Informal Caregivers' Experiences of Covid-19 pandemic in Aotearoa

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Tyrone Barnard

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Abstract

Informal caregivers have been reported as an understudied population and are recognised as the backbone of the health care system. The technology available today has led to increased life expectancy, and in New Zealand, 20% of caregivers are over the age of 65, which is higher than the general population. Older people are more susceptible to and at risk for the Covid-19 virus. The guidelines and rules put in place to protect the people of New Zealand from Covid-19 reduced socialisation, impacted daily activities in our lives, and created challenges for caregivers. Although caregiving is well-theorized, further research is necessary for the recent Covid-19 pandemic. This study focuses on understanding and exploring older informal caregivers' experiences of caregiving during the Covid-19 pandemic. The literature to date yields contradictory findings about how informal caregivers experienced the pandemic. Grounded theory from a constructionist perspective was used as a qualitative method in this study to explore knowledge from those who have experienced caregiving during the pandemic. Purposeful sampling was used to select participants from the Health, Work and Aged Retirement data base. This study had a sample size of 8 participants and 7 were used during data analysis. This study found the core themes of caregivers' experiences of the pandemic to be dominantly negative, and caregivers voiced the need for pre-existing supports to continue during a pandemic. The findings of this study showed caregivers experienced anxiety, felt they had a lack of information aimed at caregivers specifically and experienced a lack of support during the pandemic. These experiences are intertwined and linked, resulting in the overall negative experiences of carers. Participants asked for pre-existing supports to continue and had no suggestions outside of this as to how they can better be supported. The discussion focuses on caregivers’ experiences and how they are intertwined and connected resulting in central themes. I further explore alternative ways of providing support for caregivers that meets their needs during the pandemic. It is hoped the findings of this study will contribute to the

literature and support, and policies can be provided to improve caregivers' experiences in a pandemic situation.

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Chapter 1: Introduction

1.1 Why we need to research caregivers

Caregivers have been recognised as an essential part of the health care system internationally (Greenwood et al., 2019a; Rodger et al., 2015). The caregiver population is growing rapidly and has been recognised as understudied (Greenwood et al., 2019a; Stephens & Breheny, 2022; Swain, 2018; Smeets et al., 2020). This paragraph will explore the need for adult caregivers. According to the National Health Committee's 2007 report, literature on informal caregiving in the New Zealand context is scant and patchy in its coverage. In New Zealand, there are approximately 430, 000 carers, with one in ten New Zealanders being caregivers (Ministry of Social Development, 2021). The caregiver population is older than the New Zealand population, with 20% of caregivers being over the age of 65, compared to 15% of the general population (Ministry of Social Development, 2021). World Health Organisation (WHO, 2015) has reported ageing populations as a global phenomenon, which is reflected in the predicative rise from 600 million in 1980 over the age of 60 years to approximately 2 billion by 2050. Due to the increasing ageing population and technological advancements that have resulted in higher life expectancy, there is a growing need for more caregivers in both professional and informal capacities. Harwood et al. (2004) have reported that family caregivers who are often unpaid have increased dramatically, partially due to an increasingly ageing population. These caregivers are often informal.

1.1.2 Defining informal caregivers

It is important to differentiate between a professional and an informal caregiver here. Pearlin and colleagues' (1990) work refers to informal caregiving as providing assistance and helping in daily activities for someone who is unable to do it themselves. Caring refers to how one's attitude reflects a behaviour; therefore, caregiving is the behavioural expression of a commitment to the wellbeing of another (Pearlin et al., 1990). The work of Pearlin and colleagues (1990) refers to caring as an extension of caring about a person, and from this perspective, caregiving and caring are essential to any close relationship. This means both caring and caregiving are involved in any relationship where the wellbeing and protection of others are valued. It is clear that aspects of caregiving are present in all relationships, but informal caregiving differs in its unequal distribution of the burden. Examples of unequal distribution include physical and mental declines like Alzheimer's disease and reduced mobility. A code of conduct shapes professional caregiving, and professional caregivers are rewarded with money (Goodhead & McDonald, 2007). According to Goodhead and McDonald (2007), informal caregiving is characterised by undefined rewards and affection for the care recipient. Roth et al. (2015) refer to providing assistance with activities of daily living or care to a person living with a chronic illness or disability as informal caregiving. Informal caregivers are usually family or close friends.

The study will focus on the actions and unknown experiences within the context of caregiving rather than treating caregiving as a role one fulfils. Instead, this study focuses on the actions found within the context of caregiving. It is important to note that caregivers are not a homogenous population and that informal caregiving often occurs due to diverse and complicated circumstances. Research has often focused on the formal domains of caregiving and has failed to address the needs of older aged caregivers, who are an already stigmatised population. This study will focus on older aged informal caregivers in a New Zealand context.

1.1.3 Informal caregivers a misunderstood population

Metzelthin et al. (2017) have highlighted that informal caregivers are understudied, and more knowledge is needed on this population to support the growing nature of informal caregiving better. Research tends to focus on intergenerational caregiving (e.g., adult children caring for older parents or older parents caring for disabled children). It fails to address age groups outside of this, as work by McGarry and Arthur (2008) has highlighted. This means research has failed to address the older aged carer and the effect that this has on the caregiving process. Moore and Gillespie (2014) found that caregivers and care recipients must work together to avoid stigmatisation. This can impact caregivers and care recipients by creating different social and emotional demands which impact the relationship (Bevans & Sternberg, 2012). Moore and Gillespie (2014) suggest that the causes of misunderstandings and disagreements between care recipients and caregivers are not fully understood. Caregivers face daily challenges that the general population does not, such as specific types of stress, difficulties performing daily activities, the pressures of caregiving, and the stigma that comes with it, especially if the care recipient has cognitive impairment or disability (Bevans & Sternberg, 2012).

Harris (1993) suggests that the difference between caregivers is apparent and can often lead to contradictory findings, reflecting that caregivers are a misunderstood population. McGary and Arthur (2008) suggest that the main concern for service providers is the care recipient. This results in the needs of caregivers being overlooked and potentially misinterpreted. Work by Carmeli (2014) states that satisfying the workers within their roles is vital as it leads to increased levels of care and performance. Nguyen and Connelly (2014) report that a lack of strategic policy for informal caregivers can lead to a lack of support, confusion, and mismanagement. This will be explored later. Unfortunately, unpaid caregivers have been found to be undervalued and reported as the backbone of long-term care systems worldwide; this has been reflected in policy reforms (Lorenz-Dant & Comas-Herrera, 2021). This will be explored next.

1.1.4 Neoliberal approach

The neoliberal approach to reforms and policies related to caregiving will be explored here. The shift in policy reflects a neoliberal approach because governments shift the power of care from state domains, reducing accountability from national levels to individual and public responsibilities (Cash et al., 2013). The reorganisation of state involvement is aimed at organising political, economic, and social life by reference to market principles (Brown, 2000). This approach attributes one's failures and successes in life to the self. By engaging in neoliberalism, the state absolves itself of any responsibility, and it is often up to family members and relatives to provide care and income (Luxton, 2015). The need to explore such an understudied population is clear. The neoliberal discourse will be explored more below concerning caregiving.

Furthermore, research suggests that many western countries have been and are still implementing reforms in long-term care (Wittenberg et al., 2018). This is reflected in cutbacks in professional and residential care, resulting in more attention being directed towards informal care. In this case, informal care is looking to provide care, increase the normality of family caregiving even for non-kin, and reduce reliance on and responsivity of the government (Broese van Groenou & de Boer, 2016). The increasing costs of the health care system will result in more home caregivers (McCann et al., 2015; Tappenden et al., 2012). The neoliberal shift from institutionalised to informal caregiving fails to capture the realities of life and families, which are encouraged to be self-reliant and self-govern rather than rely on state support.

The neoliberal approach that many countries have adapted does not consider the inequalities and hierarchies in our society already. These differences are reflected in carer reasonability, which often leads to some form of economic disparity and creates power imbalances, despite disparities likely existing independently of the caregiver role (Fineman, 2004; Thompson, 2018). Informal caregiving is going to be essential in the future due to reforms and ageing populations across the world. This is emphasised by research showing that one-third of the European population spends time caregiving informally (Verbakel et al., 2017). The responsibility of older adult care is typically placed on family members (Rodger et al., 2015) and is reflected by the shift in government policies towards care in the home (Kelly & Sharp, 2013). Caregivers are essential to us today, and informal caregiving has recently become more common. Yet, research on caregivers, in general, is neglected, and this is more so for informal caregivers and the older aged population (Greenwood et al., 2019a).

1.1.5 Summary

Due to caregivers being an understudied population, they are likely misunderstood, as the way they experience the world may differ when compared to non-caregivers. The taken-for-granted assumptions held towards caregivers may not reflect the daily challenges, pressures, and activities that caregivers partake in. It is clear from the literature to date that more research is needed on older aged caregivers, as they are an undervalued, understudied, and potentially misunderstood population, as research often focuses on care recipients rather than caregivers. This research will provide an opportunity to recognise older caregivers' vital roles and address emerging issues, especially health inequalities, from their experiences. The importance of caregiving will increase over time, as shown by changing health, care needs, and the ageing society that we live in (Greenwood et al., 2019a; McCann et al., 2015; WHO, 2014; Wittenberg et al., 2018). This has been reflected in the above changes to reforms and policies that promote individual responsibility for caregiving, moving the focus away from institutionalised domains and government responsibility. This review will explore the literature on the perceived positive and negative effects of being a caregiver.

1.2 Positives and negatives of caregiving

Factors associated with both the positive and negative aspects of caregiving are related to the older care recipient, the caregiver, and caregiving (Vellone et al., 2011). For this study, I have broken the positive and negative aspects of caregiving into two separate sections in the hope that this will aid in the understanding of both positive and negative effects. This is partly due to the lack of studies that analyse both positive and negative effects together using the same sample (Andrén & Elmstahl., 2005; López et al., 2005; Seoud et al., 2007), except for a few (e.g., Greenwood et al., 2019b). It is worth noting that, in reality, the negatives and positives of caregiving cannot be separated. Therefore, some degree of overlap is likely to occur between the positives and negatives associated with caregiving. Now the positive effects of caregiving will be delved into further.

1.2.1 Positives of caregiving

Here I will explore the positives of the caregiver role. It is important to note that the benefits of caregiving do not necessarily eliminate or reduce the burden of caregiving; however, research has shown that a more positive attitude towards caregiving may lead to improvements in carers' health and well-being (Cohen et al., 2002; Miltiades & Pruchno, 2002; Pinquart & Sorensen, 2004).

1.2.1.1 Individual perceptions

Caregiving has become a part of the carer’s identity, as reflected in research by De Boer et al. (2009), who found that only 7% of informal caregivers in their study reported zero positive experiences in their caregiving role. Brouwer et al. (2005) found that half of their participants would be less happy if the caregiver role were taken over by someone else or if someone were to do their tasks for them.

It is important to note that the positives of caregiving do not necessarily remove or take away from the burden of caregiving, but research has shown that a more positive view on caregiving may lead to improvements in health and wellbeing for caregivers (Cohen et al., 2002; Miltiades & Pruchno, 2002; Pinquart & Sorensen, 2004).

Moreover, findings in McKee et al. (2003) and Balducci et al. (2008) linked the positive effects of caregiving to individual caregivers' perceptions of their ability to cope, their worthiness of caregiving, a good relationship with the care recipient, and the feeling of being appreciated as a caregiver. Supporting research reported that the perceived positive experience of caregiving is linked to gains, personal growth, satisfaction, and the feeling of being useful and needed (Hanyok et al., 2009; Kuuppelomäki et al., 2004; Shirai et al., 2009). These factors can result in reductions in stress and depression (Kuuppelomäki et al., 2004; Shirai et al., 2009). This shows the positives of caregiving, and their implications are often ignored in research.

Greenwood and Smith (2016) reported in their narrative synthesis review that positive caregiver experiences tended to be reported by qualitative research focusing on caregivers' experiences. Quantitative research uses hypothesis testing, which values preconceived ideas such as caregiving is challenging, whereas qualitative research from a grounded theory perspective which will be used in this research, looks to explore unknowns (Charmaz, 2006; Chigbu, 2019). In addition, Rose and Bruce (1995) highlighted that underplaying a situation as manageable when it was unmanageable was common for older-aged caregivers. This can help explain the difference in results between quantitative and qualitative research, with qualitative reporting more positive effects. On the other hand, Rose and Bruce (1995) further suggested that in-depth interview processes in qualitative research often led to caregivers opening up about their lived experiences and providing high levels of detail on their situation. This often led to caregivers breaking down and being in emotional states. Additional research found positive outcomes (for example, developing resilience, receiving appreciation from patients, improving family cohesion, and gaining a sense of self-worth and accomplishment) related to the caregiver role (Bauer et al., 2013; Pinquart & Sorensen., 2003).

Further research has reported that older aged caregivers may have more and better strategies to cope with the stresses of caregiving and have a more positive outlook on caregiving and more positive perspectives in general than younger caregivers (Greenwood & Smith, 2016). The effects of caregiving can go beyond the physical and has implications on caregivers' mental and emotional well-being. This is the case for both positive and negative effects. The above literature shows that caregivers' perceptions of their role can influence how they experience being a caregiver. Next, we will explore what motivates individuals to become caregivers and to continue to be caregivers.

1.2.1.2 Motivation for caregiving and cultural factors

This section will examine caregivers' motivations to become a caregiver. Research has shown that love and positive attitudes influence the caregiver's experience. Greenwood and colleagues’ (2019a) study highlights that caregivers’ positive attitudes and love for caregiving impact their experiences of the caregiver role. This shows that each individual's perspective impacts how they experience the caregiver role. The study (Greenwood et al., 2019a) reported that older-aged caregivers consciously made an effort to be positive. Participants also reported that they did not think this was any different for younger caregivers (Greenwood et al., 2019a). Caregivers often viewed their role of informal caregiving as a part of family life that occurred through love and acceptance. The sense of family is a strong reason for taking up caregiving, as it is seen as one's duty to do so from a traditional family perspective, and quite often, spouses report a sense of duty and reasonability to look after their spouse during their decline (Bauer et al., 2013). Additional studies support the idea of love as the main driving factor for taking on the caregiving role (Swain, 2018).

Work by Zarzycki and colleagues (2022) found that cultural values, expectations, and beliefs are vital to an individual's motivation to become a caregiver. The ethnocultural context of people reflects the norms, values, beliefs, and expectations of that group. These socially constructed expectations can act as a motivating factor for becoming a caregiver. Zarzycki and colleagues' (2022) work has highlighted how obligations to be and become a caregiver can be motivated from a cultural perspective. Work by Zhou et al. (2016) reports that people's beliefs about providing care are influenced by deeply rooted cultural beliefs. For example, Pharr and colleagues (2014) found that some groups experienced caregiving as an expected part of life passed down across generations. This is often the case for Chinese families (Zhou et al., 2016). Additional research by Hsiao and Tsai (2014) and Zhou et al. (2016) has found the family's cultural values to be more prominent in non-western societies and an influencing factor on one's motivation to become a caregiver. Zarzycki et al. (2022) found that social pressure and social recognition were two reasons caregivers chose and continued to be carers despite caregiving being a societal expectation. Pang and Lee (2019) showed that caregivers want to sustain the image of ‘the good caregiver’ and that being recognised by others is a motivating factor for being a caregiver (van Wezel et al., 2016). The Critical Appraisal Skills Program (CASP, 2014) suggests that pressure from others and the expectation to provide care left little choice due to the negative consequences and loss of respect that would occur from refusing to become a caregiver for a loved one. Pharr et al. (2014) study reported that for some, caregiving is done without question because it is so culturally embedded that the choice to be a caregiver is irrelevant.

1.2.2 Negatives of caregiving

Negative aspects of the carer role are commonly reported in the literature, such as declining mental, emotional, and physical health, a shrinking social circle, less life satisfaction, tiredness, higher rates of stress, and financial burdens associated with the caregiving role (Caputo et al.,2016; Hanyok et al., 2009; Mosquera et al., 2016; Vellone et al., 2011; Vitaliano et al., 2014). Greenwood and colleagues (2019a) used focus groups of caregivers aged between 70 and 86. They found that older caregivers believed that all caregivers experienced the same positive and negative effects in their role. However, the study participants believed that older-aged caregivers experienced more negative effects due to their own decline in health, physical ability, and emotional states. Informal older-aged caregivers were believed to have a more challenging time overcoming barriers of the role due to their increasing age (Greenwood et al., 2019a). For example, physical activities that were not difficult in the past have become more challenging.

The literature supports that age affects one's ability to provide care because older age results in a decline in one's ability to carry out tasks due to loss of mobility and strength (Bass et al., 2012; Milanović et al., 2013; Kong et al., 2021). Smeets et al. (2020) specifically found that a minority of caregivers believed tasks took longer to complete due to their age and decline in physical ability and mobility.

Additional research found that caregiving in all settings had higher burdens on their own well-being; however, at-home caregiving (often informal caregivers) was associated with lower levels of care-related quality of life (Metzelthin et al., 2017). Further studies accounting for income, time spent caregiving, personal characteristics, positive effects, random effects and stress as shown by a correlation between care-related subjective stress and daily bodily pain using a multilevel model for caregivers of Alzheimer's patients (Ivey et al., 2018). This showed that pain experienced by older-aged caregivers is related to the stress and deterioration of those they are caring for. From this, we can see that adverse effects are associated significantly with the caregiving role (Bass et al., 2012; Caputo et al., 2016).

Furthermore, limitations of such studies have been identified, such as their lack of consideration of factors outside the caregiving role, but few studies addressed this issue (Budnick et al., 2021; Ivey et al., 2018), the focus on female caregivers (Lorenz-Dant & Comas-Herrera., 2021; Smeets et al., 2020) and the lack of generalisability of results (Falvo et al., 2021; Rodger et al., 2015; Smeets et al., 2020). However, offering generalisable results is not the goal of qualitative research. Yuan and colleagues (2021) have found that gender did not have a significant statistical impact on the participant groups in their study despite the sample consisting of 64.9% females. This means that studies using female-only participants' results may be more generalisable to the population than originally thought.

1.2.2.1 Social support and social capital

Past literature has identified social support and support systems as a major impacting factor on the caregiver experience. Greenwood et al. (2019a) findings reported that as age increased, social circles often decreased, resulting in less support for older-aged caregivers. This can occur due to a lack of understanding by others of the pressures of the caregiver role and due to their ageing. Additional studies further supported this (Greenwood et al., 2019b). Rodger et al. (2015) found a lack of support for informal caregivers. This was supported by other studies such as Wenger (1990) and Falvo et al. (2021); this was for both internal, which refers to family, friends, and personal social support groups, and external support systems, such as professional help.

