd say so, and of course you worry about the person themselves because they get to the stage where they can't communicate, so you're never quite sure. She had got to the stage where she really didn't know me as her husband, she knew me, ah, the best way she described it to the doctor was I was just a good friend that helped her out. So, I think, yes, those sorts of things play on your mind.

Later in the interview the mental toll carried by Harry was further illustrated in the way he described his felt sense of needing to be there constantly to tend to his wife Molly's incontinence, and how this was always on the edge of his mind.

HARRY: …So you were very – as I say, you were very conscious you had someone that had no control. You had to make sure that you got in there quite frequently, and quite often it would be a matter of, even if you get her there, she'd be saying she didn't want to go and all of that

– but she would. So, I think that as far as the sleep goes, that was the biggest problem. It's on your mind all the time.

Carers also discussed how they experienced a lot of guilt around incontinence care, particularly regarding leaving their care recipient in wet or soiled bedding for extended periods of time when they weren't immediately available to assist them. Often this would occur overnight when the carer was getting some much-needed sleep. During this time, carers were unable to immediately clean-up accidents, or they felt guilty that they weren't there to intervene prior to the accident occurring to prevent it from happening in the first place. The constant need to be on standby, to be ready to assist their care recipient around the clock was a common narrative throughout the interviews, and as is stated in the title of this narrative, carers were extremely grateful when they got up to find a clean and dry bed in the morning, as this was a rarity and an occurrence that significantly helped to alleviate their stress and feelings of guilt. To illustrate this point, 66-year-old carer Emma describes caring for her husband Matthew with frontotemporal dementia for three years. This next excerpt provides an example of the extra workload experienced by Emma and many other carers due to managing incontinence, and as the title suggests, it also illustrated the relief they experienced when their care recipient has a clean and dry bed in the morning.

EMMA: That's another thing, you know, you go to bed, and you know in the morning with every other thing you've got to do, you've got to get up and it wasn't just the sheets, it would be the whole bedding. The worst thing is he's been lying in that.

INT: Yeah, that's not nice, is it?

EMMA: No, no, well you feel as though you're neglecting them and things. I know yours is a sleep survey, but those things do affect you because you're worrying about it the next day, you know that's how it's going to be, and that made a huge difference when he had a dry bed in the morning.

This narrative also illustrates the impact that managing incontinence had on the carers ability to enjoy leisure activities, particularly activities that involved getting out and about in their local community to do things with their care recipient that they had both previously enjoyed. One particular carer named Sue, a 79-year-old lady caring for her husband Brent with Alzheimer's Disease for four years, had a very good example of how dealing with incontinence impacted their usual church outing, having implications for the rest of their day. Below is the excerpt from her interview.

SUE: I remember one day a friend picked us up and we went to church but just before we went he went to the toilet and as he walked past me to get in the car I thought 'oh he smells, I wonder if he's just blown off of has he not cleaned himself properly' and I thought and she was waiting and I thought 'oh well, just better hope, no perhaps the smell was clinging on him from just coming from the toilet' but all the way through church every time he stood up or sit down the smell got stronger and all I could, I just wanted to get home.

Furthermore, this situation also had ramifications for the carer's mental and emotional wellbeing in terms of her dreading the clean-up ahead, as well as managing other feelings such as embarrassment over the unpleasant smell throughout church; guilt about inconveniencing her friend; and fear about what others might be thinking, and about the judgements they might be making about her and her care recipient.

SUE: So but we sat the whole service out because the friend was sitting somewhere else and I couldn't make – and I was conscious about people around me, anyhow as soon as we came in, our ritual was we'd come in, have a cup of coffee, a nice bit of cake, put the heater on if it was winter and all that sort of thing, and I said ‘look I think you’ve dirtied yourself, we better go to the shower’ so there I’m still in my good clothes, get him undressed, he was like ‘oh’ cause he can’t stand on one leg and it’s awkward, he’s a big tall 6 foot 2 guy and anyway and it’s he – you know they don’t realise it’s such as business as what it is.

Sue’s experience described above also highlights how the carer and their care recipient’s usual rituals were interrupted and essentially ruined by incontinence. Rather than enjoying their outing and their post-outing rituals, the carer spent the entire time worrying and mentally managing the situation with the goal of getting home as quickly as possible to clean up.

Eventually, carers found that the stress associated with managing incontinence and the impact on their sleep were among the key drivers for seeking out formal care options for their care recipient. For most carers, this decision was associated with the impact managing incontinence had on their mental and physical wellbeing and their sleep, as well as the wellbeing and sleep of their care recipient. This is illustrated by this excerpt from a participant named Hannah, a 76-year-old lady who supported her husband Charles with Alzheimer’s Disease for eight years.

INT: Yeah, and that’s kind of what… I’m quite interested in that really, you know, obviously your role is not like it ends when…

HANNAH: I couldn’t, I just couldn’t sleep and I was – however, that all sorted itself out and now I’m sleeping.

INT: And how much of role, you know I mean, making the decision to move him into permanent care, was obviously you know, it is quite a difficult decision to make, but was there anything that initiated that or, what was the…

HANNAH: Yes well I had decided some time – going back a bit, I had been working in a gerontological hospital prior to all of this happening, well even while he was in the early stages, but I had decided that if he became aggressive or when he became incontinent, I would not cope with him at home. And although he didn't ever become aggressive, I could see that it could happen and as far as incontinence went, I realised that I was actually toileting him and keeping him regular, and all that sort of thing, and it wasn't until he actually had nocturnal incontinence that I thought, no I can't go on much longer, but we got incontinent products and we did everything possible, but he still rather took the product off and still decided that the bed was the best place. And that's when I really said this is it.

Some carers, like 64-year-old wife Nathalie, who cared for her husband William with vascular dementia for three and a half years, had the opportunity to gain input from their care recipient regarding this difficult decision. This excerpt illustrates Nathalie's experience.

NATHALIE: And I said well look, the way he was. He was so anxious. He wasn't sleeping. He was. He was incontinent. He was urinating everywhere. Yeah. So that's when he said, he said go and look for homes, and, you know?

INT: Right. So, he's kind of, it wasn't a decision you sort of?

> NATHALIE: It wasn’t a position where I had to think look, its, you know. He’s not bad enough, but maybe he needs to go in or whatever. It, at that time he was, yeah, and I. God I’m so glad I did because like in the home he was just even worse. They, they, yeah. All they could have in his bedroom was a bed. Because he urinated in drawers. He urinated up the wall. He urinated over the chairs.

Carers also spoke about their care recipients wishes prior to becoming incontinent, which they described in terms of knowing that becoming incontinent was a significant future concern for their care recipient. For some carers, this knowledge helped them validate the decision to move their care recipient into formal care, as they felt it was what their care recipient would have wanted. The below excerpt from Nathalie’s interview highlights the difficult position she faced when dealing with incontinence and the decision to transition her husband into formal care.

> NATHALIE: Oh, poor guy I just think. Look he’s, his nightmare’s come true. The two things were being in a home. He used to say shoot me. Don’t do that to me, just shoot me. And being incontinent. That was just his terror. Absolute terror.

“It was Just a Nightmare”

This second narrative outlines the struggles some carers reported in terms of accessing effective incontinence products and gaining helpful incontinence advice from health professionals. Several carers found that health professionals didn’t seem to have appropriate awareness or knowledge around effective incontinence management, and they found getting advice from health professionals about good incontinence products extremely difficult. This seemed to create a considerable amount of stress for carers, who were already experiencing high levels of stress due to their busy role, and mainly due to managing incontinence day and night. The below except provides a good example of this point, and the quote from the title of this narrative comes from the earlier introduced Emma, who cared for her husband Matthew with frontotemporal dementia for three years.

EMMA: …and actually that was one big battle I had, was to get them to give me continence supplies. It was just a nightmare.

INT: Again, unfortunately it’s not an uncommon story the troubles of getting that sorted and it’s something that can make such a big difference, isn’t it, especially for night-time if they have incontinence.

EMMA: Well, every morning I was having to change the whole bed because the ones you can buy are of no use at all, and apparently he did have a condition where he does all his urinating at night almost, and the other thing, his bowels just went continually so there was that. But in the end the only way I got the continence supplies was my friend just went to the district nurse in town and just demanded them. I never did see the continence nurse or anyone, but yeah, it’s those things…

Another carer’s experience was similar to Emma’s in terms of the struggles associated with trying to get effective incontinence products for dealing with incontinence. Sonia, a 68-year-old lady caring for her husband Martin with mixed dementia for six years describes her relentless ordeal in trying to get support for incontinence. Sonia describes her frustration in the below excerpt, which outlines how she experienced continuous frustration, which was underpinned by confusion and disbelief at the service provided by the local healthcare system, mainly because she was disappointed with the lack of knowledge and advice offered regarding managing incontinence, despite the fact that she offered to pay good money for the best advice and products available, but still she was left with what she described as sanitary pads, which were not even slightly effective at containing urinary leakage at the level of which she was experiencing.

SONIA: I shouldn't talk badly of people, but he was under the incontinence clinic at the hospital, and they were the worst people that I've ever come across.

INT: That's a shame.

SONIA: They were absolutely hopeless. And I understand that they have got a duty not to sell me the best products. But I was buying them. It's not like I'd be getting them for free. So, and I'm explaining that I had this terrible problem with incontinence, and they would give me, or give me to try, and then I was buying them, more, like a sanitary towel.

INT: Yeah, yeah, wouldn't work.

SONIA: And I felt well, these must work because the professionals have given it to me. And like an idiot I think the professionals know what they're doing. But unfortunately, I've discovered, sadly, that they don't know any more than I do. And I kept going back to the clinic and saying these aren't working. Could we try something else? Cos I don't know what's available. It's their job. Then they'd try me with a larger size. But it was still…

INT: Not the right thing.

SONIA: It was still nothing. It's just like a period pad. It just wasn't doing the job.