The findings of Rodger and colleagues' (2015) study reported that other family members of the caregiver were viewed as having failed to take up the responsibility of carer, provide additional support, and were seen as visitors. Despite this, when help was requested from family members, there was difficulty in receiving support, even for short periods of time. Triantafillou et al. (2010) found that some caregivers viewed the carer role as their reasonability alone. It is their reasonability to step up and ensure the care recipient is supported, no matter the time commitment (Triantafillou et al., 2010). External support, such as professionals in the community, is useful, but often caregivers feel they are not entitled to access these or are not aware of them (Rodger et al., 2015),

Falvo and colleagues (2021) attributed the seeking of help by caregivers to the stigma and discrimination surrounding the caregiving role. The role of social capital views caregivers' motivations to care, continue caregiving, and their reasons for rejecting help from a different perspective. Social capital reflects the norms within networks and how society and culture can create levels in terms of networks. These cultural and social determinants can reflect processes and mechanisms that motivate individuals in their caregiving roles. For example, those of an Asian cultural background had more notable cultural expectations and values around caregiving than those of Caucasian ethnicity (Donovan & Williams, 2015; Han et al., 2008; Kong et al., 2010a; Lee et al., 2019; Meyer et al., 2015). In this study, culture has been described as and is considered a 'learnt system of symbols and shared values, meanings, and behavioural norms’ (Kavanagh & Kennedy, 1992, p. 12). In simple terms, culture acts as a guiding force in individuals' decisions to become a caregiver and continue to be a caregiver based on what is expected of the individual, what they deem as right and what they believe is their responsibility. These things impact an individual's decision and motivation to participate in caregiving (Dilworth-Anderson et al., 2005). Further research identifies that caregivers' capacity to cope with challenges, economic situations, emotions, and logistics in disaster situations can be driven by social capital (Uekusa, 2019). Caregiving in disaster situations will be explored later.

1.2.2.2 Availability of support

This section will explore what resources are available to caregivers. Research has reported that confusion exists around what support is available for older caregivers or where to obtain information about what support is available (McGarry & Arthur, 2008). Various levels of support for individual caregivers can impact the reported experiences of caregivers; however, research reports a general lack of support for informal caregivers (Greenwood et al., 2019b; Rodger et al., 2015; Triantafillou et al., 2005).

Participants in Greenwood et al. (2019b) study reported that older aged caregivers may be less likely to seek support due to their pride in having worked in the caregiving role for years compared to younger generations. This was supported by the findings of Pickard et al. (2000). McGarry and Arthur (2008) found that older aged caregivers tended to prefer informal services to formal services when available. However, the reason for this is not known. It is important to note here that McGarry and Arthur (2008) used interviews, and it was not always possible to interview caregivers alone, which may impact the result and whether the information was withheld during the interviews. This is a limitation of the study. It is suggested that older-aged caregivers are reluctant to seek support due to their age, and getting help is a sign of a decline in one's health and ability to be a caregiver (Rodger et al., 2015; Falvo et al., 2021).

The caregiver role was seen by participants as a role of love and a part of family life, which may impact their decision to seek additional support from outside the family (Swain, 2018; Greenwood et al., 2019b). Hong and Harrington (2016) investigated the impact of resources on the caregiver role. They found a substantial relationship between available resources and other variables (e.g., negative caregiving situations and higher caregiver burden). The relationship between the perceived health of caregivers and resources was found to have a value of –0.43, which was stronger than the relationship between caregiver burden and perceived health (.14) (Hong & Harrington, 2016). This shows that resources available to caregivers impact the health of caregivers more than the burden associated with the caregiver role**.** Sołtys and colleagues (2021) suggest that caregivers' capacity to cope is impacted by their personal resources and their ability to cope with stressful situations. Research on cultural narratives shows that resources are distributed based on the intertwining of cultural narratives with institutional narratives (Loseke, 2007). When cultural narratives and institutionalised narratives do not align, the results are often reflected in disproportionate resources and disparities.

On the other hand, service providers' concerns focus on the care recipient's needs and often overlook the caregiver, as McGarry and Arthur (2008) reported. This may explain why informal caregivers feel a lack of support in their role. Greenwood and colleagues' (2019b) study did not account for differences between long-term and short-term care and did not consider gender differences in the caregiver role, with the majority (86%) of the participants being female. However, research has shown that females dominate the caregiver role in the general population (Paraponaris et al., 2012; Kong et al., 2021; Triantafillou et al., 2010; Sharma et al., 2016). This study included care recipients with a wide variety of health conditions. This means the findings in this research are not limited to one specific illness or health condition but a representation of a variety of issues that occur across different health conditions. The person's experiences of caregivers are complex, with many factors impacting one's own experience. Further research is needed in this area to increase support, reduce confusion about available resources for caregivers, and counteract the stigma of caregiving. Next, I will explore research related to caregiving and its links to depression, stress and anxiety.

1.2.2.3 Links to depression, stress, and anxiety

Here I will explore links between the caregiver role and negative health outcomes. A research team from the Department of Epidemiology and Public Health at University College London has investigated the well-being of older people and found that both male and female caregivers were at greater risk of depression (Steptoe et al., 2015). This was shown by participants reporting more depressive symptoms than non-caregivers. This contradicts other research, such as Allen et al.'s (2022) and Steptoe and Rafnsson's (2015) report for the International Longevity Centre UK, which showed that being a caregiver was not linked to increased depressive symptoms but rather individual circumstances of the caregiver that led to symptoms of depression. The difference in findings can be explained by incorporating both short- and long-term effects of caregiving into research, either together or individually. The negative impact on caregivers is likely caused by the continual stress associated with the role of being a caregiver and accumulates over time (Kramer & Lambert, 1999; Steptoe et al., 2015). Six out of ten caregivers in a survey of UK Caregivers have reached breaking point due to their carer role, and a quarter of those that have reached breaking point have required medical treatment (Carers UK, 2014). The survey reported that outside help was needed to look after the care recipient while the carer recovered. Worries about who will look after the care recipient when an older aged carer is unable have been a common worry of caregivers throughout research (Carers UK, 2014).

On the other hand, research by Kramer and Lamber (1999) showed that entering the caregiving role was not significantly associated with reported depression or lower quality of life for older people. This finding contradicts findings that older aged caregivers face higher stress levels and have more worries than younger caregivers due to their age and own decline in physical abilities (Greenwood et al., 2019; Falvo et al., 2021; Rodger et al., 2015). Kramer and Lambert (1999) reported this as surprising as it is often assumed that negative health and wellbeing are part of the caregiving role. Swain (2018) found that physical and emotional health and personal and social restrictions were the most burdensome. The burdens of caregiving have been well supported in research (Baji et al., 2019; Hayashi et al., 2021). Morrison and Williams (2020) suggest that the positive and negative effects of the caregiving role can fluctuate and only partially explain experiences and potential impact. They further reported that predictive factors are an understudied area among caregivers. This could explain the difference in findings across studies. It is clear from the research that further research is needed into the experiences of older-aged caregivers. Greenwood and Smith (2016) suggest that reaching a meaningful conclusion is unlikely due to comparisons in research between informal caregivers and professional caregivers, older and younger caregivers, and a wide range of health issues associated with caregivers and care recipients. They suggest it is impossible to confidently say whether older caregivers' experiences in quality of life, such as depression, are worse than those not in a caregiver role. Greenwood and Smith (2016) suggested the need for more longitudinal studies to address this issue and see how caregivers' experiences in their role change over time.

1.2.2.4 Explaining the contradiction in findings

The findings and results yielded in studies across the literature have contradicted each other. This paragraph will cover some of the reasons this may occur. Current research that focuses on the caregiving role in relation to specific illnesses found that illnesses that are long-term and deteriorate over time, such as dementia and mental illness, pose a different set of challenges than other illnesses the care recipient may have. It is believed that the type of illness a care recipient has can impact the mental, emotional, and physical states of caregivers differently (Tuijt et al., 2021). This is one explanation for the above contradictions in findings across research and shows a need to add further literature to this field of study. The literature has also suggested that the more severe an illness faced by the care recipient leads to greater reasonability for caregivers (McCann et al., 2015; Spiers et al., 2020). This generally leads to more sacrifices being made by the caregiver to support the care recipient and their declining health. Research shows that caregivers sacrifice their social lives, their well-being, and vast amounts of time, and often suffer from changes in their relationships to be informal caregivers (Smeets et al., 2020; Swain, 2018; Tuijt et al., 2021).

Alternative research, such as Harris (1993), suggests that research findings may not be contradictory at all but reflect the complexity of caregivers. They refer to the difference in findings as factors relating to the caregiver. For example, male caregivers that had been caregiving for longer periods reported low stress related to the role. In contrast, newer male caregivers reported higher rates of stress related to the role. This may help explain some of the contradictions found in the research. I believe this emphasises the need to further explore the personal experiences of caregivers, and more specifically, informal caregivers, the roles they play, and the challenges and benefits of the caregiver role.

1.2.2.5 Summary

The above literature has highlighted that the caregiving role has become part of the caregiver's self-identity. Because of this, many would not choose to give up being a caregiver if they had the opportunity, despite the daily challenges they face as a caregiver. Caregivers’ own views and perceptions of their role, their worth, and the rewards associated with the caregiving role impacted whether they had more positive or negative experiences as a caregiver. Those with a more positive outlook reported more positives associated with being a caregiver. In addition, the larger societal expectation has clearly impacted one's decision or lack of decision to become a caregiver. This is intertwined with cultural expectations that promote the idea of duty to care for family, which is often the case in eastern societies such as China. Others report that they chose to partake in the caregiver role due to love and affection for the care recipient. All these factors impact one's decision or lack of decision to become and continue to be a caregiver, as shown by the above literature. Now we will explore the negative effects of caregiving.

In contrast, the caregiver role has been linked to negative outcomes such as increased symptoms of depression, stress, and anxiety. In addition to this, caregivers faced confusion around what resources were available to them during Covid-19 and that caregivers' access to resources impacted the experiences they had. Social support has been shown to impact caregivers. The literature showed that caregivers often felt they had little support from family and friends when providing care. Social capital helps explain some of the societal and cultural factors that influence whether one becomes a caregiver. The research to date is somewhat limited, and caregivers’ experiences have been traditionally undervalued. Recently, a rise in research in this area has occurred, yet findings still contradict each other. The above literature has outlined factors such as conditions and illnesses of the care recipient that can pose many different challenges, challenges faced by caregivers due to the sacrifices they have made to become and continue to be caregivers, and that many of the contradictions in research are not contradictions at all but reflect complex differences experienced in the caregiver role due to factors like individual characteristics and situations. Next, I will explore the implications of theory, which can help shed more light on why contradictions in the literature may occur.

1.3 The implications of theory on the positives and negatives of caregiving

This section will build on the above chapter and explain how different theories used in research may explain some of the contradictions found in the literature. The literature to date cannot agree on the nature of positive and negative impacts on caregiving. López et al. (2005) viewed positive and negative aspects of caregiving as two coexisting, unrelated components, meaning they do not affect each other. Alternative research (Balducci et al., 2008; McKee et al., 2003) reports caregiving as one-dimensional, meaning the positive and negative aspects of caregiving end with that continuum. Vellone and colleagues (2011) reported in their research that the relationship between positive and negative effects of caregiving is not clearly understood to be coexisting and unrelated or as a one-dimensional continuum, making it difficult to report on the relationship between the two. However, there is no sufficient evidence to indicate whether positive and negative are one, two, or multidimensional. The difference in factors and variables associated with negative and positive effects on caregivers can be attributed to the theoretical approach taken, which focuses on the issues through a specific lens.

One theoretical approach is Kuhn’s theory of incommensurability, which suggests that different paradigms within science do not necessarily align. This can be due to a lack of common measures, resulting in cross-purposes (Bird, 2000). Communication between different paradigms within science and theoretical approaches in research limits communication across them as they can hold different standards for what they consider science (Bird, 2000). Theoretical approaches in research and different paradigms of science use different concepts, methods, and definitions, resulting in a lack of common measures across them for factors like positive and negative experiences of caregivers. This may explain some of the variations in findings amongst research on caregivers. The theory of incommensurability is still debated, with works such as Chen (1997) arguing that incommensurability does not imply incomparability and Mizrahi (2015) arguing that there is neither strong deductive nor inductive support for such a theory. The difference in factors and variables associated with negative and positive effects on caregivers can be due to the theoretical approach taken and the focus on an issue through a specific lens.

In addition, Cho (2007) suggests that social network theories focus on the interactions between relationships that have different levels of support. Cho (2007) proposes a task-specific theory. This theory implies that each relationship is different and optimally manages different tasks. In this theory, care is provided by different support networks or people depending on the task that is needed. This may explain some of the contradictions in results as each study takes a slightly different theoretical perspective. A second social support network theory Hierarchical-compensatory theory, focuses on the care recipient’s preferences (Cho, 2007). Social support is recognised as the tasks and functions addressed through social relationships (Uchino, 2004). The link between social support and social relationships in relation to health outcomes is addressed by social support theories (Cho, 2007). However, each model of social support theories focuses on various aspects and processes (Cho, 2007). Schulz et al. (2020) support this and propose that caregiving is a diverse topic with many different levels of analysis and methodological approaches. Social support is provided by relationships, and social support theories link these relationships to health outcomes, although each theory within social theory operates differently, emphasising different aspects (Cho, 2007). Schulz et al. (2020) suggest that one study may focus on health and social systems while looking at impacts on caregivers and care recipients Alternative research may focus on a population-based level and use a longitudinal approach to assess the impact and levels of stress exposure and so on (Schulz et al., 2020). The theoretical approach taken allows us to answer different questions within the diverse topic of older-aged informal caregiving, and this lens through which we view the topic may explain differences in results across research. Theory in qualitative research has been recognised as being able to be used in different ways and view topics of interest from different lenses, which can shape how findings are interpreted (Collins & Stockton, 2018).

On the other hand, a lack of a theoretical framework can explain the variation in findings and the relationship between the positives and negatives of caregiving. Nguyen and colleagues (2022) report that qualitative research often lacks theoretical guidance in its research design. This is because qualitative research does not take a deductive and positivist approach (Bahari, 2010). This is one reason why grounded theory will be employed in this study. Heng (2020) suggests that international research often lacks the appropriate theoretical engagement needed, which limits the study's abilities to relate results to their origins and draw correlations. Collins and Stockton (2018) have suggested that overreliance on theory in qualitative research can further limit the findings in the data of a study and caution the use of theory for this reason.

1.4 Impact of Covid-19 on informal caregivers

This chapter looks to further explore the scope of research on older aged informal caregivers, focusing on how disasters impact them and the potential challenges and conditions this may exacerbate in relation to the caregiving role. To address this issue, disaster research will be taken from a wide range of literature before I narrow our focus on specific issues and experiences of caregivers in relation to Covid-19, which is one of the aims of this study. This approach has been taken as Covid-19 is still a recent phenomenon, and research in this area was limited when this study began; however, research in this area has grown drastically.

1.4.1 Disaster research on caregivers

Disaster research on the caregiver population is essential in current times. Literature has identified challenges such as a lack of preparedness for disaster situations. American Red Cross (2020) reports that disaster preparedness is important for all ages, but adults are more vulnerable due to factors such as the greater prevalence of chronic conditions, cognitive impairment, medication concerns, dependence on assistive devices (e.g., walkers, glasses, etc.), potential social isolation, concerns for psychological distress, support requirements from caregivers and others, and gaps in how prepared caregivers and supporters are. Pickering and colleagues (2021) identify a lack of preparation for disasters as a major concern for caregivers and a need for further support and education to better prepare caregivers for potential disaster situations. An example of an area where caregivers may need more training and preparedness is related to medications. Medication is vital to those with long- and short-term illnesses and to those who are experiencing health declines due to age. Understanding how to use medication and medical equipment was an important aspect of the literature (Pickering et al., 2021). Pickering et al. (2021) identified adults as most reliant on medication. Just over half of family caregivers in Kyota and colleagues (2018) stored medications for the care recipient in the event of an evacuation. Another study identifies that the most common services provided after Hurricane Katrina in evacuation shelters were chronic health services and prescription refills (Mace & Doyle 2017). The need for medication and the right documentation and devices to identify the correct medication needed for care recipients is essential to being prepared for a disaster (Oliva et al., 2013; Sakashita et al., 2013; Ahmadi et al., 2018). Numerous studies have identified age as a risk factor due to declines in health related to age and noted that during a disaster, older persons are at greater risk of danger and exposure to danger during a disaster (Acierno et al., 2006; Aldrich & Benson, 2008; Sakauye et al., 2009; Mace & Doyle, 2017).

Christensen and Castañeda (2014) found Alzheimer’s or related dementias to be correlated with age and that this diagnosis may impact the decision of caregivers during a disaster situation.

In addition, Brown et al. (2012) research shows that the disruption of daily activities during an evacuation due to a hurricane can be impacted by existing physical and mental health conditions, which may become exacerbated by such changes. Brown and colleagues' work found that it may be more beneficial for higher-risk individuals who may not respond well to changes in daily activities of living in a disaster situation (such as evacuation) to be housed by family members, which may result in better outcomes. In the event of Hurricane Katrina, nursing homes that evacuated versus those that took shelter were investigated. Dosa and colleagues (2010;2012) found that evacuating nursing homes contributed significantly to increased rates of morbidity, hospitalisation, and mortality for nursing home residents compared to those who took shelter during the storm.

Further research found that historically older adults have had the highest rates of disaster-related deaths relative to the general population, and older adults aged 65 years and older were the least prepared subgroup of the population (Duggan et al., 2010). However, not all experiences in disaster situations have been negative. One stress reduction technique that has shown positive effects is the use of music for people with Alzheimer’s or related dementia. Christensen and Castañeda (2014) highlight that the use of activities such as listening to music can redirect the attention of care recipients with Alzheimer’s or related dementia, turning a potentially stressful situation (the sound of the wind, darkness, and pressure changes) into a positive and entertaining experience. This positive experience from disaster research with hurricanes highlights the importance of being prepared. For example, having a battery-powered device available that can play music for care recipients with Alzheimer’s or related dementia can reduce potential outside triggers and create environmental continuity (Gallagher-Thompson et al., 2012; Kong et al., 2010b; Raglio et al., 2008). It is important to note that Covid-19 is an unpredictable phenomenon that is unprecedented and has not been seen before in our lifetime. This makes preparing for such a disaster increasingly difficult, meaning the effects of the Covid-19 pandemic may have greater implications than shown by past disaster research. It is clear that older aged people are more at risk in disaster situations, and that is why this research looks to explore this population.

1.4.2 Covid-19 and caregiving

The Covid-19 pandemic is one of the latest phenomena in the world that has caused chaos, with many countries implementing lockdowns, closing their borders, and mandating the wearing of face masks and vaccinations. This phenomenon continues to spread and adapt and is still a concern today. These responses to the pandemic have impacted the daily running of our lives; however, the majority of the research at the time of writing looked at disease prevention and the economic implications of Covid-19 (Cumming, 2022). It is clear from general research on disaster situations that older populations are more vulnerable and at risk (Oliva et al., 2013; Pickering et al., 2021; Sakashita et al., 2013; Ahmadi et al., 2018). In the case of Covid-19, this is no different, with older people being at higher risk of getting the virus and experiencing more severe symptoms (Chee, 2020; Falvo et al., 2021; Legget et al., 2021; Wilder-Smith & Freedman, 2020). A study shows that eight out of ten Covid-19 cases that resulted in deaths reported in the United States have been among adults aged 65 years and older (Kang & Jung, 2020). Further research shows that fatality rates are more than five times higher for those aged 80 years and over compared to the general population (World Health Organisation, 2020). It is clearly established that the ageing population is at greater risk in the event of a disaster and, more specifically, the recent global pandemic. However, the majority of the initial research related to Covid-19 has focused on disease prevention and the economic implications of Covid-19. Although this is valuable and needed, it has left the experiences and voices of people who have experienced the pandemic in the shadows (Cumming, 2022). This further impacts the ageing population, which requires practises and policies to empower them and promote the highest degree of self-reliance possible (Carers UK, 2014). In the United Kingdom, a lack of information about Covid-19 guidelines existed, which led to widespread confusion about government recommendations and advice that should be followed (Carers UK, 2020; Lorenz-Dant & Comas-Herrera, 2021).