INT: So, you’re having to change sheets in the night and…

SONIA: Not only sheets but all the blankets. It’s just a nightmare. And then, I don’t know how, I’m not sure how eventually we got the right product, but, but it took two years. It took two years to get the right product. And the right product in the end was pull up pants. But going backwards and forwards thinking. I didn’t even know, you see, in ignorance I didn’t honestly know, that that would be the best product.

INT: Well, and, like you say. It’s not your, it’s not your place to know that.

SONIA: No.

INT: Yeah that’s, I can imagine that’s frustrating. Yeah.

SONIA: Yeah and getting the right size you know. You’ve got to have the right size. So that was another couple of months trying to get the right size. It was really frustrating.

Gaining effective support may have helped improve the overall quality of life for both Sonia and her husband Martin, allowing her to manage her husband’s incontinence more easily. Sonia’s excerpt also highlights the amount of time and energy spent on trying to get incontinence advice and products, which was especially frustrating due to the limited time and energy she already had over and above caring for her husband. The way this carer repeats herself (“it took two years; it took two years”) really emphasises the frustration she felt over this situation. Moreover, the lack of support Sonia experienced eventually contributed to her seeking out formal care options for Martin, which would have been delayed if Sonia had access to effective support that enabled her to continue caring for her husband in their own home.

“We Still have Emotional Problems, you Know?”

The last interview narrative provides insight into the implications for carers once their care recipient had transitioned into formal care. Carers seemed to have similar emotional responses to this life-altering transition, with most experiencing a combination of relief, sadness, and guilt. Alongside other feelings, the feelings of relief were mainly attributed to no longer having to deal with their care recipient’s incontinence. Along with relief, there was also often an extreme sense of guilt felt by carers, which was mostly associated with the decision to move their care recipient into formal care. Some carers explained dreading making such a difficult decision but went on to say that at the point they had reached it felt like the only option available to them. Olivia, a 73-year-old female caring for her friend Holly with Alzheimer’s Disease for three and a half years, explained how the discission to transfer her friend into formal care was almost taken out of her hands. The following excerpt describes the unfolding events.

INT: Yes, interesting isn’t it. I mean a few people have said that, you know, there's an event for yourself as the carer and so yeah, they go into respite, then actually the decision is kind of taken out of your hands.

OLIVIA: It was made for me and then I felt guilty for a long time, that should I bring her home again? I think that's all part of it. We shared this house for 25 years, so it was a long time, but she's not far away and I go in most days. She thinks I actually live there now so that's quite good. She doesn't know, she doesn't even remember the house so that's good, but she's still very incontinent of both bowels and urine, so I'm glad I haven't got that work to do.

This next excerpt gives an example from Harry's perspective, in terms of his feelings of guilt around moving his wife Molly into formal care. Harry seems almost haunted by his decision as he reflects on whether he did enough, as he talks about coming to terms with his loss.

> HARRY: It brought tears to my eyes, put it that way. Yeah, it really upset me, and I felt like a real, how would you say, a real heel to do this to somebody, you know, particularly when the person was, you know, your wife is complaining they shouldn't be there, and why am I going and quite agro with that. Yes, you felt really, really terrible, and even to go to visit her in the rest home, I think your memories of what the person was and all of that, and what it's done to them, and yeah, no but it takes a long, well, it's hard to convince yourself that that was necessary. You keep thinking, could I have done it better?

Conversely, there were some positive aspects in terms of marked improvements to carers overall quality of life, and ability to enjoy participating in activities outside the home again, which they found extremely difficult to make time for during their time as a full-time caregiver. The excerpt below illustrates the relief and sense of freedom experienced by Sonia, the 68-year-old lady who cared for her husband Martin with mixed dementia for six years. Sonia describes no longer having to manage her husband's incontinence. It also highlights the invaluable support that can come from connecting with others who have shared similar experiences.

> SONIA: I've joined everything. I go to the coffee tomorrow morning, is the [x] coffee club. And that's for people who've put their care recipients in homes… yes so that's really good because although we don't have to

worry now about what pads they're using or if the beds wet, what a relief, we still have emotional problems, you know?

Another more positive consequence of their care recipient moving into formal care included significant improvements to the carers sleep. The stress carers endured throughout their role of caring is rather evident in the way they talk about their lives post-care, particularly with regards to changes in their sleep patterns and routines:

INT: I was saying you've been through a few transitions, and I was just wondering, you know, when your wife moved into the care home, did your sleep improve immediately without having those disruptions at night or …?

HARRY: Oh yes, yes, much better, eh? You didn't have all that stress or worrying about trying to convince them for those odd days they were going, and they didn't want to go, so that's taken away from ya, and obviously you weren't waking up in the night-time thinking, 'Right. Oh quick, I've gotta jump out of bed and get her to the toilet', or whatever. Yes, no, it did improve.

The excerpt above from 81-year-old Harry nicely sums up the intense sense of freedom and autonomy over their own sleep that carers experienced post-care upon gaining some form of normality back in terms of their sleep patterns and routines. However, the majority of carers had mixed responses, and the quote which entitles this last narrative kind of sums their experiences up perfectly; although they haven't got the same level or work to do, and they aren't as sleep deprived as when they were caring for their friend or relative, they still have to adapt to their new sense of reality as they navigate the grieving process involved in loss, and as they heal and move forward with their lives.

Chapter Six: Discussion

This research aimed to explore how managing dementia-related incontinence impacted informal carers in terms of their sleep, health, wellbeing, and quality of life. This was explored using two sets of previously collected data, which produced content on how the sleep and health of family carers was impacted by managing incontinence in the setting of in-home dementia care. One of the key findings that came from both the sleep survey data and the interview data was the awareness caregivers had in term of the progressive changes to their continence with age, and with the developing or worsening of dementia symptoms among their care recipients. Carers were able to talk about the trajectory of their care experiences and reflect on continence changes throughout their lifespan, including the changes they noticed pre-care, during their care role and then post care upon reflection during the interview process.

Continence Changes

Pre-care, most carers noticed a slight increase in the frequency of their own toileting needs as they aged, which they mostly described as a normal and expected consequence of ageing that didn’t impact their sleep, health, or daily life too much and therefore wasn’t much of a concern for them. This finding is in-line with what research suggests naturally occurs at the pathological level in response to ageing. According to Nazarko (2019), whose research is around the palliative care of older adults, as we age, there are pathological changes that occur within the body’s main organs which reduce normal functioning and impact our day-to-day life. The changes that specifically affect continence mainly occur within the kidneys, which are the organs responsible for several vital bodily functions including: balancing fluids, maintaining electrolyte and PH levels, excreting waste, and producing essential vitamins such as vitamin D (Nazarko, 2019). The result of these normal age-related changes mean altered kidney functioning, causing the kidneys to be less effective at concentrating urine and balancing PH levels, which leads to an increase in the frequency of urination as we age (Nazarko, 2019).

Carers discussed noticing an increase in their own toileting, especially at night, which was even more impactful to them if they were also helping their care recipient manage their toileting needs, particularly if they had incontinence. The pathological changes that occurred in response to ageing were generally conceptualised as normal and natural, and as such the carer was able to adapt over time. In contrast, continence issues and incontinence caused by dementia occurs at a much faster rate. These findings are in support of previous research carried out as part of an Australian study involving 100 older adults aged 65 years and over with dementia who, at the time of admittance to acute and sub-acute hospital care, were completely continent. Furlanetto and Emond (2014) illustrated a correlation between the development of incontinence and longer stays in acute and sub-acute hospital care over a two-year time period (Furlanetto & Emond, 2014). This study points out the importance of maintaining continence for as long as possible in individuals affected by dementia, and it also suggests that nurses and continence promotion practices are vital for maintaining the dignity and health of people affected by this disease and their carers (Furlanetto & Emond, 2014).

There is growing research to suggest that the greater decline we experience in terms of kidney functioning, the greater the risk is for developing neurocognitive disorders such as dementia (Dyer et al., 2022). Recent research by the above-named authors, who conducted a study among 4887 community-dwelling older adults living without neurocognitive disorder, identified a strong correlation between declining kidney functioning and the development of dementia-related conditions. Most interestingly, the study pointed out a potential opportunity to target interventions aimed at reducing the risk of older adults developing dementia-related cognitive impairment, particularly among those aged between 60-and-70-years old living free from cognitive impairment (Dyer et al., 2022). This could be something that future research could consider exploring among informal carers, who at the time of data collection for the present study were free from dementia symptoms themselves and were experiencing the beginnings of declining kidney functioning. Bearing in mind of course that there are other causes of increased toileting and the development of dementia-related incontinence which are not associated with kidney function; but rather may be due to sleep disruptions and/or memory-related cognitive decline which can cause behaviour such as forgetting to use the toilet or thinking they have already gone (Dyer et al., 2022).

Managing Incontinence and the Impact on Sleep and Health

The most notable finding that came from the present study was the immense impact that managing dementia-related incontinence around the clock had on the sleep, health, and quality of life of carers. Because the wider study pre-empting this thesis was on the sleep health of informal carers in the setting of dementia (Gibson & Gander, 2021; Gibson et al., 2020) the interviews were framed around caregiving experiences in relation to sleep, and as a result sleep disturbances were the most commonly discussed consequence of caring for a care recipient with dementia. However, despite the lack of interview questions relating to continence and/or incontinence there was the revelation that carers who dealt with incontinence day and night experienced even greater disruptions to their sleep, as well as a noticeable decline to their own mental and emotional health which impacted their overall quality of life and, eventually, their ability to cope.

One of the key concerns relating to sleep that was constructed from the data was the impact to the quality of sleep that carers achieved each night, which was significantly reduced during their role as an informal carer. This negative impact to quality sleep was mostly attributed to managing night-time incontinence, particularly due to the number of times carers had to get up to assist their care recipient in the night, or due to carers having to sleep on high alert waiting for the need to get up and assist their care recipients.