On the other hand, in Germany, 87% of unpaid caregivers felt they were able to respond to the pandemic and had access to information that was clear and comprehensible to follow (Eggert et al., 2020). This confusion has the potential to impact caregivers' ability to be safe, be prepared, provide the best care, and follow guidelines. A lack of information or contradicting information can cause confusion for caregivers. This, along with a lack of preparation, can be problematic.

1.4.3 Social isolation and Covid-19

Social isolation of the ageing population has been a theme occurring throughout the literature (Greenwood et al., 2021a; McCann et al., 2015; McGarry & Arthur, 2008; Spiers et al., 2020; Steptoe et al., 2015). The response to Covid-19 around the world is debated and has resulted in further isolation of the ageing population. Various studies have found social isolation and loneliness to be an issue for caregivers before the Covid-19 pandemic and suggest that the restrictions implemented, such as physical distancing, may lead to negative effects on mental and physical health (Cacioppo et al., 2006; Chen & Feeley, 2014; Losada-Baltar et al., 2021; Rico-Uribe et al., 2018). The stay-at-home restrictions on older age people have been found to be stricter and lasting longer in the United States, contributing to increased fear of Covid-19 and anxiety in older adults (Monahan et al., 2020). This reflects Falvo et al.'s (2021) finding that an already stigmatised population (older people) will be further stigmatised by the labelling of older people as more at risk and susceptible to Covid-19. The mitigating techniques used by countries around the world have resulted in further isolation of the ageing population, in particular, community restrictions. This has led to an increased risk of loneliness in older adults (Brooke & Jackson, 2020; Tyrrell & Williams, 2020). The limited research on this topic has suggested that older people are avoiding outings due to the increased threat and severity of Covid-19 (Stephens & Breheny, 2022).

Furthermore, in residential care, Chee (2020) found that care recipients often kept to themselves and were isolated to reduce the threat of infection and spread resulting in isolation. This effectively means older people are in complete social isolation (Stephens & Breheny, 2022). This is partially due to the perceived susceptibility of older age groups compared to younger ones. Falvo et al.'s (2021) study found that participants were reluctant to leave their homes, which often resulted in feelings of isolation and reclusion. A few participants in Falvo et al. (2021) study viewed their house as a place of protection from external threats. Research has found that individuals perceived the experience of staying at home as a form of imprisonment (Falvo et al., 2021). One participant from Falvo et al. (2021) study stated, "even prisoners need an hour of yard time". A study by Tuijt et al. (2021) reported that, although older caregivers and their care recipients understood lockdown and social distance procedures, they were more often than not associated with negative connotations. Alternatively, Falvo and colleagues (2021) found that half of their participants expected that a lack of social contact and reclusion could have an impact on both their mental and physical health, such as loneliness and depression. Individuals also reported that confinement at home led to the experience of emotional tension (Falvo et al., 2021). Further studies such as Bergmann and Wagner (2021), Rahimi et al. (2021), and Russell et al. (2020) have reported on the negative effects and experiences of caregivers concerning Covid-19; however, a greater depth of research in this area is needed.

Social isolation due to policies, social distancing, and lockdown procedures disrupts the daily routine of caregivers as well as the general population. Informal older-aged caregivers often reported that social distancing and lockdowns led to daily disruption and that it was hard to replace daily activities, especially those with a social element (Tuijt et al., 2021). The daily activities and running of caregivers and their care recipients' lives have been affected by Covid-19. As a result, older aged caregivers of dementia patients have tried to organise alternative ways for the care recipient to receive social interaction, such as activities using online technology to interact with others, like Zoom or WhatsApp (Tuijt et al., 2021). A drawback to this was the care recipients' ability to use technology, especially those with dementia. The study (Tuijt et al., 2021) reported that a telephone call was not always enough to replace the missed social interaction of those with dementia. Tuijt and colleagues (2021) work found that a lack of social engagement was the most detrimental factor experienced by people living with dementia during the first UK lockdown of Covid-19.

In contrast, research has shown Covid-19 lockdowns to improve relationships between caregivers and care recipients (Ragimi et al., 2021; Tulloch et al., 2022). This will be explored more later on in the benefits of caregiving during the Covid-19 chapter but is worth noting here.

Reduced physical activity and increased loneliness in the general population are seen as risk factors associated with worsening mental health during the Covid-19 pandemic (Creese et al., 2021; Tuijt et al., 2021). An abundance of literature has supported the link between social isolation and a decline in mental health, yet there is plenty of literature that contradicts this finding (Allen et al., 2022; UK Carers, 2014). Holt-Lunstad (2015) and Novotney (2020) show a link between social isolation and loneliness and the increased risk this poses for premature mortality and poorer mental health. This is supported by the National Academies of Sciences, Engineering, and Medicine (2020) and Rohde et al. (2016). The experience of anger, sadness, and other negative emotions, as well as reduced satisfaction in life (i.e., self-esteem) and decreased cognitive ability, has been linked to brief forms of social isolation by Pancani et al. (2021). If social disconnection is prolonged, then experiences of increased suicidal thoughts, depression and risk of early mortality are increased (Baumeister and Leary, 1995; Holt-Lunstad et al., 2010). The impacts of reduced social engagement due to covid are debated in the literature. Tuijt's findings suggest that those who live alone or rely on social routines are experiencing or have experienced increased feelings of isolation due to the pandemic. The true experience of social isolation and emotions among informal older caregivers in relation to Covid-19 still needs to be further explored. Next, I will discuss carer and care recipient relationships.

1.4.4 Carer and care recipient relationship

The caregiver and care recipient relationship will be explored here. It has also been reported that social isolation has put a strain on the caregiver and care-recipient relationship (Leggett et al., 2021). A range of in-depth qualitative interviews found challenges in relation to the pandemic may affect their stress; challenges identified in the literature are social isolation, reduced social contacts, health decline of the care recipient, lack of support and services, and new caregiving responsibilities (Lightfoot et al., 2021a; Lightfoot et al., 2021b; Legget et al., 2021). Other barriers identified in research that may affect carer and care-recipient relationships are the risk and threat of contracting Covid-19, especially from a caregiver point of view (Lorenz-Dant & Comas-Herrera, 2021). One of the greatest fears of caregivers compared to non-caregivers during the pandemic was that the caregiver would pass the virus onto their care recipient, as shown by research in the US and Germany (Eggert et al., 2020; Rothgang et al., 2020; University Centre for Social and Urban Studies, 2020). This poses additional fear and worries about what would happen if the caregiver were no longer able to care for the care recipient (Carers UK, 2020; Vaitheswaran et al., 2020). In some studies, caregivers reported spending less time with care recipients to reduce the risk of infecting the care recipient, which has likely led to further feelings of isolation (Bergmann & Wagner, 2021; Cipolletta et al., 2021). Further research supports this finding, showing that those with pre-existing medical conditions are at higher risk of complications from Covid-19, and these complications can act as a barrier to caregiving due to the fear and worry associated with infection (Leggett et al., 2021).

Evidence supports the fact that health care systems during Covid-19 had fewer available resources to deal with other medical conditions (Le Couteur et al., 2020; Rimmer, 2020). The older population is likely impacted more due to needing medications and their susceptibility to Covid-19, which exacerbates pre-existing conditions (Disease and Control Prevention, 2021; Le Couteur et al., 2020; Mueller et al., 2020; Rimmer, 2020). It is clear how this can lead to fear and worries about the uncertainty of Covid-19, the impact it has on all areas of our lives, and the implications this may have on mental health and psychological wellbeing. The psychological and mental health implications of this isolation are not fully understood in the context of Covid-19; however, there has been an impact on the mental and psychological health of the caregiver. Budnick et al.'s (2021) findings suggest that the need for support is likely to be even higher during the pandemic than before for caregivers, and they recommend the implementation of Covid-19 specific care services to offer support and buffer against the additional burden that Covid-19 has imposed on caregivers.

The work of Pearlin and colleagues (1990) takes a different approach to the stress faced by caregivers. This approach does not look to separate the increased burden caused by Covid-19 from other factors but combines them. They emphasise the processes of relationships and the many conditions that lead to stress itself. Pearlin and colleagues (1990) report that the relationship and development of stress can change over time. This perspective does not simply look to identify conditions like those in the above literature but rather to know how these conditions arise and their relationships with one another. Rather than focusing on potential causes of stress, this approach looks to understand the relationships between different components, how they interact, and how they result in stress. This is done by focusing on four main domains, such as the stressors; the mediators of stress; and the outcomes or manifestations of stress. Pearlin and colleagues (1990) positioned the caregivers' characteristics as a key component that impacts the stress experienced by the caregivers. From this position, we view occupations, education, and economic status as characteristics that result in unequal distributions of opportunities, responsibilities, rewards, and privileges. These impacts on the kinds of stressors individuals can be exposed to are because of the personal and social resources available to them and because people experience different levels of stress. For example, the lower available social and personal resources an individual has, the more likely they are to experience more intense levels of stress than someone with more available resources. Therefore, stress is subjective to individual characteristics. Caregivers may, at times, feel cut off from the larger society, but they are still impacted and influenced by the organisation of society.

Moreover, the association with increased pain, burden, and psychological distress has been suggested in findings for caregivers relative to before the pandemic (Archer, 2021; Sheth et al., 2021). It has been suggested that the pandemic further exacerbates these negative factors for caregivers due to increased stress, a potential increase in workload, reasonability, a lack of available support, and the discrimination of ageism due to the caregivers and care recipients' age (Ammar et al., 2020; Budnick et al., 2021; Falvo et al., 2021; Lightfoot et al., 2021a; Lorenz-Dant & Comas-Herrera, 2021; Monahan et al., 2020); however, as Lorenz-Dant and Comas-Herrera (2020) have noted these experiences are largely absent in public reporting. Evidence supports that long-term caregiving has increased, with more people becoming unpaid caregivers due to the pandemic (Lorenz-Dant and Comas-Herrera, 2020). Chee’s (2020) study reported that care recipients often noticed the tiredness of caregivers in formal care settings and that caregivers struggled to cope with all the needs and demands caused by the pandemic. All participants in Chee’s (2020) study agreed that there is a need for more caregivers and that a lack of human resources exists, causing overstrain on caregivers. In Savla and colleagues' (2021) sample, they found services accessed by 41% of dementia patients whose caregivers reduced their hours or terminated them due to the pandemic. This led to insufficient support for caregivers that faced increased workloads due to Covid-19 (Savla et al., 2021). In contrast, 59% of carers of dementia patients had access to support services during the pandemic. It is evident that a lack of support and an increased need for caregivers have become apparent in the context of Covid-19, and this has implications for the negative impacts on both caregivers and care recipients.

A nationally representative comparison of non-caregivers, short-term carers, and long-term caregivers (more than a year) was made in an internet panel of US adults, finding that both short- and long-term caregivers faced increased mental health and fatigue symptoms than non-caregivers (Park, 2021). Park (2021) found that long-term caregivers reported greater somatic symptoms (e.g., headaches, abdominal pain) compared to non-caregivers and short-term caregivers. Findings from a survey in the United Kingdom and Germany reported that the burden of being a caregiver has increased due to the current pandemic and that those caregivers that relied on professional support had difficulty accessing services, making the caregiver burden harder for them. This further suggests a limitation of resources due to the pandemic, which impacts family and informal caregivers heavily (Budnick et al., 2021; Giebel, 2021). Legget et al. (2021) have further emphasised the need to understand the support available to caregivers and the care recipient in order to bolster support, prevent the spread and transmission of Covid-19 and understand the true nature of stressors specific to caregivers in relation to the pandemic.

Although the literature in this area is growing, there is still a need to explore caregivers' experiences and support during the Covid-19 pandemic. It is believed that by better understanding individual experiences of the pandemic, we can better improve future support, policies, and responses in the case of future pandemics and pre-existing ones. However, literature outside a pandemic context does suggest that caregiver stressors stem directly from the care recipient's condition and are believed to impact other aspects of the caregivers' lives, having potential impacts on mental health and quality of life (Aneshensel, 1995; Pearlin et al., 1990). It is important to note that appropriate support systems can combat stressors in caregiver lives that impact mental health and wellbeing (Aneshensel, 1995; Pearlin et al., 1990).

Alternative research has also called for more to be done to counter the negative impacts associated with Covid-19 (Chee, 2020). One of the limitations of research in this area is its lack of ability to separate the increased burden caused by Covid-19 from other factors. This is why Pearlin and colleagues' theory is valuable, as it is a combination of external and internal factors that lead to experiences. Therefore, I argue that there is no point in separating them. Research is mixed about the implications for caregivers and care recipients. It is clear, however, that lockdowns have impacted caregivers, whether these impacts are positive, negative, or a combination of both. This highlights that Covid-19 procedures and lockdowns implemented by countries and regions may create circumstances that lead to negative health effects. Next, I will consider the negative implications for caregivers' wellbeing in relation to the pandemic. I would first like to note that more research is needed in this area to fully understand the complexities of caregiver experiences, as Covid-19 is a recent phenomenon.

1.4.5 Summary

To conclude, disaster research has been found to be vital in current times due to the recent phenomenon of Covid-19 and its various strains. Disaster research on caregivers has highlighted a lack of preparedness leading to challenges. For example, in order to get medications that the care recipient relied on during a disaster situation, they often required proper medical documentation, which caregivers often did not have or could not bring with them due to the disaster situation. It was suggested that disaster situations cause pre-existing conditions to be exacerbated and routines to be disrupted, which leads to challenges. The literature emphasised that adult populations and older were more at risk of mortality during a disaster situation. With this in mind, we moved our focus from disaster situations to the events of Covid-19 specifically.

Research shows social isolation to be a difficulty faced by many caregivers and their care recipients. In addition, the rules put in place to protect the older aged population led to further stigmatisation of an already stigmatised population. The feelings of isolation due to Covid-19 responses showed effects on both caregiver and care recipients' mental health. The relationship between the caregiver and care recipient has been impacted. Research reported that caregivers often avoided the care recipient in order to reduce the chance of the care recipient getting infected by the caregiver. In contrast, alternative research showed the caregiver and care recipient relationship to be strengthened due to Covid-19 lockdowns. Work by Pearlin and colleagues (1990) took a different approach and did not look to identify conditions like we saw in the literature but rather looked to understand the relationships between them and how they interact with each other. Research has shown pre-existing conditions to be exacerbated due to Covid-19, which can result in an increased workload for caregivers. However, it is important to remember that findings around the positives and negatives of caregiving are mixed. This is why caregiving in relation to Covid-19 needs to be explored further.

1.5 Negative health outcomes and Covid-19

The negative implications of Covid-19 have been explored in relation to what can be done to improve support and reduce barriers for caregivers, both in professional and informal capacities, but more research is still needed. One area that the research lacks is the voice of older age informal caregivers and their true experiences of Covid-19, lockdown policies, and social distance procedures. It is already reported in the above literature that increased social isolation, stigmatisation of the ageing population, increased workload of caregivers, and diminished support have resulted in more stressors for caregivers, which has potentially negative implications on carer lives. However, findings in this area continue to be mixed. Past research has shown links between the caregiver role and reduced life satisfaction and increased physical and mental health issues compared to the general population (Bom et al., 2019; de Oliveira et al., 2015; Greenwood et al., 2019a; Vellone et al., 2011; Tuijt et al., 2021). There is no doubt that the new stressors and increased uncertainty of Covid-19 have some negative implications for caregivers and care recipients; however, the link between these factors and their implications is not fully understood to date. Past studies have identified older aged people as more at risk of Covid-19 (Kunz & Minder, 2020; Wang et al., 2020). Before the pandemic, findings confirmed that informal caregivers had higher mental and physical health burdens compared to non-caregivers (Ammar et al., 2020). It is believed that these factors will increase due to the pandemic situation. In addition, it was found that the lockdown as a result of Covid-19 has impacted caregivers, causing their wellbeing and depressive symptoms to worsen compared to non-caregivers (Schorren, 2020), but the general findings are mixed. Alternative research has shown that the pandemic resulted in a change in the pace of life, and this slower pace of life had positive implications for caregivers (Leggett et al., 2021).

On the other hand, Budnick et al. (2021) found that caregivers reported no change in their situation due to Covid-19 unless their care recipient had dementia or the caregiver relied on professional help prior to the lockdown. This implies that challenges for caregivers are characterised by the care recipient's health status, the caregiver's health status, and whether they relied on professional help or not. In the next paragraph, the availability of resources for caregivers during Covid-19 will be investigated.

1.5.1 Resource availability

The literature in this chapter will highlight the effects of reduced resources and reduced support during the pandemic. A wide range of literature, such as Falvo et al. (2021), Legget et al. (2021), Lorenz-Dant and Comas-Herrera (2021), and Tuijt et al. (2021), suggest that resources were reduced due to the pandemic.

Roth et al. (2015) found that burnout is associated with a lack of available resources and high demands. Results from Allen et al. (2022) found that those who had lower available resources reported higher but consistent levels of anxiety pre-post lockdown, while those with high levels of available resources reported increased anxiety post-lockdown. Lorenz-Dant and Comas-Herrera (2021), established unpaid caregivers, found access to resources (e.g., hygiene products, medical items, food, and personal protective equipment) difficult during Covid-19, particularly at the beginning. Legget et al. (2021) report that medication has become a harder resource to obtain for certain conditions. Care recipients who had less access to their medication became at risk for severe complications from Covid-19 (Legget et al., 2021). This may explain why some carers experienced heightened stress in a lockdown situation and show that available resources can impact caregivers' experiences in disaster situations. As a result, Budnick and colleagues (2021) study found that informal caregivers who usually relied on professional help or were caring for someone with dementia had more concerns, demands, and loss of support and showed more negative feelings than their counterparts. Caregiver burnout has been experienced by family caregivers due to spending the majority of their time helping with daily tasks and caring (Mthembu et al., 2016). It is clear how burnout can increase for carers who rely on professional help if those support systems are no longer available in disaster situations.

Research in the United Kingdom showed a lack of reliable information for caregivers, which led to confusion about government advice, guidelines, and how to access available resources (Carers UK, 2020). However, research in Germany showed that 87% of unpaid caregivers felt they had access to clear and understandable information (Lorenz-Dant & Comas-Herrera, 2021). This shows that confusion about available resources may depend on the type of approach each country has taken to Covid-19 and supports the need to explore caregiver experiences in a New Zealand context. The United Nations has reported that inadequate support for caregivers can result in negative implications for their health and wellbeing. Some of the risks identified with a lack of support are social exclusion, negative impacts on physical and mental health, and a higher risk of job dissatisfaction. The recent Covid-19 pandemic has caused uncertainties for the future, and this will be explored next.

1.5.2 Uncertainties and their impacts

The pandemic has led to uncertainties around available resources and financial security, which will be explored here. It has been noted that the Covid-19 virus has led to economic uncertainty for many families (Institute on Aging, 2022). Massazza and colleagues (2022) report that negative mental health outcomes (for example, anxiety and stress) are associated with uncertainty. Godinic et al. (2020) highlight that not all members of society are affected equally by the uncertainties related to Covid-19. They suggest that those with fewer available resources will be impacted more (e.g., marginalised groups, low-income families, and those suffering from mental and chronic illnesses) (Godinic et al., 2020). Caregivers have expressed the complex nature of managing chronic illnesses by prioritising which conditions require immediate attention (Zhang et al., 2022). The prioritisation of which conditions require immediate attention has likely become more crucial in the recent pandemic due to the increased pressures on health care systems. This may cause delays in receiving medications for chronic conditions. Dellafiore et al. (2022) reported that informal caregivers are involved in the diagnostic process, treatment, and recovery of patients with chronic disease and play a significant role in these processes and have impacts on the caregivers' own health (Zhang et al., 2022). An example of the pandemic is caregivers avoiding contact with care recipients due to fear of infecting care recipients with Covid-19. Factors such as recipients' conditions and caregiver characteristics (e.g., financial situation, own conditions, support available, and their own ability to cope) impact caregivers; however, these impacts can be mitigated by outside resources. The literature shows how caregiver experiences can be so different and provides us with an idea of how complicated they can be.

In contrast, the challenges and uncertainties caused by Covid-19 can have a positive impact on caregivers. Work by Leipold and colleagues (2008) found that the caregiver role and the challenges that carers face can lead to personal growth, which can have positive effects on caregivers. They suggest that cognitive maturity and personal growth can be explained by cognitive processes such as life reflection and ruminative thoughts (Leipold et al., 2008). Caregiving is complex, and there are many factors, such as available resources (before, after, and during Covid-19), available support, the conditions of the care recipient, financial factors, burnout, and the caregivers' own characteristics that impact caregivers. These factors often interact and are intertwined, adding to the complexity of caregivers' experiences. An example of this interaction is anxiety, which is known to be a serious health concern for older adults and is reported by many caregivers, according to Cotton (2007). Anxiety can be further exacerbated by pandemics, uncertainties, lack of resources such as financial security, and other factors such as worry and stress that are related to caregiving roles. Although anxiety is experienced by most people, if not everyone, to some degree, the literature shows us how available resources can impact caregivers' experiences in disaster situations.

Additional work by Yu and colleagues (2018) found a sense of personal accomplishment, feelings of maturity, improved family cohesion, improved relationships between the carer and care recipient, and functionality to be positives of caregiving for family members with dementia. Yu and colleagues' (2018) work reflects how challenges and uncertain times can bring people together and improve the positive aspects of those relationships. Research by Polenick and colleagues (2018) has reported that carers often find meaning in their lives because of their role as a caregiver. It is clear from the above literature that caregiver experiences, and relationships are complex and depend on many factors. Chee (2020) has emphasised the need to explore the true experiences of the Covid-19 pandemic and to build a greater base of research in the area. This research looks to explore the complexity of caregiver experiences and unknown phenomena that have arisen because of the lockdowns during Covid-19 in New Zealand.

1.6 Benefits of care during the pandemic

The benefits of caregiving during a pandemic situation will be explored here; however, minimal research to date was found to report on the positive effects on caregivers in relation to Covid-19 and those that have often only briefly mentioned these. Positive factors that were reported in the research were a decrease in the pace of life, more time to build relationships with the care recipient, a decrease in responsibilities, and enhanced technology (Legget et al., 2021). It is important to note that many of these factors have also been reported to have the opposite effect, leading to negative implications. For example, a decrease in responsibility has also been reported along with an increase in workload and reasonability for some caregivers, and enhanced technology can be seen as a substitute for physical face-to-face social interaction. Lorenz-Dant and Comas-Herrera (2021) have also noted that, although they focused on the negative experiences of caregivers in relation to the pandemic, positives did come out of the pandemic for caregivers. They established that the experience of Covid-19 has led to increased resilience and adaptability for caregivers, who have relied more on support from family. This contradicts other research that has stated that isolation policies and lockdowns have led to the isolation of the carer and care recipient, with family members helping by dropping off groceries but not necessarily being involved in any form of care. Lorenz-Dant & Comas-Herrera (2021) outlined that caregivers adapted by making more time for themselves, which can have positive implications for their lives and reduce stressors. However, their study did not focus on these aspects but only briefly mentioned them as possible positives that may have come out of the pandemic for caregivers. Tuijt and colleagues (2021) noted that positive effects on caregivers due to the pandemic exist, but the sample used in their study focused on the negative aspects. It is clear that there is an argument to be made for the positive effects of Covid-19 on caregivers; however, research has reported mixed findings. Tsao et al. (2021) found that media platforms are a crucial communication tool that impacted public attitudes towards Covid-19. For example, a CBS News (2022) article reports that nearly half of the young people see only the negative effects of Covid-19 crisis in oncology, and a NursingNews (Fischer, 2021) article reports on caregiver burnout during Covid-19. The Conversation (Ravenswood et al., 2021) reports that caregivers have become invisible in New Zealand despite being essential workers. The New York Times (Span, 2021) suggests that family caregivers are feeling the weight of the pandemic. Yet, other news sources report that the pandemic has caused caregivers and their efforts to be recognised, as well as their need for benefits and support (White, 2021; Schiavo, 2020).

CBN News (Dore, 2021) reports that more than 4 in 10 family caregivers must choose between paid jobs and caregiving. The recent news coverage of caregivers due to Covid-19 has publicised this often-overlooked population. It is hoped that this new recognition and acknowledgement by society will lead to better policy changes and reforms and improve the support available to caregivers. It is clear from these media reports that the findings and attitudes of caregivers are mixed in their experiences of Covid-19.

Recent research by Tulloch and colleagues (2022) shows that lockdown situations in Australia improved relationships between carer and care recipient. Caregivers learned to prioritise self-care and respect personhood by providing the care recipient with more decisions and freedom and making practical changes. Tulloch et al. (2022) reported that caregivers connected with their own virtues and values due to lockdown situations in an Australian context. Research has reported that the Covid-19 pandemic led to positives such as working together, improving relationships, actively seeking support, prioritising self-care, and strengthening commitment to the care recipient (Ragimi et al., 2021; Tulloch et al., 2022). Irani and colleagues' (2021) study showed the positive effects of caregiving in a pandemic situation were that caregivers were able to spend more quality time with the care recipient (loved one), able to access new support systems, and it made them worry less about other reasonability's. Onwumere and colleagues (2021) found that when caregivers had a more hopeful outlook and fewer symptoms of depression, they were more likely to have positive experiences during the pandemic. This shows that carer characteristics play a vital role in how the pandemic is experienced by caregivers. Caregivers have experienced positive effects in relation to Covid-19; however, more researcher is needed to fully understand the complexity of caregiver experiences in a pandemic situation.

1.7 New Zealand context

Here, caregiving will be explored from a New Zealand perspective. New Zealand Immigration recognises personal caregivers and other critical health workers as scarce in their 2021 visa applications (New Zealand Immigration, 2022). This shows that New Zealand has a need for caregivers. Additionally, a report prepared by Grimmond (2014) identified that informal caregivers' mean age is increasing at a faster rate than the national average and that Māori and Europeans have a higher incline to undertake a family caregiver role. Just like in other countries where growth in ageing populations has been identified, research on an Australian population (Australia is often seen as the most similar society to a New Zealand population) has shown that approximately 80% of older people with age-related illnesses have care provided by informal caregivers such as family, friends, and spouses (Productivity Commission, 2011). It is believed that due to the similarities and proximity, the New Zealand population will reflect similar findings. The economic value of informal caregivers in New Zealand is recognised with unpaid family caregivers’ hours of work estimated to lie within the range of $7.3 bn (3.4% of GDP) to $17.6 bn (8.1% of GDP) (Grimmond, 2014). This further identifies a need to study older aged informal caregivers' experiences in New Zealand.

Research on Covid-19 on an Australian population found it difficult to interpret and apply Covid-19 guidelines advised by the government (Hosking et al., 2020); research in the United Kingdom and the United States showed confusion around Covid-19 rules, policies, and regulations (Carers UK, 2020; Legget et al., 2021). New Zealand's response to the pandemic was different from other countries, as New Zealanders believe we took a stricter approach with the early implementation of our lockdown. This is reflected in the government's response of 'going hard and early' (Ministry of Health, 2020). New Zealand is an isolated country, which had given us the benefit of seeing the spread of Covid-19 in other countries before it came to our shores. It is likely that due to this, New Zealand's response to the lockdown will be different from other countries, hence the need to explore the Covid-19 pandemic in New Zealand.

In addition to this, the implications of Covid-19, both around the world and in New Zealand, make it clear that research on caregivers is needed. This research will focus on older age caregivers' experiences, specifically in relation to Covid-19 in New Zealand. Now, I will explore how this research will address some of the gaps and limitations of pre-existing research.

Initiating the research questions

The above background provides us with the means to produce a question to expand knowledge of caregivers' experiences of Covid-19 and identifies gaps in the current literature that this study can address. Grounded theory was used to produce the research questions. It does not start with a hypothesis or theory that needs to be proven or disproven but starts by collecting data on the phenomenon of interest. The data is then analysed to generate an emerging theory (Strauss & Corbin, 1990). Hence, a research question must first be produced to collect data on a specific phenomenon or area. The research questions are what connect all the components of the design and model and should inform the research design, as has been done in this study (Maxwell, 2012). Below are the following research questions and aims guided by the above research and the gaps identified in the literature.

Research Aims

1. To discover the unknown experiences of older aged informal caregivers in a pandemic situation in New Zealand.
2. To provide insights into the responses of older caregivers in a pandemic situation.

Research Questions

For the reasons identified in the literature above, I propose these research questions:

1. What are the experiences of older informal caregivers in a pandemic situation in New Zealand?
2. **2.** What are the needs of older caregivers in a pandemic situation in New Zealand?

Chapter 2: Methodology

This chapter will start by justifying why grounded theory has been selected as the methodological approach in this research. Next, I will explain how participants were recruited, the justification for the sample size used, and the participants' characteristics. In addition, the procedures will be explained for participant selection, data collection, and data analysis which will include reflexivity. Finally, ethical considerations will be explored.

2.1 Methodology and justification:

2.1.1 Rational for a qualitative approach for this study: grounded theory

This study will justify its selection of grounded theory as a qualitative method here. The aim of this study was to explore relatively unknown lived experiences, challenges, struggles, and positive effects that Covid-19 lockdowns have had on informal caregivers in New Zealand.

Qualitative methods have been recognised as useful because as new, historical, and unusual events occur, there is no way to quantify them, and by the time a measure is developed, the event has either changed or disappeared (Sofaer, 1999). As Covid-19 is a recent phenomenon and the first global pandemic experienced in our lifetime, the selection of qualitative methods in this study is appropriate. Quantitative methods of research have been reported to record only what we already know (Sofaer, 1999). If we only measure what we already know how to quantify, then important factors and variables that are crucial to understanding lived experiences, realities, and relationships will be missed (Sofaer, 1999). Bölte (2014) suggests that qualitative research is valuable as it can enable a deeper understanding of certain human experiences and processes. As this study focused on caregivers' experiences of the pandemic, the use of qualitative methods to obtain insights into the feelings and thought processes of another’s world is valuable to understanding their experience

(Austin, 2014). Numerical ways of recording data can be insufficient for capturing these experiences (Austin, 2014). This is why I have chosen to use qualitative methods in this study.

I have selected a constructionist epistemology standpoint for grounded theory as older aged caregivers can work in diverse settings with care recipients who have various illnesses, and physical and social difficulties, meaning the realities of caregivers will likely vary. A constructionist approach to grounded theory is better positioned to deal with this diversity in realities than other forms of grounded theory that are available (Charmaz, 2006). This is because a grounded theory approach is valuable as it uses knowledge from those who have experienced the event and is not limited by pre-existing frameworks to fit the data into (Hallberg, 2006). This allows for in-depth understanding by allowing the data to guide me rather than using pre-existing knowledge to put the data into categories. By doing this, bias is less likely to occur, as I am not privileging other theories over what the data is telling me. Grounded theory allows for the literature to be explored before engaging in research, allowing for an understanding of the topic prior to the research; however, the past literature is not taken as true or final and does not impact the findings (Charmaz & Thornberg, 2021). If a theory emerges from the data, then the past literature will be used to assess the new theory in light of the existing knowledge and literature. This process is known as the integrative phase (Charmaz, 2006). I took reflection notes to record my reactions, thoughts, personal opinions, and coding choices in relation to the data to ensure that the findings in this study did not take pre-existing knowledge and theories for granted but rather explored new processes and meaning (Charmaz, 2006). This is one strength of grounded theory, which allows for new meanings and theories to emerge. Charmaz’s (2006) approach to grounded theory is appropriate when we know little about the social phenomenon of interest (Glaser & Strauss, 1967; Strauss & Corbin, 1994), and such is the case with informal caregivers and their experiences with Covid-19, as this is still a recent phenomenon.

Another strength of this approach to grounded theory is my own ability to be reflexive, which further reduces the likelihood of preconceived ideas occurring (Charmaz & Thornberg, 2021). As mentioned earlier, I took notes by engaging in memoing to record my decisions for coding the data in certain ways and my own opinions, bias, and reactions to the data to ensure a logical and justifiable decision was being made in how the data was being coded. Engaging in reflective practises like memoing allows for ideas that emerge to be explored in greater depth when coding the data. This means caregivers' experiences can be better understood and the richness of data enhanced. Charmaz's (2006) approach to grounded theory is equipped to deal with diversities in situations and experiences as ideas, themes, and realities emerge from the data. This means the data is less impacted by pre-constructed knowledge. The aim is to understand meanings, actions, how people construct these, and situate experiences in the local, historical, and social contexts of the participants (Charmaz & Thornberg, 2021). This makes grounded theory equipped to deal with the diversity in realities of caregivers and their experiences of Covid-19 lockdowns in New Zealand (Charmaz, 2006).

Furthermore, grounded theory is valuable as it allows the findings of this research to construct a theory. Although caregiving is well theorised in the literature, caregiving during the Covid-19 pandemic is not due to its recent occurrence at the time of writing. The reason grounded theory was chosen to produce a new theory is that it takes an inductive approach (Charmaz, 2009). This means the knowledge and ideas come from the data rather than trying to prove or disprove a theory. Many theories become dominant because they have been proven and re-proven but are not absolute truths (Alabdulkareem, 2013). Theories often get amended and revised over time as new knowledge occurs. This study looks to explore relatively unknown social phenomena and discover new theories and concepts by using grounded theory, which is less impacted by preconceived ideas and knowledge. By exploring informal caregivers' unknown social realities, I can better understand their experiences. This study looks to influence caregivers by helping provide better preparation, policies, and guidance in disaster situations such as a pandemic.

2.1.2 Recruitment

The Health and Aged Research Team (HART) database is a collection of studies, surveys, and reports from an interdisciplinary team of researchers focused on health and ageing research based at Massey University in New Zealand. Participants were selected from the HART database who showed interest in participating in further studies during the 2020 Health Work and Retirement (HWR) survey;1937 respondents indicated their interest in interviews, particularly regarding their pandemic experience, and provided their contact details. In this survey, 407 respondents reported themselves as informal caregivers and were identified as potential participants: of these 407 respondents, 147 reported being of Māori descent. This showed a willingness of caregivers from past HART research to participate in a study around the Covid-19 pandemic and caregiving experiences. This study used purposeful sampling to select participants from the pre-existing national longitudinal HWR study. Purposeful sampling is appropriate for this study as it allows participants who meet the criterion, such as being older informal caregivers (55+) that experienced caregiving during the pandemic in New Zealand, to be selected. Recognising informal caregivers' diverse experiences, both men and women, informal caregivers with various ethnic and socio-economic backgrounds were selected in this research.

The HWR study manager contacted participants on my behalf. This ensured personal details about the HWR study participants, such as their names and addresses, remained confidential until they agreed to participate. The HWR manager then selected participants based on the following criteria:

- Aged 55+.
- Experienced caregiving as an informal caregiver during the pandemic in New Zealand or willing to talk on behalf of somebody who was an informal caregiver during the pandemic.

- Showed willingness to participate in future research in the 2020 HART survey.

The HWR manager was provided with letters from myself for participants that included: 1) Participant Information Sheets (Appendix A) explaining the study; 2) a list of help numbers (Appendix B) if they were struggling and felt the need to seek support; 3) Consent Forms (Appendix C) to sign to ensure consent is given by participants; and 4) prepaid envelopes in which to return the consent forms. The HWR manager mailed participants the letters with information about the study, and participants were given two weeks to respond via email or by calling the 0800 number provided if they wished to participate in the study or required any more information. Participants were also given the option of providing an email address or phone number so that I could contact them to arrange an interview. This process was repeated until a minimum of six participants was obtained. Due to logistical reasons and the small number of interviews, the majority of participants in this study were recruited locally.

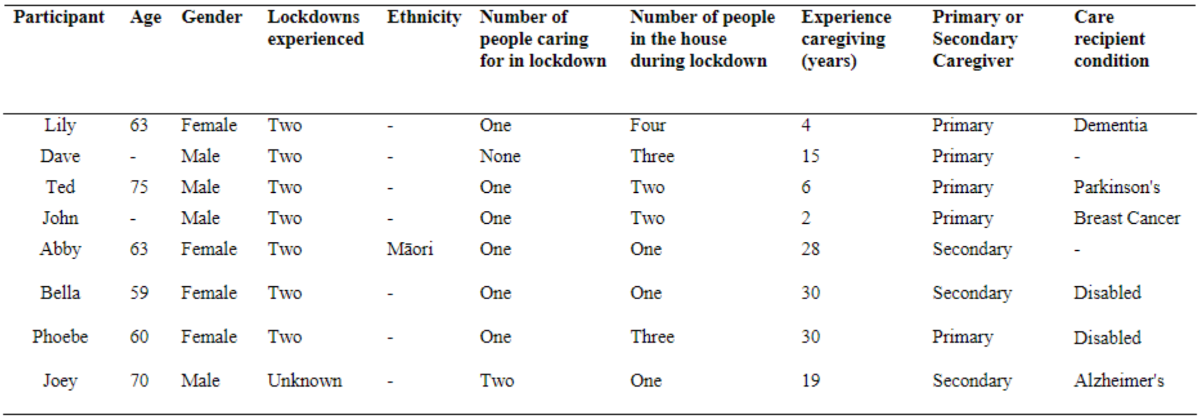
2.1.3 Sample size

Qualitative research does not require as many participants as quantitative methods of research. This is due to the in-depth and rigorous processes of data analysis using qualitative methods such as grounded theory (Charmaz, 2006). Past research has shown that anywhere between 5-50 participants is an appropriate sample size for in-depth qualitative research using grounded theory (Dworkin, 2012); however, some believe that the quality and saturation of the data are more important than the sample size (Mason, 2010). This study aimed to select 10 participants who reflected a diversity of voices. However, I only obtained a sample of 8 participants after contacting 30 potential participants. This sample size was considered appropriate for a master's research project due to time constraints and funding.

2.1.4 Participants

Participants in this study were aged 55 and over with diverse gender, ethnic, and socioeconomic backgrounds. The participants' characteristics and conditions of care recipients are shown in Table 1. The pseudonyms for participants have been randomly generated to protect participants’ identities and for ease of reading.