These findings are complementary to the sleep research by Gibson and Gander (2021); and Gibson et al. (2020), whose research explored how the many factors of sleep health, including getting enough quality sleep, were impacted by the challenges associated with the role of caring for a friend or relative with dementia. Quality sleep was explored in a systematic review by Almutairi and Zauszniewski (2022) who also looked at sleep disturbances among informal carers in the setting of dementia. Their review outlined the links between sleep disturbances, poor sleep quality and mental strain and illnesses such as anxiety and depression. An interesting finding that came from the review was the reciprocal relationship between sleep disturbances and anxiety and depression, whereby each had the tendency to affect and even induce the other. This finding, alongside the findings from the present study, have the potential to produce positive health and wellbeing outcomes for carers because these factors can be modified through more appropriate support, which could be developed to enable carers to effectively manage some of the negative aspects of the informal caregiving role (Almutairi & Zauszniewski, 2022). The implementation of proper support for carers would likely help facilitate better sleep quality, and possibly allow them to continue on in their role for longer, which would enable their care recipient to remain in their own home, rather than being moved into formal care facilities.

The significant impact of managing incontinence within the role of caregiving was also explored in similar recent research by Talley et al. (2021) who carried out a systematic review and meta-aggregation of the experiences of carers managing incontinence in a formal in-home caregiving setting. Their research showed how managing incontinence causes significant stress and affects all areas of the carer’s health, including mental, emotional, physical, spiritual, social, and financial; and it also pointed out the need for better support and education for caregivers to allow them to stay in their roles safely and without burning themselves out (Talley et al., 2021). These results were reflected in this thesis, which illustrated how managing dementia-related incontinence impacts carers sleep, health, wellbeing, and quality of life. Further, the impacts on carers sleep and its nuanced link to waking indicators of burn out, such as stress, emotional distress, and a decreased capacity to cope were also revealed.

Caring for the Carer

This thesis has highlighted that carers of people living with dementia require proper support to do their role effectively, and to ensure that they are able to maintain their own health and wellbeing alongside their care recipient. Furthermore, the societal issues around carers seeking advice and support need to be addressed, particularly around taboo subjects such as continence and incontinence, with the aim of normalising support seeking. This could be achieved through education and social marketing whereby the challenges of the caregiving role are brought to light so that carers can easily access advice and support services without feeling guilty or stigmatised.

The demands and challenges involved in the caregiver role can be considerable (Drennan et al., 2011), and as such carers need support to empower and enable them to continue their role safely. One of the ways informal carers may get some reprieve from their role is by engaging in external support services such as respite care. Respite might be sought out if carers are suffering from significant stress or become unwell and struggle to care for their family member. According to Brandão et al. (2016), “respite care is a formal and specialized support service that includes a set of interventions aimed to provide a temporary relief to informal care givers so they can temporarily relinquish their duties and responsibilities and ameliorate their stress” (p. 254.).

In New Zealand, the Ministry of Social Development website has information on how one can access different respite services, which varies between different regions. Some of the options available include carer support, individualized funding, family/whānau home support, and facility-based respite (Ministry of Social Development, 2022). Although there are support services available, there are also barriers that prevent carers from seeking out help. One barrier that bares a mention involves the social elements which influence the carer's personal feelings around support seeking. Some carers appear to struggle with the decision to send their family members into respite care, often because they feel guilty about not being able to cope, or they worry about what other family members or friends might think of their ability to fulfil their role (Brandão et al., 2016). Moreover, some carers worry about the quality of care their care recipient might receive in respite, so they refrain from accessing this type of support service (Phillipson et al., 2022).

Some qualitative research that produced narratives from individual interviews that focused on how carers experienced and found meaning within the role of caring for a family member or a friend with dementia, alongside the influences of respite care, were presented by Tretteteig et al. (2017). Their research found that carers struggled with maintaining a good working balance between looking after their own personal health and wellbeing needs and the needs of their care recipient. However, carers who utilized respite care, particularly day-care services, found that they were better able to meet their own needs and felt empowered and more motivated to care for themselves and their care recipients (Tretteteig et al., 2017).

Another similar qualitative study also looked at the perceived effectiveness of respite care for people with dementia. The study involved 35 various stakeholders including carers, managers, healthcare professionals, academics, and people living with dementia-related conditions. The study explored the factors that made respite care effective and beneficial for carers and those they supported. Three key themes were identified within the research as needing serious attention and further development, these themes were: person-centred respite care, recalibrating respite, and phases of transition (O'Shea et al., 2019). One stand-out finding from the above-described study was how well quality person-centred care helped support carers and people with dementia transition smoothly into respite care, and in doing so made it more successful and beneficial for both the person with dementia and their carer (O'Shea et al., 2019). On the other hand, there was a consensus that person-centred care was most desired by people with dementia and their caregivers, and staff also agreed that this type of care was crucial, however a vast majority held outdated biomedical definitions of what diligent person-centred care actually resembled (O'Shea et al., 2019).

This finding was echoed throughout the present research findings and underlines the importance of understanding what the people living with dementia and their support systems want and need to live well in place with dementia. It also highlights areas for development that will improve current health understandings, so that people living with dementia can receive the best and most up to date support as possible. Personalised in-home and community-based care that focuses on the person with dementia's strengths and needs, and tailors support to that individual and their carer was found to be the most valuable in terms of future recommendations for support development (O'Shea et al., 2019).

The Stigma Around Incontinence

Another important finding that came from the present interview data was the shame carers experienced associated with managing incontinence. Carers shared their feelings of embarrassment and shame, which they attributed to a need to protect their care recipient's dignity. Similar findings were also identified by Drennan et al. (2011), whose research revealed that carers often chose not to discuss incontinence issues with healthcare professionals as a way to protect their family members honour, and this was particularly common among family carers who cared for their spouse with dementia (Drennan et al., 2011).

An Australian study that aimed to ascertain the best methods for supporting family carers and those living with dementia who also had suffered from incontinence, found that there were several factors that prevented them from accepting support including embarrassment, fear, cultural taboos, and social stigma; however, these very factors were also found to be what triggered carers to seek out support for managing incontinence in the first place (Bostock & Kralik, 2006). This particular Australian study pointed out the importance of individualised incontinence assessment and intervention for supporting carers and those living with dementia-related incontinence and concluded by saying that incontinence is in fact treatable and even curable, but early detection and effective management is vital for this to occur (Bostock & Kralik, 2006). These findings suggest the need to develop routine continence assessments for informal carers caring for their friends or family members in their own homes, to give them the best possible chance of manging effectively.

Another way to interpret these findings could be in relation to the carer's feelings of success within their role, or in this case their perceived sense of failure at being unable to meet an essential need of their care recipient, or of fulfilling their role (Bostock & Kralik, 2006). This may have unintentionally created a conflicting situation, whereby the carer refrains from seeking help in order to protect their care recipient's dignity, however in doing so their care recipient loses dignity by way of embarrassment, when in fact their dignity could have been protected by engaging healthcare services that may have offered them alternatives to help them cope with incontinence more effectively. Research has documented the immense benefits of conducting proper incontinence assessments in a nursing care setting, with the aim of ascertaining the individuals' unique needs and tailoring a management plan specifically for them (Payne, 2018; Bostock & Kralik, 2006). The result of which involves effective incontinence management that preserves that individual's dignity and improves the overall quality of life for both them and their carer (Payne, 2018).

Despite the potential success of the above-described intervention, another common theme presented in this thesis is the lack of support provided by healthcare professionals in terms of managing incontinence effectively. Carers explained how even trying to get advice on how to manage, let alone finding effective products was a serious challenge and great cause of stress. As mentioned earlier, some carers chose not to seek support for how to cope with incontinence, however there were a number of carers who actively sought out advice and pleaded with healthcare professionals to no avail. Themes within "It was just a nightmare" illustrated the common stress and frustration experienced over trying to get proper advice and guidance for managing incontinence more effectively. Franken et al. (2018) highlighted the importance and effectiveness of qualified and experienced incontinence nurses in a community setting, saying that because of the prevalence of older adults globally, the nurses' role is becoming more and more crucial for improving the health of community-dwelling older adults in terms of continence management, and it also reduces the long-term associated costs of urinary incontinence (Franken et al., 2018).

Stress, Anxiety, Depression, and Subsequent Sleep Disruptions

The role of caregiving is consistently reported as being extremely challenging and taxing even without the additional workload involved in managing incontinence (Drennan et al., 2011; Lee & Lawson, 2021). Due to the level of cognitive impairment caused by dementia and the subsequent impact to activities of daily living, carers are faced with a heavy workload as they support their care recipient with dementia, the result of which is high levels of stress which takes its toll on their body and often leads to the development of stress-related health conditions such as anxiety and depression (Ervin et al., 2015). Research carried out among family carers in the setting of dementia showed that those with depressive symptoms which were present prior to the death or their family member with dementia were among those with psychological distress and sleep disturbances post-care (Corey et al., 2020).

In the present study, the mutual relationship between stress, anxiety, depression, and sleep disturbances was evident throughout both sets of data, with carers who reported experiencing higher rates of sleep disruption also reporting increasing levels of stress and worsening symptoms of both anxiety and depression. Similarly, Almutairi and Zauszniewski (2022) found that the most significant factor associated with sleep disturbances among family carers of people with dementia was the presence of depressive symptoms. These findings are somewhat reassuring because these factors have the potential to be modified and improved upon through changes to behaviour and thinking, which is possible with the implementation of appropriate interventions, proper education, and effective support for carers.

Incontinence Tips the Coping Scales

For most of the carers included in this study, manging incontinence was a significant source of stress, and eventually the impact on the carers sleep, health and quality of life led them towards seeking out formal care options for their care recipients. Even though dementia is widely acknowledged as a significant risk factor for developing incontinence, there is still a lack of support available to help community-dwelling individuals living with this symptom, as well as those who care for them (Murphy et al., 2021). There is also still such a large gap in research that looks at the specific impacts of managing continence and incontinence and the subsequent effects on the sleep, health, and wellbeing of informal carers in dementia care settings. One Canadian study showed the efficiency of implementing an intervention programme for informal carers supporting friends or family members with dementia in formal care settings (Ducharme et al., 2005). The programme was underpinned by empowerment and person-centred philosophies. It was entitled ‘Taking Care of Myself’ and involved 10 90-minute sessions of group psychoeducation (Ducharme et al., 2005). The sessions focused on identifying stressors; empowerment through identifying personal strengths and capabilities and developing awareness; and then learning to manage and control stress and stressors through reframing and problem solving (Ducharme et al., 2005).

Some carers in the present study discussed their experiences of utilising coping strategies such as medication and respite care, which helped them manage the associated stress and sleep deprivation that accompanied managing dementia-related incontinence. The psychoeducation programme highlighted in the Canadian study above could be a useful future direction in terms of non-pharmacological coping strategies for managing dementia-related incontinence.

Coping Strategies

To help them manage, carers developed coping strategies that offered them a sense of autonomy and control within their role. The use of medication was one strategy that was identified as a way to reduce some of the incidences of incontinence among people living with dementia. Carers described significant issues in terms of urinary accidents and sleep disturbances pre-medication, which was completely reversed upon their care recipient beginning regular medication. Carers reported how medication not only reduced the number of times their care recipient got up in the night, but it also allowed both the care recipient and the carer to sleep better, and it also reduced the incidences of incontinence, meaning that carers had less washing and cleaning, and care recipients were not left in wet and uncomfortable conditions. For this reason, medication was identified as a coping strategy utilised by carers.

This finding may warrant some concern considering that the use of these types of medications can have side effects pertaining to further cognitive impairment for the individual (Sura et al., 2013). Another important consideration here is around the individual's decision to utilise medication, and of course other underlying conditions and medications being used (Payne, 2020). Medications are also not advised as the best way to manage incontinence caused by dementia as they are only used to minimise symptoms and are only generally effective in easing symptoms of urge and stress incontinence; rather than the more complicated incontinence mostly seen in individuals with dementia (Payne, 2020). This finding also suggests the need to consider ethical issues around the utilisation of medication. More specifically, does the person with demean have the cognitive ability to comprehend the potential risks and benefits? This highlights the significant impact incontinence has on both the individual with dementia and their caregiver, because ultimately the decision to use or not use medication is an important one, and the carer is responsible for making that decision.

Another strategy that was identified as managing the impact of incontinence was respite care, and time for the carer to have a break away from their care responsibilities. Some carers talked about having the opportunity to get their care recipient into respite care and as a result they were able to spend some time catching up on sleep as well as doing other things they had neglected to do due to being so tired and busy in their role. A systematic review that endeavoured to ascertain how respite care supports informal carers of people with dementia found that day-care support was extremely effective for reducing stress and caregiver burnout, and it also served to minimise adverse behaviour in people with dementia, improving the caregivers overall care experience (Vandepitte et al., 2016). These findings were also reflected in the present study, whereby carers wished for more help and support from health professionals to alleviate some of their stress. These findings also further highlight how challenging the role of caregiving can be, and also validates the need for better in-home support for informal carers, to enable them to remain in their roles for longer; and to ensure that they are thriving as much as possible within that role.

Strengths and Considerations

The original sleep study focused on sleep and wellbeing in the setting of informal in-home dementia care. The present study has gone beyond these boundaries to explore how carers specifically experience and manage continence-related sleep disruptions and the impact on the overall caregiving situation. This included how their experiences affected them in terms of their sleep, health, and overall quality of life. Because the data came from two studies which were primarily about sleep and dementia care, the participants were primed to talk about their care experiences in terms of these factors; rather than being asked specifically about managing continence and/or incontinence within their role, and how this aspect of care might impact them. Further, because incontinence was not a key focus of the study there was no pressure or expectation for the carers to talk explicitly about continence and/or incontinence. This highlights the significance and impact of the topic, which more than half the carers interviewed chose to raise of their own accord.

In addition, the initial sleep survey was completed anonymously, and therefore the issue of stigmatism was removed, and carers had the freedom and anonymity to openly discuss issues such as continence and/or incontinence without feeling shame or embarrassment for themselves or their care recipient. Thus, this needs to be considered when interpreting these research findings. Interestingly, despite not being asked any questions relating to continence or incontinence carers brought this subject up for discussion of their own accord, without any prompting from the researchers, which further highlights the significant impact that managing incontinence has on the experiences of informal carers across the entire trajectory of in-home dementia care.

Furthermore, the carers who participated in this study mostly identified as being of New Zealand European ethnicity and all were members of regional Alzheimer’s New Zealand or Dementia New Zealand organisations. Membership of these and such other organisations has been identified as more likely among those of higher socioeconomic status, therefore underrepresenting the diversity within New Zealand (Horrell et al., 2015). This also lent them towards those who were more accepting of their situation, meaning they were better connected and more open to talking about their experiences, therefore themes may differ within a more diverse population. The sample did not adequately represent other demographics within the New Zealand population such as Māori, Pacific Island, Indian and Asian communities, which due to their different cultural beliefs and world views on health and practices and family structures would have likely yielded rather different results. Another strength of this study was its coverage of both rural and urban populations within New Zealand, and considering this study was the first of its kind, and despite its limitations, it was able to provide valuable insight into the care experiences of informal carers in the setting of in-home dementia care New Zealand.

Future Considerations

When this thesis discusses how managing incontinence impacts elements of the informal carer's health, this definition of health includes not only the physical dimensions, but also the mental and emotional elements of health, which creates a more holistic understanding of the carer's health as a whole, rather than segmenting the different elements. These research findings touched on elements which are increasingly recognised as important for health models in New Zealand's multi-culturally diverse population. This growing acknowledgement of health aspects such as emotions, family, and spirituality are all areas to be considered in future health research, particularly research involving Māori and other diverse populations in New Zealand. Further, future research should include not only the person-centred approaches, but also incorporate a Māori perspective including Māori researchers and people living with dementia. The findings from this thesis will provide foundational work on sleep and incontinence and the methods and interpretation can be adapted for other contexts and cultural groups.

The importance of looking at dementia through a Māori lens is vital due to the number of Māori living with this disease, and due to the negative implications for individuals, whānau, and the wider community. Māori tend to view health and wellbeing in a very holistic way, particularly in terms of the spiritual elements which are underpinned by their strong cultural values and connection to their language and to the natural environment (Staniland, 2011). Te Whare Tapa Whā is one Māori health model which was established by Professor Mason Durie in 1982 and outlines a common Māori view health as comprising more than just the mental (taha hinengaro) and physical (taha tinana) elements; but also, the spiritual (taha wairua), and the social and family (taha whānau) components as well. Maintaining balance in these four areas is deemed important for optimal health and wellbeing across the lifespan, and that lack of balance in any of these areas can be attributed as the root cause of illness and disease (Campbell, 2020).

As previously stated in the introduction, the rate at which New Zealand's ageing population is increasing is at record levels, in fact we are experiencing exponential increases in the number of older adults globally, which will only continue to surge over the next 20 years (Krishnamurthi et al., 2022). With that growth, the number of older adults being diagnosed with dementia will also increase, as will the number of informal carers who will stay home and care for their care recipients affected by this debilitating disease. Because of this, and because of the significant impact managing dementia-related incontinence has on informal carers and those they support, it appears vital to develop good support that can be rolled out to our most deserving and needing communities, as good support will not only help improve the quality of life among those living with dementia, but it may also improve the quality of life of informal carers, and even lower the risk of them developing neurocognitive disorder.

In terms of coping strategies, the literature review provided examples of some of the positive spiritual coping strategies adopted by carers that were shown to be protective in terms of maintaining their health, these included a sense of commitment to their care recipient and religious prayer (Talley et al., 2021). The broader belief systems such as religion and spiritual elements could be something future research explores in terms of helping carers cope with some of the challenging aspects of their role.

In terms of incontinence, although the incontinence assessment and subsequence incontinence management plan described earlier took place in a nursing setting in the United Kingdom (Payne, 2018), there's no reason why something similar could be developed and implemented here in New Zealand to be utilized by informal carers living in the community caring for their care recipients with dementia. This exact recommendation was made by Burholt et al., (2020), who conducted a critical review of continence management in people living with dementia in the community. Their review identified a large gap in existing community-based interventions and support for those impacted by continence issues including those living with dementia and their caregivers. It also pointed out how future research could explore good incontinence support in formal settings and determine how that can be tailored and implemented in the setting of in-home dementia care (Burholt et al., 2020). The aim of implementing this personalised person-cantered approach is so that people living with dementia are able to remain in their own homes for longer, and so that the valuable people who support them also get the support they need to enable them to continue on in their role safely, and so that they can maintain their own health and quality of life at the same time.

Conclusion

This research aimed to understand how managing dementia-related incontinence impacted the sleep, health, wellbeing, and overall quality of life of carers caring for their friend or relative with dementia in an informal in-home community setting. Two sets of data were used to explore this phenomenon, including confidential sleep survey data, and face-to-face and over the phone semi-structured interview data. This research is among the first of its kind to represent how managing dementia-related incontinence impacts informal carers in terms of their sleep, health, and overall quality of life within a New Zealand context.

The main findings from this study were the significant impacts involved in managing dementia-related incontinence in an informal care setting. In particular, how the associated demands of caring negatively affected the carers sleep, health, and quality of life. The present study findings also highlighted a lack of accessible education and support for informal carers of community-dwelling individuals living with dementia. Future research as well as the implementation of incontinence assessments and interventions that aim to reduce the negative impacts for informal carers is urgently needed in order to maintain and optimise their health, wellbeing, and quality of life. Furthermore, effective support would likely allow them to remain in their roles for longer, enabling their care recipient to continue living safely in their own home for as long as possible. The implications of this would mean a reduction in the number of people with dementia living in formal care facilities, and it would also mean supporting people with dementia to maintain as much cognitive functioning as possible, which can be achieved by enabling them to remain in their own familiar environments, which is considered most favourable among those living with dementia.