Table 1: ***Participant Characteristics***



Participant	Age	Gender	Lockdowns experienced	Ethnicity	Number of people caring for in lockdown	Number of people in the house during lockdown	Experience caregiving (years)	Primary or Secondary Caregiver	Care recipient condition
Lily	63	Female	Two	-	One	Four	4	Primary	Dementia
Dave	-	Male	Two	-	None	Three	15	Primary	-
Ted	75	Male	Two	-	One	Two	6	Primary	Parkinson's
John	-	Male	Two	-	One	Two	2	Primary	Breast Cancer
Abby	63	Female	Two	Māori	One	One	28	Secondary	-
Bella	59	Female	Two	-	One	One	30	Secondary	Disabled
Phoebe	60	Female	Two	-	One	Three	30	Primary	Disabled
Joey	70	Male	Unknown	-	Two	One	19	Secondary	Alzheimer's

Many participants felt that they were the sole caregiver for the recipient and provided most, if not all, care duties, even for participants who were married. Caregivers in this study reported that being a caregiver "just happened" and was never something they set out to do. The mean age of participants was 65 years, and the mean number of years of caregiving across participants was 16.75 years. No caregivers in this study had formal training for caregiving.

2.2 Procedures

2.2.1 Data collection

Data collection was done by organising interviews via Zoom, phone, and face-to-face interviews at days and times that best-suited participants. In total, I conducted two face-to-face interviews, three phone interviews, and three online interviews via Zoom.

2.2.2 Interviews

I conducted interviews via Zoom, phone, and face-to-face interviews, depending on the participants' preferences. Initially, only phone and Zoom interviews were offered to participants;

however, when Covid-19 cases decreased, I was allowed to conduct face-to-face interviews. Participants that had not yet been interviewed were given the option of in-person face-to-face, Zoom, or phone interviews. Face-to-face interviews were conducted in a place where participants felt comfortable and at times and locations convenient for them.

Before interviews began, participants were reminded that the interviews would be audio-recorded, and I double-checked that the consent form had been signed. In the interviews, a semi-structured approach was taken (see Appendix E for a copy of the questions and prompts used in the interviews) to help encourage participants to recall, articulate, and share their emotions, feelings, and experiences of Covid-19 lockdowns in New Zealand. It also allowed me to keep the interviews on topic when required and to explore participants' accounts in more depth by expanding on ideas and coming back to a particular event in their accounts. Interviews lasted for approximately forty-five minutes to one hour, with an extra thirty minutes being allocated after the initial hour was up. The extra thirty minutes of availability provided was helpful when participants felt they had more to say, when they were late to interviews, and when interviews ran slightly over an hour.

Rapport was an essential part of the interview process, as this allowed participants to be more comfortable when sharing their accounts. I built rapport with participants by introducing myself, using open body language, showing interest in their lives, and allowing them to introduce themselves. The use of rapport building allowed interviews to flow more like a conversation than an interview. The questioning process started lightly by asking participants basic questions such as how many people they cared for during the pandemic, who else was with them during this period, and if they could explain a typical day during the pandemic to me. By starting with light questioning and introductions, participants began talking before I moved into more in-depth questions focusing on their experiences. To help in this process, I always used my video camera for phone and Zoom interviews, and I encouraged participants to use video cameras if they were able.

I ensured that I allowed participants to introduce themselves, made sure that I was not sitting on a pillow, which is inappropriate in some cultures, and allowed whanau to be present during the interviews to help build a stronger relationship with participants. Participants were informed they could stop for breaks as needed throughout the interview process and that the voice recorder could be turned off at any point if they requested it. Interviews were conducted over a one-hour period. The interview process was guided by the interests of this study, such as the research questions, and was open-ended and semi-structured to allow me to explore ideas further, gain greater depth in accounts, and keep interviews within the scope of the research to ensure the suitability and richness of the data in this study. Interview questions were generated by following examples from Mohammad-Sajjad Lotfi's lecture (2018) and incorporating past research (Charmaz & Thornberg., 2021). The questions used in this study were tailored to focus on informal caregivers and the pandemic. To ensure the questions used in this study were appropriate and would yield high-quality data, a trial interview was conducted. The trial interview was successful, and the wording of some questions was modified to be easier to follow. Once each interview was completed, the participants' accounts were transcribed by myself, and the process of data analysis began.

2.2.3 Transcription

The software NVivo was used to transcribe participants' accounts. The paid version of this software was selected as it is password protected, ensuring the confidentiality of the data. The audio recordings of participants' accounts were uploaded from the computer, where they were stored in the transcription software. To avoid any machine errors, I read the transcribed accounts while listening to the audio recordings. Participants were given the option to view transcripts and made redactions if they wished. Only one participant wished to have their transcripts returned to them. This was done once the transcriptions were complete, and I cross-checked for errors during transcription.

2.2.4 Data analysis

In the initial phase of data analysis, I inductively coded as many codes as possible from the data. This was done by identifying and labelling important words and groups of words through line-by-line coding, which is simply the process of applying coding to each line of the data and summarising what was said in a given line. This procedure was valuable for getting the most out of the data and allowed for themes to emerge from the data. In addition, line-by-line coding has been shown to be useful for analysing data in understudied areas. I used the computer software NVivo for analysing as it simplified the data analysis process, allowed for better organisation of codes, and gave me the ability to easily find specific lines or quotes that I wished to access. Throughout all phases of analysis, I immersed myself in the data and incorporated "memoing", which is a process of reflexivity that allowed me to reflect critically and reduce my own bias in the research (Charmaz, 2006). I used the NVivo software memoing function to record my thoughts, interpretations, reactions, assumptions, and feelings about the participants' accounts. When entering a memo account, I started by recording the time and day, and the memo was linked to the specific line or section that it was referring to. The recording of these ideas as they occurred during data analysis is known as memoing (Charmaz, 2009; Mohajan et al., 2022). The process of memoing allowed me to explore, challenge, and improve their ability to test and capture the true nature of the social and psychological processes of the data (Birks et al., 2008). Memoing is one way I achieved reflexivity, which is essential to the data analysis process of grounded theory, as has been highlighted by DiCicco-Bloom (2015) and Priya (2016).

In the next phase of data analysis, I incorporated axial coding. Axial coding (also known as focused coding) identifies similarities and differences in the data and begins to identify patterns in the data by fracturing the data in order to compare incident to incident (Charmaz, 2006; Cho & Lee, 2014). It looks at actions that lead to outcomes, taken-for-granted knowledge such as routines, and compares accounts or different incidents within the same account and across transcripts (Charmaz, 2013). Data were organised into excerpts, and from these excerpts, first-hand experiences of participants were coded for identifying reoccurring codes in the data. To ensure codes are not missed, constant comparative analysis will also be employed here. The constant comparative analysis looks to compare data across the same data set, same data item, and emerging codes to ensure all meanings of participants' accounts are recorded (Chun Tie et al., 2019; Urquhart, 2013). At each stage of analysis, I read and re-read transcripts several times to ensure all codes were found. Axial coding is a vital procedure to qualitative research that evaluates the data gathered, codes it, compares it across categories, accounts and identifies differences and similarities, and finally is refined as new data is obtained (Urquhart, 2013). Participants' entries that reflect the same code were organised by identifying the transcript, the line the code was found on, and a quote of where the code was found. All codes that are the same across participants' accounts were saved on one word document. To ensure that participants were happy with the wording of their accounts, they were given the opportunity to cross-check their transcripts. If no reply was given within two weeks, it was assumed that participants were happy with the wording attributed to their accounts. Next, selective coding (also known as theoretical coding) was used. In this stage of analysis, the fractured pieces of data from the earlier analysis were put back together to give structure and organisation to the analysis (Charmaz, 2006; Chun Tie et al., 2019). This results in the integration of data, accounts, and themes to produce a theory or, in the case of this study, overarching themes (Chun Tie et al., 2019). This was done by attributing the connections and categories identified in axial coding to core categories. From core categories, all codes across all accounts were connected, and from this, the overarching themes emerged. An analytical story is being told here of informal caregivers' experiences of the pandemic. The connecting of categories and codes here has the potential to generate a theory (Charmaz, 2006). It is worth noting here that the generation of themes in this approach to grounded theory is a result of the interactions between participants and myself, resulting in co-constructed themes that have emerged from the data (Chun Tie et al., 2019). Data was thoroughly read and re-read in order to identify key codes through axial coding, selective coding, and reflexivity. It is important to note that, in both coding and memoing, I looked to move beyond descriptions of the data and identify inherent psychological and social assumptions within the data, as suggested by Charmaz (2000).

2.3 Ethics

Ethical approval was obtained from the Massey Human Ethics Committee (Appendix D) before this research was conducted to ensure ethical standards and the safety of participants and researchers were met.

2.3.1 Quality and integrity of research

Participants were required to give informed consent by filling out a consent form to take part in the study. This ensured that participants wished to take part in the study and that the choice to take part was theirs. As it was voluntary to take part in this research, participants could withdraw from the study at any point. The data already collected was used to help identify overall codes that present a category(s) across accounts.

2.3.2 Anonymity and confidentiality

I ensured that no information that could identify participants was used in the findings of this study or made public. Participants' identities were kept confidential and stored separately from the data. I reported on the transcripts using phrases and quotes, but all identifiers were removed from the report of this study. This means street names, addresses, locations, and other identifiers used in participants' accounts were modified to ensure participants' information was kept safe and their identities remained anonymous.

2.3.3 Avoiding deceptive practices

This study avoided deceptive practices by providing participants with the means to make a fully informed decision about participating in the research. This was done by providing participants with an information sheet for the study, explaining procedures before the interviews began, and allowing participants to contact me for further information on the study. Participants were provided with detailed information on the study that includes all the information they will need to make an informed decision.

Recalling lived experiences may cause some level of distress due to the nature of the experiences being recalled in this study. It was unlikely that physiological distress may have been caused; however, participants were given opportunities to stop the interview at any time, leave the study at any point, and take breaks during the interview process as they needed.

2.3.4 Storing of data

The data, transcripts, audio recordings, and any personal information of participants were kept on my computer behind password-protected files to ensure the information remained confidential. I am the only one who had access to these records. It is also important to note here that no information that can be used to identify participants was reported in the study. The information and data for this study would be kept for five years, and participants would have the option of having their transcripts and audio recordings returned to them. If participants do not wish for these to be returned, all records will be destroyed after five years by the researcher.

2.3.5 Informed consent

Participants were contacted with an information sheet (Appendix A) and consent forms (Appendix C), which gave a detailed description of the purpose of the study. Once a signed consent form had been received, an interview time was scheduled. During the interviews, I ensured that participants had signed a consent form and still agreed to take part in the study. I reminded participants that the interviews would be recorded and ensured they were willing to be recorded. I also reminded them that the recorder could be paused or stopped at any time if they wished. I informed participants of their right not to answer questions if they did not wish to and explained the secure storage process for the data that was collected.

2.3.6 Participant and research safety

Due to the effects of Covid-19 and the spike in cases around the time interviews were being conducted for this research, the interviews were done initially by Zoom or phone calls. This ensured all Covid-19 procedures were followed and that both the participants and I were safe. As time progressed, I was able to conduct face-to-face interviews. I ensured that participants were happy to participate in either face-to-face or online interviews and provided them with a brief list of telephone contact numbers if they felt they needed additional support. This list was sent to participants with the information sheet and consent forms.

Chapter 3: The experiences of older informal caregivers in a pandemic situation

The following combined results and discussion section will be broken down into two sections. Chapter 3 will answer the first question: ‘What are the experiences of older informal caregivers in a pandemic situation in New Zealand?’ and Chapter 4 will answer the second research question: ‘What are the needs of older caregivers in a pandemic situation in New Zealand? ‘. Here I will focus on answering the first research question. I will do this by discussing themes identified in the analysis that show common experiences of caregivers during the pandemic. Many of the experiences identified here are connected and overlap across themes. It is essential to consider these overlaps to understand the general experiences of informal caregivers in the Covid-19 pandemic. The experiences of caregivers are not isolated events and concepts but incidents that interrelate with each other to make up the caregivers’ experiences of the pandemic. Therefore, to understand caregivers' experiences, I will discuss the links across accounts and themes next.

The common themes that describe caregivers’ experiences were labelled as experiencing anxiety, impacts of isolation, support, difficulties with medication, and caregivers’ health. I will begin by introducing each theme individually and providing a brief overview, and I will later show connections between these themes. Next, I will discuss the links between participants’ accounts and experiences to fully understand the general experience of caregivers in this study.

3.1 Experiencing anxiety

A common theme was feelings of anxiety about the pandemic situation, which resulted in precautions and concerns around real and hypothetical situations. This section will be broken down into two parts to describe anxiety about keeping Covid-19 away and accessing health care systems.

3.1.1 Keeping Covid-19 away

Participants experienced anxiety around care recipients contracting Covid-19 and implemented systems to help deal with this. The vulnerability of care recipients led to elevated levels of anxiety among participants. The account *“I basically, if I went to, like the bank robber, balaclava and gloves, masks gloves, sanitiser because it was a real worry for us. And that was one of the stresses of it “*from Ted shows this. This may have been a general experience for many of us during the pandemic, but when linked with other quotes within the same account:

> I had a notice on the gate. Even at the beginning of the first lockdown because my GP told me. He said that without being rude about this, you need to go into lockdown. He says I know the government hasn't said that yet. But he said if your wife catches this, it will kill her *(Ted).*

We can see that the fact that care recipients are immunocompromised leads to increased levels of stress and anxiety for caregivers. Joey’s account, *“Yeah, there was stresses in terms of anxiety not to get it and particularly in the case of someone in the condition of my wife, who, probably, almost certainly but probably wouldn't survive COVID If she got it”* further highlight increased anxiety related to caregiving.

Preventing the care recipient from getting Covid-19 was a significant concern. Understanding the severity of Covid-19 for those with a weaker immune system is important. Covid-19 was a matter of life and death to many care recipients. It is no wonder this study found that caregivers experienced increased anxiety concerning caregiving during the pandemic. In addition, this study found discrimination towards caregivers for their decision to continue safe practises such as the wearing of face masks and the use of gloves when shopping despite mandates to do so being removed. The following accounts show such situations:

> But when someone comes along and says, oh, yeah, stupid wearing a mask which someone did, and I turned around, told them where to go in words that start with F and then followed by off. And they just turned around and ignored them when they muttering and carrying on, just ignoring them and loading my groceries into the vehicle, because I was wearing a mask

and gloves to go and do my click and collect *(Phoebe).*

Maćkowiak et al. (2021) found that isolation and anxiety were experienced by caregivers in their study in relation to Covid-19. Maćkowiak et al. (2021) reported that the pandemic exacerbated negative emotions such as fear of being infected, additional care duties, and a decline in one's own mental health. Their findings revealed that participants reported negative experiences and a decline in their own health in relation to the caregiver role. Fear was not recognised in this study but instead framed as anxiety, which was experienced similarly in Maćkowiak et al. (2021) study by participants. Maćkowiak et al. (2021) report that social distancing intensified feelings of loneliness for caregivers. This study found that isolation caused by social distancing rules led to increased loneliness for caregivers. This was a major challenge that many caregivers faced.

Past research has shown that caregivers already faced barriers to asking for help and may be even more reluctant to ask for help now, given the fears and anticipatory guilt of having outsiders who could transmit viruses come into their homes (Messina et al., 2022).

In addition, a New Zealand-based longitudinal study following the initial response to the pandemic found that informal caregiving was associated with increased depression but not anxiety (Allen et al., 2022); however, this study found caregivers felt anxiety due to Covid-19 and the need to protect the care recipient.

3.1.2 Anxiety and health systems

The data has indicated that a concern for caregivers was reduced support and feelings of isolation. Caregivers worried about what would happen if they needed support from health care systems. Ted, a 75-year-old male participant, did have to access health systems over lockdown periods. Their concern for this as shown in the following accounts *“The extra stress that Covid induced, I don't know what could have been done about it. I mean, obviously, we don't have enough nurses”* and *“Once again, understaffed, overworked, that same thing, I've never run into a bad district nurse takes special people, Same thing hospice and hospital”*. Participants experienced increased anxiety, which was exacerbated by the uncertainty of the pandemic and whether health systems would be available to help if they were needed. A respondent answered, *"Even worse, because I was really worried at that point, more worried because if something went wrong"*, when I asked: "Did you feel your sleep was affected during Covid-19?'

The anxiety being experienced here concerns whether health professionals would be able to respond to a pandemic situation in the pandemic if one were to occur. The strain on the health care sector was a significant concern during the pandemic and was often reported in the media (1News, 2022; Daalder, 2022). It is evident that care recipients faced increased risk due to their age and prior health problems, which has led to increased anxiety for caregivers if there was a need to access health professionals during a pandemic. Although the account above refers to a hypothetical situation, this was a significant concern for caregivers. Many caregivers worried about 'what if' situations. This account, *"you're just very worried and because you just don't know"*, from Bella shows this.

Caregivers experienced concerns about the staffing and pressure on the health care systems and their ability to function and meet the needs of the New Zealand population. Due to care recipients being immunocompromised, they would likely need medical assistance if something were to happen; hence, caregivers worry about accessing health services and whether health services have the staff to provide care for care recipients if they need it. Research in New Zealand has highlighted that the health systems were unprepared to deal with the demands of the pandemic (Cumming, 2022). Chee's (2020) study outlined that a lack of available human resources existed, which put additional strains on caregivers. Caregivers in this study have reported an increase in anxiety related to issues of caregiving and have shared concerns about accessing health care.

In addition, Kent et al. (2020) reported that caregivers feared the exposure of Covid-19 to care recipients, which impacted their ability to engage in employment, created barriers to services, and increased caregiver duties. Work by Ellen et al. (2017) has suggested that research often focuses on health outcomes and experiences, while less research tends to focus on accessibility and the cost-effectiveness of health care.

3.2 Impacts of isolation

Caregivers in this study experienced isolation during the pandemic, and these experiences are essential to understanding the general experience of caregiving. This theme will be broken down into two sections: social interactions, which emphasise the feeling of being alone that caregivers experienced, and loss of friendship, which refers to caregivers losing friends because of the situation created by the pandemic.

3.2.1 Avoiding social interactions

Isolation was identified as a common theme in this study. Participants' accounts here refer to the shutting down of the country and the need to isolate. This period of isolation was often longer for caregivers as the care recipients were at greater risk of Covid-19. During the interviews, it was common to hear from participants that caregivers are willing and go to great lengths to provide care recipients with the best possible care. For example, Bella states, "*it's a babysitting service. And it won't be that great because the numbers aren't that good*". The account below from John further highlights this.

> We didn't feel comfortable about inviting people over for a cup of coffee or, and that sort of thing. So, it did reduce the social interaction that we were that both she and I were able to previously enjoy *(John).*

So far, the above accounts have shown that caregivers felt they did not have a choice but to isolate and reduce social interactions to protect the care recipients more susceptible to the virus. Abby stated during the interviews that it *"Was lonely, like not sociable it was quite hard in the end"*. This account refers to lockdown specifically; however, it goes beyond lockdown. Many caregivers reported that even after the lockdowns were over, they still avoided social interactions as the care recipient was still at high risk of Covid-19. Care recipients were often older, which complicated the situation as many caregivers in this study reported that the care recipient would not survive if they were to contract Covid-19. Unsurprisingly, the anxiety and isolation themes cross over and can be linked together so well.