References

Aldridge, Z., and Dening, K. H. (2021). Dementia and continence issues. *Journal of Community Nursing, 35*(5), 58-62.

Almutairi, R. R., & Zauszniewski, J. A. (2022). Sleep disturbance in informal caregivers of persons with dementia: Systematic review. *International Journal and Caring Sciences*, *15*(2), 1533-1544.

Alzheimer's New Zealand. (2022). *What is Dementia?* What is dementia? - Alzheimers New Zealand

Alzheimer's New Zealand. (2022). *Report: New Zealand's respite care system is in crisis*. https://alzheimers.org.nz/news/report-new-zealands-respite-care-system-is-in-crisis/

Alzheimer's New Zealand. (2022) *Supporting someone with dementia*. Supporting someone with dementia - Alzheimers New Zealand

American Psychiatric Association. (2022). *What is mental illness?* Psychiatry.org - What is Mental Illness?

Annear, M.J., Toye, C., McInerney, F., Eccleston, C., Tranter, B., Elliott, K-E., & Robinson, A. (2015). What should we know about dementia in the 21st century? A Delphi consensus study. *BMC Geriatrics, 15*(5). https://doi.org/10.1186/s12877-015-0008-1

Black, D. W., & Grant, J. E. (2014). *DSM-5 guidebook: The essential companion to the Diagnostic and Statistical Manual of Mental Disorders, 5th Edition*. American Psychiatric Publishing.

Blinka, M. D., Spira, A. P., Sheehan, O. C., Cidav, T., Rhodes, J. D., Howard, V. J., & Roth, D. L. (2022). Sleep quality reports from family caregivers and matched non-caregiving controls in a population-based study. *Journal of Applied Gerontology, 42*(6), 1568-1575. https://doi.org/10.1177/07334648221079110

Bold, C. (2011). What is Narrative. In Using narrative in research (pp. 15-31). Sage.

Bonner, C. (2005). *Reducing stress-related behaviours in people with dementia: Care-based therapy*. Jessica Kingsley Publishers.

Bratfos O. (1990). Organiske kontra ikke-organiske sykdommer. En distingvering som er nødvendig for å kunne praktisere rasjonelt [Organic versus non-organic diseases. A distinction necessary for rational practice]. *Tidsskrift for den Norske laegeforening: tidsskrift for praktisk medicin, ny raekke*, *110*(7), 865–868.

Braun, V., and V. Clarke. 2019. Reflecting on reflexive thematic analysis. *Qualitative Research in Sport, Exercise & Health 11* (4):589–97. https://doi.org/10.1080/2159676X.2019.1628806

Breheny, M., Horrell, B., & Stephens, C. (2022). A participatory journal/dialogue approach to narrative research illustrated using a study of informal caregiving, *Qualitative Research in Psychology, 19*(2), 521-538. https://doi.org/10.1080/14780887.2020.1716423

Burholt, V., Davies, J., Boyd, M., Mullins, J. M., & Shoemark, E. J. (2020). A research agenda for promoting continence for people living with dementia in the community: Recommendations based on a critical review and expert-by-experience opinion. *Journal of Clinical Nursing, 00*, 1-14. https://doi.org/10.1111/jocn.15537

Byers, D. C., & France, N. E. M. (2008). The lived experiences of registered nurses providing care to patients with dementia in the acute care setting: A phenomenological study. *International Journal for Human Caring, 12*(4), 44-49.

Byun, E., Lerdal, A., Gay, C. L., & Lee, K. A. (2016). How adult caregiving impacts sleep: A systematic review. *Curr Sleep Medicine Rep, 2*, 191-205. https://doi.org/10.1007/s40675-016-0058-8

Campbell, J. (2020). Te Whare Tapa Whā. *Salem Press Encyclopedia of Health*

Cassells, C., and Watt, E. (2003). The impact of incontinence on older spousal caregivers. *Journal of Advanced Nursing, 42*(6). https://doi-org.ezproxy.massey.ac.nz/10.1046/j.1365-2648.2003.02664.x

Clarke, C. L., Wilkinson, H., Keady, J., & Gibb, C. E. (2011). *Risk assessment and management for living well with dementia*. Jessica Kingsley Publishers.

Cortazzi, M. (2014). *Narrative analysis*. Routledge. https://doi-org.ezproxy.massey.ac.nz/10.4324/9781315067421

Corey, K. L., McCurry, M. K., Sethares, K. A., Bourbonniere, M., Hirschman, K. B., & Meghani, S. H. (2020). Predictors of psychological distress and sleep quality in former family caregivers of people with dementia. *Ageing & Mental Health*, *24*(2), 233-241. https://doi.org/10.1080/13607863.2018.1531375

Cross, A. J., Garip, G., & Sheffield, D. (2018). The psychosocial impact of caregiving in dementia and quality of life: a systematic review and meta-synthesis of qualitative research. *Psychology & Health, 33*(11), 1321-1342. https://doi.org/10.1080/08870446.2018.1496250

Crotty, M. (1998). *The foundations of social research: Meaning and perspective in the research process.* Sage.

Curnow, E., Rush, R., Maciver, D., Górska, S., & Forsyth, K. (2021). Exploring the needs of people with dementia living at home reported by people with dementia and informal caregivers: A systematic review and meta-analysis. *Ageing & Mental Health*, *25*(3), 397-407. https://doi.org/10.1080/13607863.2019.1695741

Dementia Australia. (2022). *Diagnostic criteria for dementia DSM-5: Neurocognitive disorder*. Diagnostic criteria for dementia | Dementia Australia

Dementia New Zealand. (2022). *Who we are*. About Us - Mo matou - Dementia New Zealand

Drennan, V. M., Cole, L., & Iliffe, S. (2011). A taboo within a stigma? A qualitative study of managing incontinence with people with Dementia living at home. *BMC Geriatrics, 11*(75). https://doi-org.ezproxy.massey.ac.nz/10.1186/1471-2318-11-75

Ducharme, F., Lévesque, L., Lachance, L., Giroux, F., Legault, A., & Préville, M. (2005). 'Taking care of myself': Efficiency of an intervention programme for caregivers of a relative with dementia living in a long-term care setting. *Dementia, 4*(1), 23-47.

Dudley, M., Menzies, O., Elder, H., Nathan, L., Garett, N., & Wilson, D. (2019). Mata Wareware: Understanding 'Dementia' from a Māori perspective. *New Zealand Medical Journal, 132*(1503), 66-72.

Dyer, A. H., Laird, E., Hoey, L., Hughes, C. F., McNulty, H., Ward, M., Strain, J. J., O'Kane, M., Tracey, F., Molloy, A. M., Cunningham, C., Sexton, D. J., & McCarroll, K. (2022). Reduced kidney function is associated with poorer domain-specific cognitive performance in community-dwelling older adults. *International Journal of Geriatric Psychiatry, 1-11*. https://doi.org/10.1002/gps.5771

Ervin, K., Pallant, J., & Reid, C. (2015). Caregiver distress in dementia in rural Victoria. *Australasian Journal on Ageing, 34*(4), 235-240. https://doi.org/10.1111/ajag.12158

Farina, N., Page, T. E., Daley, S., Brown, A., Bowling, A., Basset, T., Livingston, G., Knapp, M., Murray, J., & Banerjee, S. (2017). Factors associated with the quality of life of family carers of people with dementia: A systematic review. *Alzheimer's & Dementia, 13*, 572-581. http://dx.doi.org/10.1016/j.jalz.2016.12.010

Franken, M. G., Ramos, I. C., Los, J., & Al, M. J. (2018). The increasing importance of a continence nurse specialist to improve outcomes and save costs of urinary incontinence care: An analysis of future policy scenarios. *BMC Family Practice, 19*(31), 1-11. http://dx.doi.org/10.1186/s12875-018-0714-9

Frohnhofen, H., Schlitzer, J., & Netzer, N. (2017). Sleep in older adults and in subjects with dementia. *Zeitschrift für Gerontologie und Geriatrie, 50*(7), 603-608. http://dx.doi.org/10.1007/s00391-017-1289-0

Furlanetto, K., & Emond, K. (2014). "Will I come home incontinent?" A retrospective file review: Incidence of development of incontinence and correlation with length of stay in acute settings for people with dementia or cognitive impairment aged 65 years and over. *Collegian, 23,* 79-86. http://dx.doi.org/10.1016/j.colegn.2014.09.013

Gibson, R., & Gander, P. (2021). Factors associated with the sleep of carers: A survey of New Zealanders supporting a family member with cognitive impairment or dementia. *Dementia, 20*(3), 919-935. https://doi.org/10.1177/1471301220915071

Gibson, R. H., Gander, P. H., & Jones, L. M. (2014). Understanding the sleep problems of people with dementia and their family caregivers. *Dementia, 13*(3), 350-365. http://dx.doi.org/0.1177/1471301212473884

Gibson, R., Helm, A., Breheny, M., & Gander, P. (2019). "I'm only as good as the sleep I get": Sleep health among family carers. *Journal of Sleep Research, 28*(1), 127-129. https://doi-org.ezproxy.massey.ac.nz/10.1111/jsr.127_12913

Gibson, R., Helm, A., Breheny, M., & Gander, P. (2020). "My quiet times": Themes of sleep health among people caring for a family member with Dementia. *Dementia, 0*(0), 1-17. https://doi.org/10.1093/ageing/aft1427

Ginev, D. (2014). The Articulation of a Scientific Domain from the Viewpoint of Hermeneutic Phenomenology: The Case of Vectorial Metabolism. In: Babich, B., Ginev, D. (eds) *The Multidimensionality of Hermeneutic Phenomenology.*

Contributions to Phenomenology, vol 70. Springer, Cham. https://doi-org.ezproxy.massey.ac.nz/10.1007/978-3-319-01707-5_2

Grandner, M. A. (ED.). (2019). *Sleep and Health*. Elsevier.

Greenberg, N. E., Wallick, A., & Brown, L. M. (2020). Impact of Covid-19 pandemic restrictions on community-dwelling caregivers and persons with dementia. *American Psychological Association, 12*(S1), S220-S221. http://dx.doi.org/10.1037/tra0000793

Health Research Council of New Zealand (HRC). (2022). *HRC at a glance*. Retrieved from HRC at a glance | Health Research Council of New Zealand

Herman, L., & Vervaeck, B. (2019). *Handbook of Narrative Analysis* (2nd ed.). University of Nebraska Press. http://www.jstor.org/stable/j.ctvr43mhw

Horrell, B., Stephens, C., & Breheny, M. (2015). Capability to care: Supporting the health of informal caregivers for older people. Health Psychology, 34(4), 339-348. DOI: 10.1037/hea0000144

Howell, K. E. (2013). Aspects of phenomenology. In *An introduction to the philosophy of methodology* (pp. 55-74). SAGE Publications Ltd, https://dx.doi.org/10.4135/9781473957633.n4

Hunt, J. F. V., Schroder, M., LeCaire, T., O'Toole-Smith, K., Marschall, K., & Walaszek, A. (2021). Effects of the Covid-19 pandemic on healthcare and community-based services use for people living with dementia: Perspectives from dementia care professionals. *Alzheimer's & Dementia: The Journal of the Alzheimer's Association, 17*(S10), 1-3. https://doi.org/10.1002/alz.050681

Innes, A., Calvert, L., & Bowker, G. (2020). *Dementia: The Basics* (1st ed.). Routledge. https://doi-org.ezproxy.massey.ac.nz/10.4324/9781315709000

Jadhav, S., Subramanyam, A. A., Raut, N. B., & Singh, S. (2021). A study of quality of sleep, quality of life, and cognition, in elderly: Healthy control, depressed and with mild neurocognitive disorder. *Journal of Geriatric Mental Health, 8*(2), 107-112. https://doi.org/10.4103/jgmh.jgmh_35_21

James, J. E. (2016). *The health of populations: Beyond medicine*. Elsevier.

Jerez-Roig, J., Moreira F. S. M., da Câmara, S. M. A., Ferreira, L. Md. B. M., & Lima, K. C. (2019). Predicting continence decline in institutionalized older people: A longitudinal analysis. *Neurourology and Urodynamics, 38*, 958-967. https://doi.org/10.1002/nau.23941JEREZ-ROIGET AL.|967

Kim, J., & Cha, E. (2022). Effect of perceived stress on health-related quality of life among primary caregiving spouses of patients with severe dementia: The mediating role of depression and quality sleep. *International Journal of Environmental Research & Public Health*, *19*(13), 7962. https://doi-org.ezproxy.massey.ac.nz/10.3390/ijerph19137962

Krishnamurthi, R. V., Dahiya, E. S., Bala, R., Cheung, G., Yates S., & Cullum, S. (2022). Lived experience of Dementia in the New Zealand Indian community: A qualitative study with family care givers and people living with Dementia. *International Journal of Environmental Research and Public Health, 19*(3), 1432. https://doi-org.ezproxy.massey.ac.nz/10.3390/ijerph19031432

Krutter, S., Schaffler-Schaden, D., Essl-Maurer, R., Wurm, L., Seymer, A., Kriechmayr, C., Mann, E., Osterbrink, J., & Flamm, M. (2020). Comparing perspectives of family caregivers and healthcare professionals regarding caregiver burden in dementia care: Results of a mixed-methods study in a rural setting. Age and Ageing, 49, 199-207. https://doi-org.ezproxy.massey.ac.nz/10.1093/ageing/afz165

Laverack, G. *Public health: Power, empowerment, and professional practice (3rd ed.).* (2016). Palgrave.

Lee, S., & Lawson, K. M. (2021). Beyond single sleep measures: A composite measure of sleep health and its associations with psychological and physical well-being in adulthood. *Social Science & Medicine, 274*. https://doi.org/10.1016/j.socscimed.2021.113800

Liao, H., Liao, S., Gao, Y-j., Mu, J-p., Wang, X., & Chen, D-s. (2022). Correlation between sleep time, sleep quality, and emotional and cognitive function in the elderly. *BioMed Research International, 2022*, 9709536. https://doi.org/10.1155/2022/9709536

Lurigio, A. J. (2022). DSM-5. *Salem Encyclopedia of Health*

Manzoli, J. P. B., Correia, M. D. L., & Duran, E. C. M. (2018). Conceptual and operational definitions of the defining characteristics of the nursing diagnosis Disturbed Sleep Pattern. *Rev Latino-Am. Enfermagem, 26*. http://dx.doi.org/10.1590/1518-8345.2582.3105

McMurray, A., & Clendon, J. (2014). *Community health and wellness - e-book: Primary health care in practice*. Elsevier Health Sciences.

Ministry of Health. (2021). *Dementia*. Dementia | Ministry of Health NZ

Ministry of Health. (2017). *Māori health models – Te whare tapa whā*. Ministry of Health. Māori health models – Te Whare Tapa Whā | Ministry of Health NZ

Ministry of Health. (2022). *Overview of the health system*.

Overview of the health system | Ministry of Health NZ

Ministry of Social Development. (2022). Taking a break from caring (respite) – A guide for carers. Taking a break from caring (respite) - A Guide for Carers - Ministry of Social Development (msd.govt.nz)

Moholt, J-M., Friborg, O., Blix., B. H., & Henricksen, N. (2020). Factors affecting the use of home-based services and out-of-home respite care services: A survey of family for older persons with dementia in Northern Norway. Dementia, 19(5), 1712-1731. https://doi-org.ezproxy.massey.ac.nz/10.1177/1471301218804981

Morgan, K. (1987). *Sleep and Ageing* (1st ed.). Routledge. https://doi-org.ezproxy.massey.ac.nz/10.4324/9781315311012

Mourrain, P., & Wang, G. X. (2019). Sleep: DNA repair function for better neuronal ageing? *Current Biology, 29*, R568-R591, June 17, 2019. https://doi.org/10.1016/j.cub.2019.05.018

Murphy, C., de Laine, C., Macaulay, M., Avery, M., & Fader, M. (2021). A qualitative study and preliminary model of living with dementia and incontinence at home: Beyond containment. *Age and Ageing, 51*(1), 1-9. https://doi.org/10.1093/ageing/afab221

Murray, M. (2008). Narrative Psychology. In J. A. Smith (Ed.), *Qualitative psychology: A practical guide to research methods* (pp. 111-132). Sage.

Nazarko, L. (2019). Providing dignified continence care to older people at end of life. *International Journal of Palliative Nursing, 25*(10), 504-512. https://doi.org/130.123.099.011

O'Shea, E., O'Shea, E., Timmons, S., & Irving, K. (2019). Respite care for people with dementia and their carers: A qualitative study with multiple stakeholders. *Age & Ageing, 48*, 17-65. https://doi-org.ezproxy.massey.ac.nz/10.1093/ageing/afz103.26

Payne, D. (2020). Manging incontinence in people with dementia. *British Journal of Community Nursing, 25*(9), 430-436. Managing incontinence in people with dementia: Discover (ebscohost.com)

Payne, D. (2018). Managing urinary incontinence in patients living with dementia. *British Journal of Community Nursing, 23*(1), 24-28. Managing urinary incontinence in patients living with dementia: Discover (ebscohost.com)

Peterson, J. L., Reynolds, A. C., & Dawson, D. (2018). Sleep schedule regularity is associated with sleep duration in older Australian adults: Implications for improving the sleep health and wellbeing of our ageing population. *Clinical Gerontologist, 41*(2), 113-122. https://doi.org/10.1080/07317115.2017.1358790

Phillipson, L., Hall, D. V., Johnson, K. M., Cridland, E., Fielding, E., Neville, C., & Hasan, H. (2022). Promoting respite for carers of people with dementia: A case study of social marketing effectiveness in hard-to-reach audiences. *Journal of Social Marketing, 12*(4), 456-472. http://dx.doi.org/10.1108/JSOCM-06-2021-012

Polenick, C. A., Stanz, S. D., Leggett, A. N., Maust, D. T., Hodgson, N. A., & Kales, H. C. (2020). Stressors and resources related to medication management: Associations with spousal caregivers’ role overload. *The Gerontologist, 60*, 165–173. http://dx.doi.org/10.1093/geront/gny130

Prerost, F. J. (2019). Ageing. *Salem Press Encyclopaedia of Science*.

Qutoshi, S. B. (2018). Phenomenology: A philosophy and method of inquiry. *Journal of Education and Educational Development, 5*(1), 215-222.

Rahman, S. (2014). What is “living well?” *In Living well with dementia* (1st ed.). Radcliffe Publishing Ltd.

Ramduny, J., Bastinani, M., Huedepohl, R., Sotiropoulos, S. N., & Chechlacz, M. (2022). The association between inadequate sleep and accelerated brain ageing. *Neurobiology of Ageing, 114*, 1-14. https://doi.org/10.1016/j.neurobiolaging.2022.02.005

Ranse, K., Ranse, J., & Pelkowitz, M. (2018). *Contemporary Nurse, 54*(2), 160–170, https://doi.org/10.1080/10376178.2018.1461572

Rose, K., Specht, J., & Forch, W. (2015). Correlates among nocturnal agitation, sleep, and urinary incontinence in Dementia. *American Journal of Alzheimer's Disease & Other Dementias, 30*(1), 78-84. https://doi-org.ezproxy.massey.ac.nz/10.1177/1533317514524814

Schluter, P. J., Ward, C., Arnold, E. P., Scrase, R., & Jamieson, H. A. (2016). Urinary incontinence, but not faecal incontinence, is a risk factor for admission to aged residential care of older persons in New Zealand. *Neurology and Urodynamics, 36*, 1588-1595. https://doi-org.ezproxy.massey.ac.nz/10.1002/nau.23160

Sheehan, O. C., Haley, W. E., Howard, V. J., Huang, J., Rhodes, J. D., & Roth, D. L. (2021). Stress, burden, and wellbeing in dementia and nondementia caregivers: Insights from the Caregiving Transitions Study. *The Gerontologist*, *61*(5), 670-679.