Caregivers' precautions to keep themselves safe have led to feelings of isolation. This is no surprise and reflects the intense nature and requirements of caregiving to ensure the care recipients' well-being. This is shown in the following account *“It has changed how we do things because before everybody was invited in, but now everybody is held at arm’s length”* from Phoebe. It is clear here that caregivers often made sacrifices to support care recipients best. The choices caregivers made to protect care recipients were not necessarily a choice at all but rather something that they needed to do. In contrast, Savla and colleagues (2021) study focused on at-home caregivers of dementia patients. Their study found that 26% of caregivers felt that the order to stay home did not affect them.

Furthermore, Parmar et al. (2021) found that family caregivers experienced a lack of social interaction and isolation due to deterioration in the physical and cognitive health of care recipients. In this study, all care recipients had severe health problems, which caregivers reported made the pandemic harder to manage.

The following account, *“And even my business fell apart. Because I put it in hardly anyone come on the property really”* from Ted, shows the effects of isolation and staying at home has had on a participant. In addition, Ted stated the following:

> And I would have liked to have been even more supportive than I tried to be. But there were things, you know like I had to, I had to go out and do things, I had to keep working, I would have preferred to caregiver completely for my wife *(Ted).*

The participant's wife being immunocompromised led to difficulties for the caregiver and impacted their business. It is clear that staying at home has impacted caregivers in this study.

On the other hand, Greenwood et al.'s (2019a) findings reported that, as age increased, social circles often decreased, resulting in less support for older-aged caregivers. This can occur due to a lack of understanding by others of the pressures of the caregiver role and their own ageing. This study cannot comment on age and its relationship to social support. However, this study found that caregivers felt alone in their decision-making, their pathways did not match the paths of non-caregivers, and the decisions they made as caregivers to protect the care recipient were not necessarily understood by other people, which resulted in a loss of friendships in the pandemic. This account, *"It's quite isolating. It's yeah. I like from when [name] was born, you're suddenly on your own path. You don't fit"* from Bella captures this. The account from Bella here refers to how caregiving for someone with a disability impacts your life. The impact of caregiving means that caregivers do not follow the daily norms of non-caregivers and often take different pathways. Lily recalls, *"Well, it was just us"*, which refers to the lack of support they had during lockdown. They had to make the preparations and decisions on navigating lockdowns and the pandemic as support stopped during the pandemic, specifically over lockdown periods.

3.2.2 Loss of friendship

Many participants have acknowledged that the pandemic has changed how they do things. As Phoebe said, caregivers reduced visitors and did not allow visitors or support workers in the house to protect the care recipient. Consequently, participants reported the loss of friendship due to not allowing anyone to enter their house. The following account, *"But yeah, the loss of a friendship. I think it's the single biggest thing"*, from Phoebe, shows this. This account reflects a loss of a "loss" of a close friend (their husband's best friend), as the participant would not allow anyone to enter their home to protect the care recipient from the virus. This loss of support led to further feelings of isolation and resulted in reduced emotional and social support for caregivers. From this, we can see why some caregivers sacrifice much of their own lives for caregiving, even when it results in a loss of social support. I believe that this account shows the problematic decisions caregivers had to make during the pandemic. This account highlights the consequences of such decisions and the impact that they can have on caregivers.

In addition, caregivers felt they had little choice in their decisions as they must protect the care recipient from Covid-19. This meant that even when additional support was offered, caregivers felt they had to decline as increased contact with people outside their home would put the care recipient at greater risk.

Research has reported on the impacts of social distancing as an unintended consequence of the pandemic. The action taken to mitigate Covid-19 can result in increased isolation, loneliness, and linked adverse health consequences already experienced by many caregivers and their care recipients (Holt-Lunstad et al., 2015; Kent et al., 2020). Caregivers have already been identified as an isolated population due to the requirements of caregiving; even in this study, caregivers have reported a lack of understanding of non-caregivers of the sacrifice they made in their caregiver role due to Covid-19 and at a broader level that once you become a caregiver you are on a different pathway to everyone else.

Bristol et al. (2021) reported that, during the pandemic, 76.7% of caregivers in their study experienced feelings of loneliness. Bristol et al. (2021) study highlighted that caregivers had limited access to their support networks, partly due to Covid-19 restrictions and the risk of Covid-19. However, caregivers in their study did not report a loss of friendship, which this study found. Media sources report difficulties with friendships and even the loss of friendships for many during the pandemic (Cohen, 2022; Mull, n.d.). To date, literature tends to focus on the loneliness and isolation of the pandemic, and few accounts report the loss of friendships among caregivers.

3.3 Support

The participants in this study felt that support was required to get through the pandemic, especially from family, friends, and formal domains such as the government and agencies.

Participants felt they were not well supported by formal services, and what support could be accessed was not necessarily practical. This section will be broken down into four sections, which are: family support; social support; formal domains of support; and accessing information.

3.3.1 Family support

Families of caregivers were willing to help during the pandemic, but due to anxiety, the fact that care recipients were immunocompromised, and caregivers implemented their own social restrictions, getting support was problematic.

The following accounts show that many family members were unable to help as the risk to the care recipient was too great. The caregivers in this study expressed that they had to carry the burden of caregiving by themselves. Ted stated, *"And yeah, although the family would help, and they were willing, it was just the logistics and the COVID. Diabolical"*, and Phoebe recalls, *"I have two older neurotypical children who are adults out there obviously, and they're a great emotional support and physical when circumstances warrant"*. These interview excerpts show that many family members were unable to help as the risk to the care recipient was too great. Therefore, the caregivers in this study expressed that they had to carry the burden of caregiving by themselves. The following account, *"So, the nearest family were 55k away. And children will work full time"* from Ted, highlights this.

Family was a form of support, but due to lockdown rules, distance, and life commitments, it was hard for the family to assist caregivers. The idea of family members' willingness to support was seen as positive but experienced as negative, as the pandemic situation did not allow for physical support from family members. This often leaves the responsibilities (or the majority of responsibilities) to the caregiver to manage by themselves; this is not new.

Past research has supported the finding in this study that family members were willing to help caregivers when needed (Savla et al., 2021). Parmar et al. (2021) showed that the experience of family caregivers was negative, which aligns with the findings in this study. This leads me to the next category of support, which is social support. This type of support refers to friends and moves beyond the immediate family.

3.3.2 Social support

Here I discuss how participants stayed connected with their social support systems, such as friends and family, over the pandemic, particularly during lockdowns. For example, Phoebe said, *"We found out how to make it work and be sociable while still following the rules"*. This account refers to a birthday party that was held close to the fence line between the participants' land and their neighbours'. This allowed for the sharing of food, drink, and celebration without breaking social distancing rules. This showed how creative people, and more specifically caregivers, were during the pandemic in order to maintain social interactions. This was seen as a positive aspect of the pandemic by the participants.

Despite the physical restriction to accessing family support, many participants were still able to stay in touch with family through forms of technology such as Skype, Zoom, and phone calls. This quote, *"We were still able to communicate with the people we needed to"*, reflects caregivers' experience of this.

Participants found ways to stay in touch with friends that were not as creative but just as effective. Participants had to make efforts to keep in contact with people as a form of social support. The following account, *"Yeah, and I have got like people that I would try to get into some routine where I'd communicate with someone every day*", from Bella captures this.

Other participants mentioned their use of technology to help stay in touch and be social with others. Lily stated, *"And so, every now and again, we telephone round to see how things were going"*. The following accounts from John and Abby further show the use of technology to stay in touch by caregivers:

> Largely by phone, by FaceTime, all our three adult children, we've all got obviously got iPhones and iPads. So, we were able to use FaceTime. And things like, you know, just the

> normal messaging and WhatsApp and that sort of thing *(John).*
>
> Just through teams, so we call it teams. Its Skype mainly, or otherwise, yeah, pretty much Skype or, you know, on your phone having nice catch-ups and yeah, but certainly you did because you had to, or you'd go bonkers otherwise *(Abby).*

From these accounts, I found how caregivers struggled to stay social during the pandemic and the many coping strategies they incorporated to allow them to stay social with friends and family. The experience of social support is a balance of positives and negatives from these accounts. However, the overall experience of caregivers, as suggested in this study, is more negative.

3.3.3 Formal domains of support

Caregivers being solely responsible for duties of care may seem like a general experience for a caregiver. However, here I will argue that it is a vital experience of caregiving during a pandemic. The link between being the sole caregiver and the pandemic can be explained by the support or, rather, lack of support experienced by caregivers. When looking at formal domains of support, caregivers experienced what they felt was a lack of support. This account, *"Well, enough to go to day-care respite care way that we've worked through COVID made a bad situation terribly worse"* from Ted highlights this. This account describes how the absence of their usual access to respite during the pandemic exacerbated an already dire situation.

In addition, Lily stated, *"I don't think the situation had really been thought about telling the truth. I mean, it just happened. Everything shut down. Yeah. And we just had to make the best of what we could"*, Phoebe said *"Because our support workers were going to other people as well. And with not really knowing how bad this whole thing was going to turn out to be"* and recalled, *"We opted for a complete lockdown".* In the above account, the idea of a "complete lockdown" refers to the refusal to let anyone outside of immediate family enter the home, even outside of mandated lockdown periods. This includes physical support systems such as support workers. These quotes show that even when formal avenues of support were available, they were not always accessed due to the nature of Covid-19 and its ability to spread rapidly. This shows how Covid-19 had impacted caregivers' ability to access support even when services were still operating during the pandemic. However, the majority of caregivers felt the support they had just shut down over night during lockdown periods. Furthermore, John stated:

> As I said, daycare and risk appeared; everything else just fell over. So yeah, COVID was a major stress. And then honestly, the medical people said to me, it's becoming a race between which of you two falls over *(John).*

A lot of the available support that was previously accessible was shut down in the pandemic, especially during lockdown periods, which is when caregivers expressed the most need for support. The shutting down of support includes care homes, caregiver agencies, support work agencies, and respite. This led to increased challenges and burdens for caregivers during the pandemic. Many caregivers stated in this study that caring for someone in a lockdown situation on your own is not recommended. The following accounts from Lily and Ted show this *"Well, you definitely need the support of some family; it's not something I would recommend you try and do on your own"* and *"I think it's true. You cannot care for someone 24/7 for more than a certain period of time before you know you probably collapse yourself".*

Bella suggests a lack of support from the agency for the first lockdown. This links in with the idea that participants have made that the support just shut down over night. The participant reported a lack of discussion around decision-making for the care recipient and what is going to happen in the first lockdown, which put pressure on the caregiver, leading to increased anxiety and deep feelings of loneliness in the decision-making process and reflecting a lack of support. I imagine the stress of making decisions that will best protect someone else can be difficult, especially in a pandemic situation. The following account, *"it's just that sense of being the decision* *making and aloneness really big"* from Bella, shows this.

A participant highlighted that if health professionals were not available, it would have made the experience of caregiving worse during the pandemic. This is shown in the account below:

> The health professions were there, and if they weren't there, then practitioners that would have sucked big time. I've heard in my case, they wouldn't there to have done what they should have done, and I hope they were there for other people. Because you know there's nothing worse than sitting around for three or four hours, and you get there, and they won't help you *(Abby).*

This shows that health care systems are essential for people. During the participant's experience, the health professions were not there to help in the way the participant felt they should have been. For example, participants found accessing the Covid-19 care package difficult, participants reported medication issues and experienced longer wait times when accessing medical services during the pandemic. This reflects the idea in Ted's statement that the health care systems are understaffed and overworked. It further shows a level of reliance on systems such as health care, especially when care recipients have medication conditions and deteriorating health due to age. Past research supports the finding that institutional support was insufficient during a pandemic and did not meet caregivers' expectations (Maćkowiak et al., 2021). Caregivers in this study have reported a lack of information and a lack of knowledge on how to access support and what was available during the pandemic. Jorgensen et al. (2010) report that in New Zealand, significant deficits in available formal support related to caregiving roles are present under normal circumstances. This shows that caregivers need more information about available services and for institutional services to be available during a pandemic situation.

Alternatively, research has reported that older caregivers are less likely to seek support due to their own pride after having worked in the caregiving role for many years compared to younger generations (Greenwood et al., 2019b). In contrast, this study found that older informal caregivers wanted and needed more support in a pandemic situation. The voice of caregivers in this research was screaming for more support during the pandemic. However, caregivers were unsure of how support could be provided.

Despite the above accounts, there were positive descriptions of formal domains of care during the pandemic. Joey recalls, *"The rest home was very good at facilitating that, and they took good care of her"*. This rest home operated under lockdowns and, at times, closed its doors to visitors. The participant was happy with the way the care home dealt with the pandemic and felt well-supported during this time by the care home. The care home was clear and consistent with its communication about lockdowns for the care home and took safety precautions. The care home provided the majority of care for the care recipient, ensured they stayed in touch with the caregiver, and allowed packages to be dropped off for the care recipient despite being on lockdown. Maćkowiak et al.'s (2021) work showed that those who accessed institutionalised care often showed appreciation for institutionalised support. In this study, caregivers who accessed care homes reported positive experiences.

Phoebe has suggested that the post-pandemic has led to increased support which is shown in the following account *"But it's not the first time that life has been like that. And as I said, at the moment I have more help and support than I've ever had in most of the 30 years I've been doing this"*. This participant attributes the recent increase in support to the pandemic. In other words, they felt that the pandemic has led to an increase in support; however, this support was not available during the pandemic.

3.3.4 Accessing information

In this study, it was clear that caregivers felt they did not have access to adequate amounts of relevant information during the pandemic. Lily stated, *"So, we didn't have any support; it was just us"* in their interview, and Joey said, *"It got more difficult as time went on because you're trying to get, I didn't quite know what help was available in what we could kind of do, and the* *doctors weren't really willing to do something"*, and *"Specifically, as a caregiver. I don't really record seeing anything. recall seeing anything that would have been just directed at caregivers was more or less applied to everyone".* John responded with, *"No, I think probably presented a COVID one. No, I don't, I don't recall. To be perfectly frank, No, I don't"* when asked about what information they could recall seeing in relation to caregiving during the pandemic.

While the above accounts reflect a lack of information in relation to what support was available for caregivers in a pandemic situation, Phoebe stated, *"We did. But most of the notification of what was available and what wasn't available came directly from our support workers ourselves"*. This quote suggests that information relating to caregivers during the pandemic came from their support workers. Although this is a good form of information, not all caregivers have access to support workers or formal care agencies. Past research has found that caregivers desired better communication during the pandemic from health care systems and institutionalised support (Parmar et al., 2021). The distribution of information for caregivers was not available to everyone, as shown in the above account. Many caregivers did not have support workers with them during lockdown periods or at other times throughout the pandemic.

The account below shows that having access to formal domains for information helped. A participant's job provided them with all the information they needed, and because of this, they felt they had access to enough reliable information. The following account, *"The information was so full was like oh my god they were going to have enough to drive you nuts"* from Abby, highlights this.

These accounts show that information was mostly available through formal support, such as support workers from agencies and workplaces. Only two caregivers in this study worked, and many did not have access to support workers (either choosing to decline or not having the opportunity). Those that did access these forms of information did not necessarily have access to them throughout lockdowns (e.g. if support workers were not allowed in homes). The overall experience of caregivers during the pandemic shows a need for more information specifically related to caregiving and Covid-19.

3.4 Difficulties with medication

Some participants reported trouble accessing medication that the care recipient had previously been using prior to the pandemic and needed during the pandemic. While the cause of this is not necessarily clear, one explanation can be that the medication was being imported to New Zealand and, due to Covid-19 restrictions, the process of getting the medication into the country became slower. Ted's account, *"A lot of your regular medication they just couldn't do"*, shows this.

In addition to this, the medications that Ted could get were not always practical. For example, the care recipients could not swallow the medication because of their Parkinson's. This led to buying over-the-counter equivalents, as shown in the following account: *"So, the chemist and I, at times, I'd been juggling around, the some of the things that she could swallow, which were prescribed by doctors, the version that Pharm-mac would fund with giant pills, which my wife couldn't swallow"* from Ted. Joey's account: *"If I'd had to do that, I would have to get it from the chemist, and you have to process your applications forever. All renewals? That might have been a bit of a bother"* shows that caregivers recognise that medication would have been a timely and problematic process to deal with during the pandemic,

Some participants had to go to extremes to get medications and borrow from other families despite having a small stockpile of medications saved up for a situation such as the pandemic. Phoebe's account, *"So, we got through, but we had to borrow some weeks' worth of medication from another family actually down in [place], so we got to finally meet masks and all"*, shows this.

However, medication issues were not experienced by all participants. Participants who's care recipients were in formal care settings such as rest homes or treatment programmes (for example, cancer treatment) did not have problems getting hold of medications. This may be in part because the formal domains of care were responsible for medication. It was only participants who cared for recipients who were not in formal care who experienced shortages and difficulties with medications. On the other hand, this could also be related to specific types of illness and health problems; there was not enough information about different types of illness for this study to report on this. Almost all the care recipients in this study did require some form of medication during the pandemic. The literature shows that the pandemic has impacted medication reconciliation and drug-related issues, and minimal research to date has focused on medication reconciliation (Rojas-Ocaña et al., 2022). Studies that do focus on medication reconciliation tend to focus on barriers to patients accessing health care and the use of telemedicine (Gomez et al., 2021; Latus-Olaifa et al., 2019; Polinski et al., 2016).

3.5 Caregivers' health

Caregiving is focused on the health of the care recipient and their needs, but often this means caregivers neglect their own needs. Although this may not be specific to a pandemic situation, it is a general experience of caregiving. Due to the pandemic, care recipients have had to move in and live with caregivers, and many part-time caregivers have become full-time caregivers. The quote below from Lily shows this:

> Usually, if I don't sleep so well, I get up and have a cup of milk or sit up for 30 minutes or so and come back to bed. But you see, I couldn't do any of that because mum was in the kitchen *(Lily)*

This quote refers to sleep arrangements for the care recipient and the impact this had on strategies the caregiver would normally use to help them sleep, such as getting up for a drink in the night. The impact of having the care recipient move in with the caregiver has impacted the caregiver's sleep.

Another problem caused by the pandemic was that over lockdown periods, the health of care recipients often deteriorated. Joey recalls, *"She deteriorated and needed greater care".* The care recipient faced deterioration, such as physical declines, including mobility, loss of eyesight, loss of hearing, and cognitive declines. The deterioration of health for care recipients resulted in caregivers putting more time and energy into caregiving as the challenges of caregiving increased. Lily found the care recipient's Alzheimer's became worse over lockdowns, which resulted in moments of panic for the care recipient and disorientation of where they were, what they were doing here, and a lack of understanding of why they could not go home, which was not present in the first lockdown.

The following account from John shows that the increased attention required for the care recipient resulted in a great focus on the care recipient:

> Yes, I guess my whole focus sort of changed to, you know, I guess the whole focus changed to provide greater attention on the needs of [name] basically. So, I guess my own my own sort of wants and desires tended to go out the window *(John)*

This quote reflects the self-sacrifice of caregivers, the impacts and challenges that a decline in care recipients' health can have, and the impact on caregivers' health.

3.5.1 Impacts on sleep

One of the main impacts on caregivers' health found in this study was the impact that caregiving had on sleep. My research found that four caregivers out of seven reported that they experienced a lack of sleep. Lack of sleep is likely a general experience of caregivers and not directly related to the pandemic; however, the pandemic likely exacerbated participants sleeping troubles. Participants reported reasons for this, such as worry, having to attend to the care recipient, ensuring that the care recipient does not contract Covid-19, and thinking about decisions related to the pandemic. Participants reported that their sleeping patterns changed during the pandemic, as they generally slept in later in the mornings as they had nowhere to be; however, participants also reported the importance of routine and continued the same sleeping patterns.