Simpson, C., & Carter, P. (2015). Th impact of living arrangements on Dementia caregiver's sleep quality. *American Journal or Alzheimer's Disease & Other Dementias, 30*(4), 352-359. https://doi-org.ezproxy.massey.ac.nz/10.1177/1533317514559828

Sittler, M. C., & Wilz, G. (2019). How well do caregivers of people with dementia sleep? An investigation of the prevalence and possible predictors. *Journal of Gerontology and Geriatrics, 53,* 303-309. https://doi-org.ezproxy.massey.ac.nz/10.1007/s00391-019-01579-3

Sleep Foundation. (2022). *Stages of sleep*. Stages of Sleep: What Happens in a Sleep Cycle | Sleep Foundation

Smith, M., Brown, M., Ritchie, L., Papadopoulou, C., & Tolson, D. (2021). Living with Dementia in supported housing: A systematic review and thematic synthesis of qualitative research. *Health & Social Care in the Community*, *00*, 1–16. https://doi.org/10.1111/hsc.13618

Staniland, N. (2011). Ngā Tini Whetū: Navigating Māori Futures. *New Zealand Sociology, 26*, 108-110.

Stokes, G. (2000). *Challenging behaviour in dementia: A person-centred approach*. Routledge.

Sun, W., Bartfay, E., Smye, V., Biswas, S., Newton, D., Pepin, M., & Ashtarieh, B. (2021). Living well with dementia: The role volunteer-based social recreational programmes in promoting social connectedness of people with dementia and their caregivers. *Aging & Mental Health, 26*(10), 1949-1962. https://doi.org/10.1080/13607863.2021.1950614

Sura, S. D., Carnahan, R. M., Chen, H., & Aparasu, R. R. (2013). Prevalence and determinants of anticholinergic medication use in elderly dementia patients. *Drugs & Ageing, 30*, 837-844. https://doi.org/10.1007/s40266-013-0104-x

Talley, K. M. C., Davis, N. J., Peden-McAlpine, C., Martin, C. L., Weinfurter, E. V., & Wyman, J. F. (2021). Navigating through incontinence: A qualitative systematic review and meta-aggregation of the experiences of family caregivers. *International Journal of Nursing Studies, 123*, 2021. https://doi.org/10.1016/j.ijnurstu.2021.104062

Tretteteig, S., Vatne, S., & Rokstad, A. M. (2017). Meaning in family caregiving for people with dementia: A narrative study about relationships, values, and motivation, and how day care influences these factors. *Journal of Multidisciplinary Healthcare, 10*, 445-455.

Vandepitte, S., Van Den Noortgate, N., Putman, K., Verhaeghe, S., Verdonck, C., & Annemans, L. (2016). Effectiveness of respite care in supporting informal caregivers of persons with dementia: A systematic review. *International Journal of Geriatric Psychiatry, 31*, 1277-1288.

Vatanabe, I. P., Manzine, P. R., & Cominetti, M. R. (2019). Historic concepts of dementia and Alzheimer's disease: From ancient times to the present. *Review Neurologique, 176*, 140-147. https://doi.org/10.1016/j.neurol.2019.03.004

Viaña, J. N. (2021). Considering people with dementia and their caregivers in Covid-19 lockdowns. *Hasting Centre Report, November 2021, 51(6), 11-12.* https://doi.org/10.1002/hast.1303

Wang, X. R., Robinson, K. M., & Carter-Harris, L. (2014). Prevalence of chronic illness and characteristics of chronically ill informal caregivers of persons with dementia. *Age and Ageing, 43*(1), 137-141. https://doi.org/10.1093/ageing/aft142

Wong, G., & Breheny, M. (2018). Narrative analysis in health psychology: A guide for analysis. Health Psychology and Behavioural Medicine, 6, 245-261.

World Health Organization (WHO). (2022). *Definition of health*. World Health Organization(WHO) Definition Of Health - Public Health

World Health Organization (WHO). (2022). *Dementia*. Dementia (who.int)

Zhang, C., Dong, F., Zheng, X., Xue, Y., Xiao, S., Shi, L., Xue, B., Zhang, J., & Ou, W. (2022). The Impact of Sleep Quality on Subjective Wellbeing Among Older Adults with Multimorbidity: A Moderated Mediation Model. *Frontiers in psychology, 13*, 813775. https://doi-org.ezproxy.massey.ac.nz/10.3389/fpsyg.2022.813775

Zimmermann, M. (2020). Introduction. In *The Diseased Brain and the Failing Mind: Dementia in Science, Medicine and Literature of the Long Twentieth Century* (pp. 1–20). London: Bloomsbury Academic. http://dx.doi.org.ezproxy.massey.ac.nz/10.5040/9781350121836.ch-001

Appendix A - Original Study Invitation

'SLEEP~WAKE'
research centre
'MOE TIKA~MOE PAI'

Sleep and Health of Family Carers: Follow-up Interviews

Lead investigator: Dr Rosie Gibson

18th June 2018

Hello,

Thank you for taking part in the 2016-17 survey study concerning sleep of people caring for a family member with a cognitive impairment or dementia. This original survey is now being analysed and reports will be made available soon. Currently I am looking for volunteers to take part in follow-up interviews as we would like to gain a better understanding of the sleep experience with caregiving and transitions into formal care.

I am writing to offer you an interview as you signed on to our mailing list regarding future research studies. This information sheet is to help you decide if you'd like to take part. It sets out why I am doing this follow-up study, what is involved, and what the benefits and risks might be. Please take a few moments to read this. You may want to talk about the study with other people, such as family, whānau, friends, or your local Alzheimers or Dementia association. Feel free to do this. You can also contact me (Rosie Gibson) on

Freephone 0800 MY SLEEP (69 75337), direct dial: 04 9793258, or email

r.gibson@massey.ac.nz if you have any questions. Whether or not decide to take part is your choice. It will not affect the support you receive.

Why are we doing follow-up interviews?

Previous research, including the postal survey you took part in, indicates that sleep problems are a common and challenging aspect of cognitive impairment and dementia. Sleep problems can contribute to waking symptoms, thus affecting the health and wellbeing of the those with dementia as well as family carers. Previous research also shows that sleep problems may contribute to decisions around moving family members with a cognitive impairment or dementia into formal care (e.g. residential or hospitalised care). However, the experiences and voices of families affected are missing from this research.

I am interested in talking to approximately 20 family carers who have recently transitioned their family member with a cognitive impairment or dementia into formal care. The aim of these interviews are to understand how sleep changes with the course of dementia and the role of sleep problems in decisions around formal care.

Who can take part?

To be eligible to take part you need to:

- Have been a carer/support person for a family member with a cognitive impairment or dementia who previously lived with you.
- Have transitioned that person into formal care setting (e.g. residential or hospitalised care) since taking part in the original postal survey.
- Not currently have a clinical sleep disorder or mental health condition (e.g. sleep apnoea, depression or dementia).

Note, you can still take part if:

- Your family member has passed away since the transition to formal care. ☐ You consider yourself a good sleeper.

Please contact me if you are unsure if you are eligible.

What would your participation involve?

To take part in this study you firstly need to complete a short questionnaire concerning who you are, your health and sleep. This can be completed by post or over the phone, your choice. You will also need to check off and sign a consent form before your interview. It is expected that interviews will last approximately 1 hour and will take place between June-August 2018. Interviews can be conducted face-to-face (e.g. in your home or at a public meeting room) or via telephone or videoconference. Location will depend on your preference and the logistics of geographical region and timing (you can discuss this with me to find a convenient option).

The interview

Your Interview will be loosely constructed, allowing for you to provide as little or much detail as you feel comfortable. During the interview I would like to explore the following topics:

- The experience of providing informal care for a family member with cognitive impairment or dementia
- How sleep changed for you both as the disease progressed
- How sleep problems were (or were not) managed
- The role of sleep disturbances in the decision to transition your family member into formal care
- How you are sleeping post the transition to care

The interview will be audio recorded and transcribed, you will be sent your transcript and will have some time to edit it should you wish. Your transcript will be analysed with the other participants' with the aim of understanding sleep changes with family caring.

What are the possible benefits and risks in participating?

Taking part in this follow-up interview is voluntary. If you decide to particulate, you will be contributing to a better understanding of the sleep of family carers and people with cognitive impairment or dementia. The information that you provide will be valuable in guiding research, policy and services to improve community health and wellbeing.

You may find some of the topics of a personal or sensitive nature (e.g. discussing the impact of your family member's sleep-related behaviours). By taking part you are not obliged to answer all of the questions if you do not feel comfortable. You are welcome to have a family member, or another person present for support.

If you have any questions or concerns regarding the survey, you can contact the me or other using the details below. To thank you for your time, we will provide you with a $20 grocery voucher.

What will happen with your information?

As with the original survey data, all of your information will be kept strictly confidential. Paper copies of the screening questionnaires and consent forms will be kept in a secure cabinet at the Sleep/Wake Research Centre, Massey University. Interviews will be transcribed using a private transcription service (with a confidentiality agreement).

Electronic data will be accessible by password by the immediate research team only.

I expect around 20 people to take part. Analysis and reports will describe grouped themes, these may be illustrated using quotes from your interview. However no information which could identify you or your family will be used.

A summary of the findings will be available to you in 2019. This will be via a report mailed directly to you as well as via Alzheimers New Zealand and Dementia Organisations. Findings will also be reported on the Sleep/Wake Research Centre's website and presented at local and/or international conferences as well as published in a scientific journal.