The following account, *"So, if I do have a sleepless night, I had to stay put because I* *couldn't get up and wondering around. So, if I had a sleepless night that was a problem"*, from Lily refers to struggles when trying to sleep. The methods they used to help them sleep, such as getting up in the night for a drink, were no longer practical due to the care recipient sleeping in the living room during lockdown.

Ted's account, *"Even a year later, it will be a year in November, I'm still struggling to sleep properly. Because five years sleeping with one eye open or one ear and have lost the ability to sleep properly"*, shows that not being able to sleep is a more general issue of caregiving rather than something just experienced in the pandemic. However, as seen in Lily's' account, the pandemic led to situations that affected sleep and even exacerbated the issue of sleep.

Another example that refers to the second lockdown shows the impact that the care recipient's health deterioration can have on caregivers and how, more specifically, it can impact their sleep. Lily's account shows this: *"As far as mum was concerned more the second time as she flipped every 2-3 days and had absolutely no idea what was going on and why she was where she was and what we were doing"*.

This often occurred in the early hours of the morning. Accounts such as the following suggest that when caregivers' sleep was impacted, it had effects on their day:

> Yes, because my brain started to drift myself, I started having problems was my short-term memory. And that was just what they said to me; it's the stress of the lack of sleep. Yes, a bit. I just didn't sort of set such high expectations or goals for myself *(Ted)*.

Reduced levels of sleep were reported by participants as a regular occurrence. Phoebe states, *"Because I think we have special needs children are often in crisis, I know how to go without sleep"*. It is clear from these accounts that disruption of sleep is a common experience of caregiving and that a loss of sleep tends to impact what caregivers are able to achieve during the day. Here, caregivers' experiences of the pandemic suggest a negative impact on their health and well-being.

A study found that good quality and getting enough sleep resulted in more positive experiences (Ercoli et al., 2021). My research found that four caregivers out of seven reported that they experienced a lack of sleep during the pandemic. While some caregivers in this study attributed their lack of sleep to the situations they faced during the pandemic, it is difficult to differentiate the effects of the pandemic on caregivers' sleep from their situations. Caregivers in this study specified factors such as worry (caused by the pandemic), having to attend to the care recipient (because they were confused about what was going on and that their health had declined), and that they often stayed up thinking about how to manage the pandemic as a caregiver. Caregivers had to think about how to manage a range of situations that the pandemic imposed on them, such as care recipients' health decline, sorting medication, how to handle lockdowns, entertaining care recipients, and ensuring care recipients are not exposed to Covid-19. It is no surprise that the uncertainty of these situations and the decisions that need to be made can impact caregivers' sleep and their health.

3.5.2 Self-care for caregivers

Ercoli et al. (2021) have identified the self-care of caregivers as vital to reducing stress in caregivers; however, caregivers tend to neglect this. In this study, five out of the seven caregivers reported that taking time for themselves was important for their health. Despite taking time for themselves, such as getting out of the house to do the shopping, gardening, and going for a short walk, caregivers' experiences in this study were still noticeably negative when discussing their experiences. The following account from John reflects caregivers' decisions to engage in self-care behaviours:

> I would probably go out for an hour or a couple of hours doing that, firstly, so that I could get out. I enjoyed getting out in the fresh air and that sort of thing. But it also just gave a bit of a break for me and a bit of a break for [name]. *(John)*

Further research shows that the burden of caregiving increased despite the hours of care not increasing for caregivers following the pandemic (Gräler et al., 2022). This suggests that other aspects of caregiving lead to a burden of care rather than hours of caregiving. The pandemic itself is likely associated with an increase in the burden on caregivers. This is interesting as it shows that time spent caregiving did not increase for caregivers on average during the period of the pandemic, and hours spent caregiving is not directly related to the burden of care. Based on the findings of this study, the burden of caregiving, as expressed through participants' experiences, was related to increased anxiety and worry caused by the pandemic, a lack of support, and isolation. The experience of these has had a negative impact on caregivers and is likely associated with the increased burden of care found in Gräler and colleagues' (2022) study. However, the relationship between these findings and the burden of care will need to be explored further and is beyond the scope of this research.

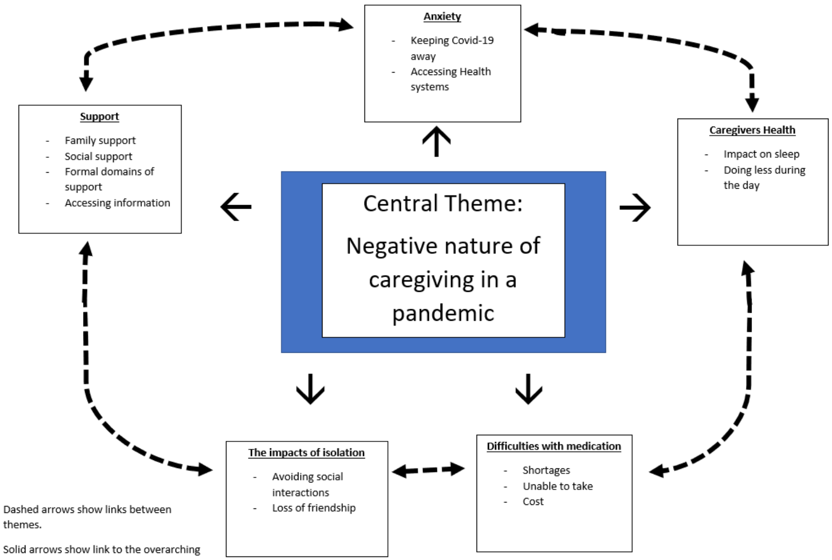
3.6 The interconnectedness and linking of experiences

The links between the themes of experiencing anxiety, impacts of isolation, support, difficulties with medication, and caregivers' health may already be clear from the above accounts; however, before concluding this chapter, it is worth providing some commentary on how these themes work together to reflect the experiences of carers in the pandemic.

Although there were positive aspects to experiences during the pandemic, overall, caregivers tended to focus on the negative impacts. For example, when we look at the theme of isolation, the focus tends to be on reduced social interactions, being absent from others, and a lack of support. In this example alone, links can already be seen between isolation and support. To take this example further, Bella talks about feelings of being alone in the decision-making process regarding what is best for the care recipient. The following account, *"it's just that sense of being the decision making and aloneness really big",* shows this.

This further links the theme of anxiety around decision-making and protecting the care recipient from Covid-19 to themes of support and isolation. The interconnectedness of themes occurs throughout this study, and all link under one overarching theme, which is labelled "negative nature of caregiving in a pandemic". Figure 1 below shows the interactions between these themes and how they relate to the overarching theme.

Figure 1:
The central theme and related categories



Dashed arrows show links between themes.

Solid arrows show link to the overarching theme.

From this, we can see how one theme is embedded in many other themes and how these elements link together to create a bigger picture of how caregivers experienced the pandemic. Now that we understand how the themes can link together and how each aspect of a caregiver's experiences can be embedded across and within multiple themes, I believe it is worth commenting on why caregivers' accounts focus on the negatives and how the positives fit into how caregivers experienced the pandemic.

Negative experiences occurred throughout the pandemic but were reported as worse in later lockdowns due to declines in participants' mental and physical and a lack of entertainment for the care recipient. This was a common occurrence in participants' accounts, for example, with the following statements: *"So, when we had the first lockdown, she was much more with it and understood what was going on"*, *"First time was manageable. But the second time was more of a problem because mom really didn't know what she was doing"*, *"But of course, as she was, as her* *physical condition deteriorated, that was becoming increasingly problematic"*, and *"And towards the end, I even had to, you know, do everything that you and I normally do on a toilet for her. So that that was that became quite, sort of difficult"*.

In this study, caregivers themselves stated that the second lockdown was harder due to the decline in the mental and physical health of care recipients. This decline in health led to daily tasks taking longer, requiring greater focus and attention towards care recipients as well as greater responsibility for caregivers. This, linked with the many support systems not available or shutting down due to Covid-19, provides an explanation for why the pandemic has been perceived as more negative than positive by caregivers' accounts in this study.

Summary

In summary, this chapter has shown that caregivers experienced feelings of anxiety and isolation. This was shown by caregivers' concerns about Covid-19 and the health care system's ability to manage them. Caregivers discussed hypothetical situations, such as the health system's abilities to cope with the pandemic if they needed to access them. Caregivers tended to avoid social interactions to keep Covid-19 away. This resulted in the loss of friendship for some as caregivers did not let non-family members enter their homes due to the risk. It is clear how isolated caregivers have become because of the pandemic and the measures they took to stay safe. Caregivers in this study voiced the lack of support they received during the pandemic, and many of the supports they accessed prior to the pandemic were no longer available, which created challenges for them as caregivers. This study found that caregivers believed the information available to them was lacking and was not specific to caregivers but just general guidelines for the pandemic. Caregivers reported deterioration of care recipients throughout lockdowns. This meant caregivers' health was impacted due to anxiety, stress and disrupted sleep. This was experienced despite caregivers taking time for themselves and initiating self-care practices. Despite some positive aspects of the pandemic, this study found that caregivers' experiences of the pandemic in New Zealand were predominantly negative.

Chapter 4: The needs of older caregivers in a pandemic situation in New Zealand

This chapter will discuss caregiver needs that have been highlighted by their experiences during the pandemic. Based on participants' accounts, the need for better support and for support to continue during the pandemic for caregivers is clear. This study identified the following areas of interest: 1) emotional social support, 2) health care support, 3) formal care support, 4) practical support, and 5) respite to improve the experiences of caregiving in a pandemic. These will be discussed here.

4.1 Emotional social support

Emotional social support is vital to caregiving. For this study, emotional social support refers to belonging to a community that provides emotional comfort and support that is positive and enhances wellbeing; however, there is no agreed-upon universal definition (Hupcey, 1998; Lewandowski & Hill., 2009; Rook & Dooley, 1985). This support often comes from people, friends, family, co-workers, and agencies. This type of support can be formal, informal, physical, or informational.

Many caregivers in this study felt that the physical connection was not there anymore and used forms of technology to stay in touch with their support systems. This account, *"The human touch may not fully be here and may have to go with the computer or phone or something, and that's a shame. A big shame"* from Abby, helps show this.

Social interaction and human touch have been identified as important to caregivers in this study. The pandemic has highlighted the negative experiences of caregivers and the need to address issues of how to better support caregivers. The participants of this study did not have suggestions for how emotional social support could be improved during the pandemic. However, they did discuss ways in which they engaged with social support, and the following accounts show this:

> We found a way to have some social interaction while still following the rules. So, they were two meters from the boundary gate with the chairs and their stereo and party stuff, and we were on the other side with our deck chairs and tables and wine and nibbles and all the rest of it *(Phoebe).*

In addition, Phoebe stated, *"My husband has started spending enormous amounts of time on the telephone talking to his mates. But then he's always doing that just spending even longer"*. The accounts above highlight the importance of emotional social support for caregivers. The pandemic has limited many caregivers' emotional support, as shown in this study, and resulted in the deprivation of emotional social support through the loss of friendships. The concept of neoliberalism is important in this context because the shift from government responsibility to informal carers is significant (Cash et al., 2013). The outsourcing of care means caregivers rely on their own support systems, such as friends and family, rather than formal domains of care, such as old age homes and health care systems (Broese van Groenou & de Boer, 2016; Luxton, 2015). It is important that strategies to improve accessibility to emotional social support are improved during a pandemic. The pandemic has reduced the emotional social support available to caregivers and has impacted the way it is accessed.

4.2 Health care support

This discussion on health care support will focus on caregivers' experiences accessing hospitals, pharmacies and ambulances during the pandemic. For this study, health care support is defined as Institutions that provide medical care, prevent disease, provide medications and exclude support agencies such as rest homes, care homes and support workers (Huber et al., 2011; Todd et al., 2022; WHO, 2006). Caregivers often need to access many health care support systems such as hospitals, pharmacies, and ambulances. Health care support will be discussed in two parts: health care support and caregiver concerns and health care support for caregivers.

4.2.1 Health care support and caregiver concerns

After experiencing caregiving during a pandemic, participants in this study reported increased anxiety about whether they can rely on health care systems in a pandemic situation. The concern of caregivers was that if they needed an ambulance or to access a hospital, one would be able to and would these services have enough staffing to provide them with support. The following accounts show this:

> And I don't know why but by talking to the staff in the hospital, it wasn't just that ward. Many wards had problems with people parading and disobeying all the rules and precautions, which everyone else did to protect their friends or family who were patients *(Ted).*

In addition, Ted stated, *"No one was helping those nurses, no one was coming. To sort this out"* and *"It basically comes down to the same old thing. The health services and completely stretched to the limit. And they're just not enough bodies to see out to a quarter of the places we should be going"*. All the participants in this study discussed their concerns with the pressures on the health system during Covid-19, and the shortage of staffing in the health industry is a problem if they wished to access services such as the hospital. The shortage of the health care system in New Zealand during the pandemic has been reported and is reflected in the government's approach to boosting health workers in New Zealand (Little, 2022; Stuff., 2022).

The results of this study have already shown the increased risk to care recipients and the consequences of contracting Covid-19. I argue that although support from health systems was reported as being positive, accessing these systems resulted in negative experiences due to the immunocompromised nature of care recipients and no way of preventing protesters, non-mask wearers and unvaccinated from accessing health systems even when they are not seeking care. There is a clear need to make health care systems safer for care recipients who may be immunocompromised to support caregivers better.

4.2.2 Health care support for caregivers

Caregivers often focus on their concerns for care recipients when accessing health care; however, health care is important for caregivers as well. Few caregivers in this study accessed health care for themselves during the pandemic, but those who did report negative experiences. The following account, *"Personally, when I got to COVID you were allowed to have an antiviral package I suppose it's called. When I rang up for that they wanted me to go in"*, from Abby reflects the failure of the health care system to provide support to caregivers. The account below shows difficulty getting access to health services such as the Covid-19 care package:

> I'm sick. I'm not lining up and the COVID line. I said can you just courier, but they refused, so anyway, I never got that antiviral package. After I got well, I did follow it up with the complaint and said this was unacceptable *(Abby).*

Participants suggested ways to improve support from health care domains, such as increased resources in areas of staffing and better access to medications which they understood may not be practical. A participant suggested that improving security in hospitals can help manage protesters allowing medical staff to focus on patients rather than deal with disruptions.

4.3 Formal care support

This discussion on formal care support will be split up into two sections: Care homes and in-home care. Formal care support is defined for the purpose of this study as the providing of support to caregivers through professionally trained services such as agencies that employ support workers, rest homes, and care homes and can provide in-home care commonly for money as payment (Li & Song, 2019). These services provide support with daily care such as meal prep, bathing and activities. Although health care support can fall under formal care support, I have chosen to discuss them separately.

4.3.1 Care homes

A participant who had access to formal domains of support, such as care homes, had a more positive overall experience during the pandemic. Participants whose care recipient was in a care home reported that they did not have to deal with medications which other participants had issues with during the pandemic. Those participants whose care recipients were in care homes were often secondary caregivers, which allowed them to have breaks and timeout from their caregiving role. Joey stated, *"The caregiving for my wife was done. I was just helping them rather than being responsible for it."* during their interview.

However, lockdowns were often difficult as the care homes did not allow visiting during these times or closed and did not operate over lockdowns putting pressure on caregivers as the sole caregiver. News articles such as NewsHub reported that self-imposed lockdowns were implemented by some care facilities in New Zealand (Small, 2022). This study found care homes to be a great support during the pandemic for those who were already accessing them prior to lockdown. Care homes often made difficult decisions, such as implementing lockdowns and how to best provide care during the pandemic on behalf of caregivers. Many stressors of the caregiver role were taken on by care homes rather than caregivers and may reflect the positive nature of experiences with care homes for caregivers. In contrast, a participant who was in the process of putting the care recipient into a home found that they were unable to access support from care homes until lockdown periods were over.

The literature to date has focused on care home staff's experiences of caregiving during the pandemic, and less focus is on caregivers' views on care, communication, and the experience of having a care recipient in a care home. Dohmen et al. (2022) found that care home staff had a strong focus on care recipients during the pandemic. Care home staff often tailored activities for care recipients based on their identities and focus on their wishes and desires rather than their limitations (Dohmen et al., 2022). Alternatively, research has found that care homes were understaffed, lacked resources and engaged in innovative ways of providing care due to Covid-19 restrictions (Marshall et al., 2021). These factors often lead to a greater workload for staff (Marshall et al., 2021).

Work by Mahase (2021) showed that fewer cases of Covid-19 deaths were reported by care homes with fewer beds. In addition, certified nurse assistants provided Greenhouse homes (homes with usually fewer than 12 beds) with significantly more hours of care than traditional resident nursing homes (Mahase, 2021). This could be due to the effects of understaffing due to illness or pre-existing shortages. A 2021 survey of residents' families reported that 69% of family members felt the facility did not have sufficient staffing for its residence (Consumers Voice, 2021).

In addition, research has shown that residents in care homes in some areas of France and Spain were reported to be confined to their rooms for days without assistance with essential needs such as drinking and eating (Mahase, 2021). Not all experiences with care homes are positive; however, this study found that participants had positive experiences with care homes in New Zealand when they were able to access them during the pandemic.

4.3.2 In-home care

In-home care from agencies often stopped altogether or for short periods during the pandemic. This left caregivers on their own to make decisions on how to best deal with the pandemic. Even when support was offered by agencies such as caregivers coming into homes, they were unable to due to Covid-19 being rampant. Lily recalls, *"Well, it was just us. The lavender blue people only were involved when she was in her own home"*, and Ted stated, *"And the caregiving, particularly with COVID. Because pretty much all the help stopped"*.

In contrast, even when support was available such as caregivers coming into homes, caregivers felt it was too great a risk for the care recipient and not practical. The following account, *"And the risk is quite high. So, we've just opted to keep her home"* from Phoebe, shows this.

Work by Giebel et al. (2020) supports the findings in this study that caregivers had to assess risks and often declined in-home support due to the risk of Covid-19. Giebel et al. (2020) reported that caregivers discontinued outside support, such as paid carers coming into caregiver homes due to Covid-19.

In addition, participants acknowledge that most of their information came from their support workers, and participants do not recall seeing any support aimed at caregivers. Phoebe stated, *"But most of the notification of what was available and what wasn't available came directly from our support workers ourselves"*, which reflects the uncertainty of what information was available and a lack of information for caregivers.

Therefore, participants in this study have suggested that to be better supported; they need access to reliable information targeted toward caregivers and better communication from agencies. The following account, *"First time round. They were not forthcoming. We were working it out ourselves"* from Bella, shows this.

Caregivers felt they needed access to better information. The literature on disaster situations has reported misinformation and confusion of information is common (Lewandowsky et al., 2012) and more recently in research on Covid-19 specifically (Modi et al., 2021; Tasnim et al., 2020). It is important that caregivers receive reliable information and that any concerns they have can be addressed. In this study, confusion around where to access information and the lack of information aimed at caregivers was present. Beyond this, caregivers were not able to state how support can be improved. This was due to the lack of practical ways for support to be provided during the pandemic. Participants often turned down physical support when they were available. Parmar et al. (2021) work suggests that caregivers wanted better communication from healthcare systems and institutionalised support, which aligns with the findings in this study.