What do I do now?

Please take the time to consider this opportunity and discuss with your family, friend or healthcare provider if you wish. If you are interested in participating, please contact me to ask any questions, begin the consent process, and set a convenient time for your interview.

Thank you for taking the time to consider being involved in this research.

This follow-up study has been approved by the Central Health and Disability Ethics

Committee (ref: 16/CEN/101/AM01). It is being funded by grants from the Lotteries Health Commission. If you have any questions, concerns or complaints about the study at any stage, you can contact the team at the Sleep/Wake Research Centre:

Lead Investigator - **Rosie Gibson, PhD**
Freephone: 0800 MY SLEEP (69 75337)

Phone: 04 9793258

Email: r.gibson@massey.ac.nz

Administrator – Travis
Steenekamp Phone: 04
979 3055

Email: swrc@massey.ac.nz

Director, Sleep/ Wake Research Centre - Philippa Gander, PhD

Phone: 04 3800633

Email: p.h.gander@massey.ac.nz

If you want to talk to someone who isn’t involved with the study, you can contact an independent health and disability advocate on:

Phone: 0800 555 050

Email: advocacy@hdc.org.nz

You can also contact the health and disability ethics committee (HDEC) that approved this study on:

Phone: 0800 4 ETHICS

Email: hdecs@moh.govt.nz

Appendix B - Interview Schedule

Carers follow up interviews

Prior – background to me
How long as X been in residential care and where are they?

Aims of the interview

- To document your sleep journey as someone who has been a family carer and been through the process of transition to formal care
- To represent the stories of yourself and others as this could not be captured in the survey's alone
- Better understand the role of sleep health in caregiving situations and decisions around formal care

Schedule

- The experience of providing informal care for a family member with cognitive impairment or dementia
    - Could you tell me a little bit about yourselves and what it was like supporting X here at home?
    - Thinking back, how were you sleeping before you were faced with dementia?
    - Had sleep changed for you much over life so far?
- How sleep changed for you both as the disease progressed
    - Could you tell me the story of how <u>your</u> sleep changed as X's condition progressed through to moving them into formal care?
    - Thinking back what do you think were the causes of any sleep problems, did these causes change with the progression of dementia
- How sleep problems were (or were not) managed
    - How did you cope with sleep problems of X – and what about you, how did you cope in times of sleep loss?
    - Did you have any strategies or behaviours to manage?
    - Use respite at all?
- The role of sleep disturbances in the decision to transition your family member into formal care
    - Clearly moving a loved one into formal care can be a difficult decision, what was this process like for you?
    - Thinking back to making the decision to move X into X, how much of a role would you say problem sleep was in your consideration and final decisions?
- How you are sleeping post the transition to care
    - What is your sleep like now?
    - Have there been any events or turning points since the transition which have influenced your sleep health?
- Is there anything we have missed?
    - Have we come full circle, back to the present?
    - Is there anything else you'd like to share before I turn the recorder off?

Appendix C - Ethics Approval

Health and Disability Ethics Committees

Health and Disability Ethics Committees

Ministry of Health
Freyberg Building
20 Aitken Street
PO Box 5013
Wellington
6011

0800 4 ETHICS
hdecs@moh.govt.nz

02 August 2016

Dr Rosemary Gibson

Sleep/Wake Research Centre

Massey University

Wellington Private Bag 756

Dear Dr Gibson

Re:	**Ethics ref:**	**16/CEN/101**
	Study title:	Factors Affecting the Sleep of Family Carers: A Survey of those Supporting People with a Cognitive Impairment or Dementia in their own Home

I am pleased to advise that this application has been *approved* by the Central Health and Disability Ethics Committee. This decision was made through the HDEC-Expedited Review pathway.

In future, please ensure that all submitted documents are final versions and not drafts. The submitted poster is a draft version.

Conditions of HDEC approval

HDEC approval for this study is subject to the following conditions being met prior to the commencement of the study in New Zealand. It is your responsibility, and that of the study's sponsor, to ensure that these conditions are met. No further review by the Central Health and Disability Ethics Committee is required.

Standard conditions:

1. Before the study commences at *any* locality in New Zealand, all relevant regulatory approvals must be obtained.

2. Before the study commences at *a given* locality in New Zealand, it must be authorised by that locality in Online Forms. Locality authorisation confirms that the locality is suitable for the safe and effective conduct of the study, and that local research governance issues have been addressed.

After HDEC review

Please refer to the *Standard Operating Procedures for Health and Disability Ethics Committees* (available on www.ethics.health.govt.nz) for HDEC requirements relating to amendments and other post-approval processes.

Your **next progress report** is due by **01 August 2017**.

Participant access to ACC

The Central Health and Disability Ethics Committee is satisfied that your study is not a clinical trial that is to be conducted principally for the benefit of the manufacturer or distributor of the medicine or item being trialled. Participants injured as a result of treatment received as part of your study may therefore be eligible for publicly-funded compensation through the Accident Compensation Corporation (ACC).

Please don’t hesitate to contact the HDEC secretariat for further information. We wish you all the best for your study.

Yours sincerely,

Mrs Helen Walker

Chairperson

Central Health and Disability Ethics Committee

Encl: appendix A: documents submitted appendix B: statement of compliance and list of members

Appendix A

Documents submitted

Document	*Version*	*Date*
Declined letter for previous application in respect of the same (or substantially similar) study: letter declining previous application	1	02 June 2016
Covering Letter: cover letter addressing points raised by Committee's review of previous project	1	11 July 2016
CV for CI: R gibson CV	1	29 June 2016
CVs for other Investigators: P Gander CV	1	19 August 2015
Evidence of scientific review: scientific and cultural review	1	07 July 2016
PIS/CF: information sheet for potential participants	2	13 July 2016
Protocol: protocol for revised study	2	13 July 2016
wording for poster/flyer	1	13 July 2016
Survey/questionnaire: survey for revised study	2	13 July 2016
Application		

Appendix B
Statement of compliance and list of members

Statement of compliance

The Central Health and Disability Ethics Committee:

- ☐ is constituted in accordance with its Terms of Reference
- ☐ operates in accordance with the *Standard Operating Procedures for Health and Disability Ethics Committees*, and with the principles of international good clinical practice (GCP)
- ☐ is approved by the Health Research Council of New Zealand’s Ethics Committee for the purposes of section 25(1)(c) of the Health Research Council Act 1990
- ☐ is registered (number 00008712) with the US Department of Health and Human Services’ Office for Human Research Protection (OHRP).

List of members

Name	*Category*	*Appointed*	*Term Expires*
Mrs Helen Walker	Lay (consumer/community perspectives)	01/07/2015	01/07/2018
Dr Angela Ballantyne	Lay (ethical/moral reasoning)	30/07/2015	30/07/2018
Dr Melissa Cragg	Non-lay (observational studies)	30/07/2015	30/07/2018
Dr Peter Gallagher	Non-lay (health/disability service provision)	30/07/2015	30/07/2018
Mrs Sandy Gill	Lay (consumer/community perspectives)	30/07/2015	30/07/2018
Dr Patries Herst	Non-lay (intervention studies)	27/10/2015	27/10/2018
Dr Dean Quinn	Non-lay (intervention studies)	27/10/2015	27/10/2018
Dr Cordelia Thomas	Lay (ethical/moral reasoning)	19/05/2014	19/05/2017

Unless members resign, vacate or are removed from their office, every member of HDEC shall continue in office until their successor comes into office (HDEC Terms of Reference)

http://www.ethics.health.govt.nz

Appendix D - Original Study Consent Form

CONSENT FORM
Sleep and Health of Family Carers: Follow-Up Interviews

Please tick to indicate you consent to the following:

I have read and I understand the information sheet dated 5.3.2018 for volunteers taking part in a follow-up interview concerning sleep changes for family carers and decisions around formal care.	Yes ☐	No ☐
I understand that I have been contacted about these interviews as I took part in the original survey component of the research and signed onto a mailing list concerning future research.	Yes ☐	No ☐
I have been given sufficient time to consider whether or not to participate in this study.	Yes ☐	No ☐
I have had the opportunity to use a legal representative, whanau/ family support or a friend to help me ask questions and understand the study.	Yes ☐	No ☐
I am satisfied with the answers I have been given regarding the study and I have a copy of this consent form and information sheet.	Yes ☐	No ☐
I understand that taking part in this interview component is voluntary (my choice) and that I may withdraw from the study at any time without this affecting my care or support	Yes ☐	No ☐
I consent to the research staff collecting and processing my information, including information about my health.	Yes ☐	No ☐
I consent to my interview being audio-recorded and that recording being transcribed for analysis.	Yes ☐	No ☐
I understand that I will be sent a copy of my transcript for review.	Yes ☐	No ☐
I understand that I can withdraw from the study at any time and this will in no way affect my support.	Yes ☐	No ☐
Direct quotes may be used, but no material which could identify me or my family members will be used in any reports on this study.	Yes ☐	No ☐
I understand that my participation in this study is confidential. Direct quotes may be used, but no material which could identify me or my family members will be used in any reports on this study.	Yes ☐	No ☐
I know who to contact if I have any questions about the study in general.	Yes ☐	No ☐

I wish to receive a summary of the results from the study. Yes ☐ No ☐

Declaration by participant:

I hereby consent to take part in this study.

Participant's name:

Signature: Date:

Please indicate if you would prefer to have your interview conducted…..

face to face ☐

by telephone/videoconference ☐

Declaration by member of research team:

I have given a verbal explanation of the research project to the participant, and have answered the participant's questions about it.

I believe that the participant understands the study and has given informed consent to participate.

Researcher's name:

Signature: Date:

Researcher contact:
Dr. Rosie Gibson
Postdoctoral Fellow Sleep/Wake Research Centre
College of Health, Massey University, Wellington, PO Box 756, New Zealand
Telephone: 04 9793258
r.gibson@massey.ac.nz