Here we can see that caregivers need more support, but the question remains of how support can be provided in a way that is practical and accessible to caregivers. Participants struggled with formal domains of support as the agency that they had been using only provided support when the care recipient was in their own home. However, due to Covid-19, the care recipient was with their caregiver and not in their home, as shown in Lily’s account below:

> The lavender blue people only were involved when she was in her own home, and because she wouldn’t accept most of their help during lockdown, there was no point in trying to do that because she needed more than that, and I knew she needed more than that. So, we didn’t have any support. It was just us

The above accounts show that pre-existing support from agencies often stopped due to Covid-19 because the care recipients change in living situations over the pandemic. Reduced levels of support during lockdown periods of the pandemic are well documented in research (Budnick et al., 2021; Gillespie-Smith et al., 2021). In addition, Gillespie-Smith and colleagues (2021) study found that caregivers felt a lack of support and that they had been forgotten. This study found caregivers felt a lack of communication from formal support systems that provided in-home care, as shown in Lily’s following accounts: *“It got more difficult as time went on because you're trying to get, I didn't quite know what help was available in what we could kind of do, and the doctors weren't really willing to do something”* and *“She was beginning to want to go home at this point, so she was very aggro to get home. I didn’t realise I could put the lavender blue people back in again at that point”*.

The above implies that prolonged stressful situations, such as care recipients becoming aggravated due to not being able to go home, could be avoided by in-home care agencies that caregivers were using before the pandemic getting in contact with caregivers. Kasdovasilis et al. (2023) UK study supports the finding that care recipients require increased levels of care.

Past research has identified that communication and lack of preparation by formal support systems such as care agencies were problematic and added to the stressful nature of Covid-19 (Kasdovasilis et al., 2023; Willis et al., 2021). This has been shown in this study. The stress experienced by carers can be reduced in future pandemic situations by better preparation from formal support systems and improved communication.

4.4 Respite

Caregivers voiced their view that no one can provide care in a pandemic by themselves twenty-four hours a day, seven days a week, without a break. Self-care has been identified as important to caregivers in this study, and respite can provide caregivers with a break from caregiving when they need it.

4.4.1 Accessing respite

Respite is essential for caregivers to get breaks from their caregiving role. Accounts such as the ones below show that caregivers needed breaks from caregiving during the pandemic, which was difficult for them to get. The account below from Lily reflects this:

> I needed some break, and I really didn’t realise how bad things had got until we cleared because I did not go to New World during that time because of the queues that took several hours to get through. So, after it sort of cleared and the first time I could get into New World, it was a euphoric experience.

Due to the issues above of support being practical, it is unlikely that in-person respite can be provided at key moments during the pandemic situation. Caregivers would be unlikely to access respite due to the immunocompromised care recipient and the risk accessing this form of support would pose to them. Past research has reported on the limited access to respite during the pandemic for caregivers (Greenberg et al., 2020). The account below was referring to accessing respite for the care recipient and opted not to access respite due to the risk:

> One of the staff actually came; he used to work there and said look, if she goes or happens, it's a babysitting service. And it won't be that great because the numbers aren't that good. And the risk is quite high. So, we've just opted to keep her home *(Phoebe).*

The participants discussed the rapid spread of Covid-19 and the risk of contracting the virus; due to this, they opted not to access respite services even when they were available. In this study, respite was found to be valuable to caregivers. A systematic review of past research has shown respite to be a valuable source to caregivers (Vandepitte et al., 2016). In Lethin and colleagues' (2016) research, respite was utilized by all, if not most, participants in France and the Netherlands. Additionally, this study showed that participants would like to be able to access respite in a pandemic situation and called for services available before the pandemic continues during the pandemic. Phoebe's account, *"I think that for a lot of people, they needed to have the caregiver support carry on"*, shows this.

In contrast, when respite was available to caregivers in this study, it was often not accessed due to the risks associated with the virus and the impact this would have on the care recipient.

4.4.2 Technology and respite

Participants in this study discussed the use of technology to provide them with support and entertain care recipients. This means respite could possibly be offered online through software such as Skype and Zoom, but this was not considered practical due to care recipients' lack of knowledge about using technology. The following accounts reflect participants' use of technology over the pandemic: *"Well, we used Zoom, we had a ladies Bible study that I go to on a Tuesday night. And we used Zoom, it was tiring, I must admit"*, *"I set up the radio and she had headphones so I could put those on for her or put on a talking book with the headphones on"* and *"And we were doing, we're doing a lot of zoom calls. But just talking and communicating and, and really sort of sharing emotion"*. In addition, Phoebe recalls their use of technology over the pandemic in the account below:

> And in actual fact, we ended up both quite liked it because we still had enough technology, you know, we've got a TV, and I don't have a radio because of don't like radios. They're always so excited to talk to you. It's a more personal thing, but, you know, we had TV, we had computers, we could still do online shopping *(Phoebe).*

The use of technology to aid caregivers during the pandemic should be considered in future research. However, participants in this study have not voiced wanting more support to be offered through online platforms but voiced their need for support that can be provided without physical contact. Caregivers would likely have to provide care recipients with additional support while they are accessing respite online, which nullifies the purpose of respite as caregivers would not be getting a break, but rather helping the care recipient navigate technology. It is clear that caregivers need to be able to have breaks from their caregiver role in a pandemic situation, and respite is one way this can be achieved.

Research by Utz (2022) found the use of technology to provide respite in different ways, such as Zoom meetings, interaction through video games, and real-time supervision from an offsite respite provider via an interactive computer screen, as beneficial (Utz, 2022). Utz's (2022) study found that caregivers reported the greatest challenge of Covid-19 was the shutting down of respite, highlighting the importance of respite and its necessity. It is unclear at what age group Utz's (2022) study was aimed at, and it would need to be explored further for older people as they may not have the ability to navigate technology.

In this study, participants did not have any suggestions on how respite could be provided to better support them in a way that is practical and accessible to them. The accounts below show caregivers needed pre-existing supports to continue, and getting care recipients to accept support was problematic. Phoebe stated, *"I think that for a lot of people, they needed to have the caregiver support carry on. I think that what they were doing was fine. A lot of people still had that caregiver support,"* and Lily reported, *"Honestly, I don't know about that. I mean, the whole struggle has been trying to get some additional help for her that she would never accept anyway"*.

In addition, research by Lightfoot and Moone (2020) has suggested the use of technology to provide caregivers with additional support, even from informal services such as the use of social media platforms to connect with other caregivers, as beneficial. Support is essential for caregivers, and the pandemic has highlighted this. The use of technology to provide respite should be explored further.

4.4.3 Keeping care recipients entertained

Caregivers said that they struggled to keep care recipients entertained for the duration of lockdowns, and care recipients' health declines did not help with this. Entertaining care recipients allows caregivers to do daily tasks such as house chores and provides caregivers with a break from their caregiving duties. The following account, *"Yeah, any other stresses have probably been just figuring out what else they can do to entertain them"*, from Abby, highlights these struggles.

Technology was used by caregivers to help with this, as shown by Lily's account *"I set up the radio, and she had headphones so I could put those on for her or put on a talking book with the headphones on"* and John's account *"We sort of watch a bit more TV than normal I suppose"*. However, declines in health over lockdowns, such as loss of eyesight and hearing, often meant strategies such as those above were not effective long term. Participants voiced their preferences for having support offered via human contact rather than by email. Bella's account shows this *"It would, it would be great. If there was enough staff on the ground and if there was human contact, not just all via emails"*.

This was interesting as participants in this study often declined support that involved physical contact. This participant found that the agency they were with was too big, and when trying to gain support from the agency, the lack of human contact was evident. This resulted in difficulties such as getting the gender of the care recipient wrong. From this, we can see that although technology can be great in a pandemic situation, additional concerns, such as lack of human contact, arise. In addition, participants acknowledge a lack of staff as a problem in accessing respite. This is likely due to the spread of Covid-19, which impacts individuals' ability to work.

4.5 Practical support

It is clear already from what has already been discussed in this section that support is lacking, and even when support is available, caregivers are avoidant of it due to the risk of the Covid-19 virus. Often caregivers do not have a choice in turning down support, as if the care recipient gets Covid-19, they will likely die. Many support workers have multiple clients across households, which results in a greater risk of the care recipient suffering from Covid-19. Here, I will discuss the practicality of support for caregivers during the pandemic.

4.5.1 Caregiver's suggestions

Participants in this study expressed the severity of Covid-19, which limited support and reduced the practicality of physical support for caregivers, as shown by Ted's account *"None of her family friends or even medical people wanted to be the one that infected her was something that was already said; it would definitely have killed her"*.

Despite the severity of Covid-19 and caregivers' decisions to decline physical support during the pandemic, caregivers proposed that an extra support worker would be beneficial to help them with caregiving duties.

However, this was not practical as it posed an increased risk to care recipients of contracting Covid-19. Even though health systems and agencies have decreased the crossing over of bubbles of their workers during the pandemic, caregivers felt the risk was still too great. Therefore, unless care services can provide a worker that only sees one client in a pandemic situation, it is unlikely caregivers will access this form of support based on the findings in this study.

The traditional support systems that have been used outside of the pandemic have not been accessed by caregivers and are often not available in key moments of the pandemic, such as in lockdown(s). Participants made no suggestions about how they could be supported in a way that was practical and accessible to them. However, they specified they had a lack of training related to their caregiver roles. The following accounts from Lily and John show this: *"And I'm not trained as a caregiver. That's, you know, I'm learning on the hoof as far as all of that goes"* and *"Not being sort of a, I guess, a trained caregiver"*.

It was interesting that all caregivers in this study felt the need to state they had not received any training for their caregiver duties, as I did not ask any questions about this. This could imply a need for caregivers to receive formal training. Past research has shown that training and education programs can be beneficial for caregivers and improve caregivers' ability to manage disaster situations themselves (Gibson et al., 2018; Wakui et al., 2017). The literature has shown us that using education and training programs in conjunction with community-based support programs can anticipate events such as a pandemic that, as shown in this study, have led to an increased need to access support through respite and other formal domains (Baker et al., 2012; Gibson et al., 2018; Wakui et al., 2017). However, this implicit implication does not imply that this is what caregivers want.

Caregivers in this study have reported that the care recipient often would not accept formal help outside of family even when it was available. Lily's account shows this: *"The second lockdown was a lot different; I knew she had deteriorated, and I had been trying to get additional help for her, which she would not accept because she thought she should do it"*. Therefore, the focus should be aimed at supporting caregivers themselves rather than care recipients, yet this can be hard as they are interconnected.

4.5.2 Practicality of technology in the pandemic

In contrast, Support being offered online is one-way caregivers can feel comfortable accepting support rather than avoiding it. This would remove caregivers' concerns about care recipients contracting Covid-19 and allow support to be focused on caregivers themselves. However, care recipients' and caregivers' ability to navigate technology can be problematic. Although in this study, all caregivers reported using technology to stay in touch with family members and their support systems.

Research to date suggests that providing services online has the potential to reach a greater number of people is probable, especially in Covid-19 circumstances (Dominguez-Rodriguez et al., 2022). Dominguez-Rodriguez et al.’s (2022) study focuses on the use of cognitive behavioural therapy (CBT) based interventions to support mental health patients during the pandemic, but as expressed, an online approach would be valuable to provide greater support to caregivers in a pandemic situation. Hedman et al. (2012) systematic review found online interventions to be cost-effective when dealing with mental health issues, and Dominguez-Rodriguez et al. (2022) study supports this. This implies that online interventions and potential services such as respite can be cost-effective to implement. This means that it is likely that implementing a form of online support for caregivers will be practical in a pandemic situation. The use of technology to provide support and how this will be done needs to be explored further.

Digital inequalities have been recognised, and research has been done on the uneven distribution of inter access amongst the general population (van Deursen, 2020). Digital inequalities go beyond simply having access to the internet but also explore concerns around including one's ability to use technology and self-perceptions (Robinson et al., 2015).

Many participants in this study were from rural backgrounds where their internet connection was not always stable and reliable. To address this, Lindeman and colleagues (2020) proposed a guide on the use of technology to target specific areas to support caregivers allowing for policy changes to be impacted, additional support to be provided, and barriers to be identified when using technology to address such issues. To address internet connection issues, I suggest the use of Lindeman and colleagues' (2020) work which suggests internet companies be incentivised to provide better internet access to rural areas, which they deem ‘extended access’ which requires specialised software allowing caregivers in rural domains to have a more stable internet connection. This can be used to reduce barriers to accessing support through technology and promote access to caregiving enhancement technologies. However, training and readable instructions for such software may be required. The idea of providing online support for caregivers will need to be explored in future research.

Mediators such as one's ability to use and navigate technology can be a barrier; however, an education and training program can be provided to caregivers and care recipients with the ability to access online support and attend online consultations. Van Houtven et al. (2010) work showed difficulties in getting caregivers to access educational and training sessions. Participants in this study have used technology such as Zoom to stay in touch with family and friends, which implies caregivers have the ability to navigate technology. This is one way that help can be accessed during the pandemic, and this approach can provide group sessions allowing for increased emotional social support and providing caregivers with social stimulation that may prevent the isolation caregivers experienced during the pandemic. Lily reported the positive implications of having a bible study over Zoom, as shown in the following account: *"It was great because at least we remained connected, and I found that was a real help for me"*.

Therefore, providing similar scenarios to this specifically for caregivers would have benefits such as social interaction for caregivers and provide caregivers with a wider support system. Technology can address issues that prevent caregivers from accessing support, such as physical contact; however, the uneven distribution of internet access and the ability to navigate it can further isolate a portion of the caregiver population in New Zealand, and by providing support they cannot access.

4.5.4 Extending pre-existing supports

Formal domains of support can incorporate pre-existing support. For example, this study found that caregivers often declined physical support from support workers; however, support workers can be used to deliver supplies such as medication, shopping, and other essential items.

Participants who were able to access online shopping and delivery found it useful. Phoebe's account, *"We could still do online shopping, which, by the way, is obsessively dangerous"*, shows this. Here Phoebe refers to online shopping as obsessively dangerous as it is easy, and you can spend a lot of money without realising when shopping online.

In addition, Abby suggested that voluntary caregivers they work with often requested Wi-Fi as a need and that the use of technology to get items like groceries, mediations and other essentials delivered to caregivers was invaluable and worked. The accounts below show this:

> It feels like some of the caregivers were no longer in employment, so they then had to ask for Wi-Fi which we were able to give them, which is a bonus. So, I think the biggest thing we have provided is Wi-Fi and small phones, not the expensive ones, just phones for communication. So, we gave a lot of those out *(Abby).*

Due to high demand during the pandemic, participants who attempted to access online shopping and delivery from supermarkets found it was frequently unavailable. Abby suggested the use of taxi services, support workers and uber drivers to be utilised for the delivery of products for caregivers, such as mediation, as this was found to be beneficial within her job. The account below refers to online shopping options not working for some caregivers:

> Yeah, just getting some of the some of the online shopping options didn't work too well for us. So, it means that I just go out and do shopping myself at the supermarkets and that sort of thing *(John).*

This is due to not being able to access online shopping that could be delivered due to the high demand. Additional support can be provided to caregivers from support agencies. For example, participants had expressed that physical interactions with support workers are not wanted, and caregivers avoided this support when it was available. On the other hand, support workers could be used to drop essential products such as groceries and medication to caregivers during a pandemic. Caregivers in this study have suggested that getting online shopping through supermarkets is difficult due to high demand during the pandemic. By support workers delivering groceries for caregivers, the pressure of shopping and the increased risk of Covid-19 can be reduced. This form of support can be provided without physical contact and the increased risk of the care recipient contracting Covid-19, which caregivers have suggested as the main reason why they declined support. This will be valuable for those caregivers who must still work as well as fulfil the caregiving role and may take the pressure of one job off those caregivers who care full time. The following account from Joey reflects the risk of Covid-19 to care recipients: *"Yeah, there was stresses in terms of anxiety not to get it and particularly in the case of someone in the condition of my wife, who, probably, almost certainly, but probably wouldn't survive COVID If she got it ...."*.

Utilising pre-existing support, such as using support workers to help supply shopping when online alternatives are unavailable, can be beneficial. This is one-way pre-existing supports can be utilised in the pandemic to support caregivers. This example of utilising pre-existing supports looks to take advantage of supports already available to caregivers that can function during a pandemic with a reduced risk of contracting Covid-19. Caregivers have called for pre-existing supports to continue in this study, and this is one-way support can continue in lockdown periods without putting immunocompromised individuals at risk. For example, Phoebe's account, *"I think that for a lot of people, they needed to have the caregiver support carry on"*, shows this. It is important to note here that this is not limited to shopping but can extend to other areas, such as the collection and drop of medications.

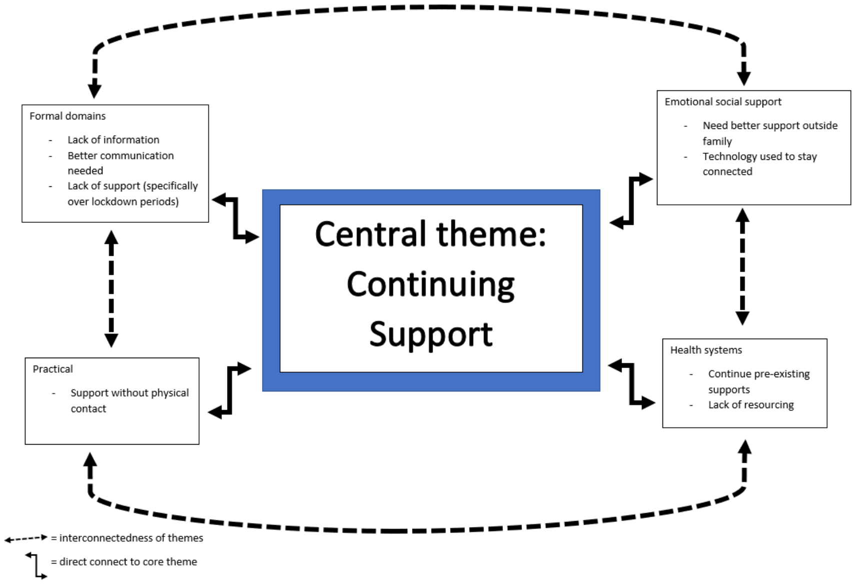
In contrast, two caregivers in this study suggest that doing the shopping is the only time they received a break from their caregiver duties; therefore, not all caregivers would accept this support if it was offered. For example, Lily's account, *"I really enjoyed the times out as it gave me someone different to talk to, which was nice. I enjoyed having the break"*, shows this. Caregivers need to have breaks from their caregiver roles, and the above account helps show this. Alternative ways for pre-existing supports to continue to incorporate non-physical contact need to be explored further.

4.6 The interconnectedness and linking of experiences

Overall, caregivers' accounts tended to focus on the following areas: formal domains of care, practical support, health systems, and emotional social support. These areas are inextricably linked. For example, having support that carers can access and need, as well as access to reliable information through support, can improve carers' emotional and social support. The overarching theme identified here is the need for support to continue during the pandemic. The accounts from participants have shown how caregivers have needed to be self-reliant in a pandemic situation which reflects the current outsourcing approach to caregiving and the focus on individual responsibility. As Lily said: *"Well, it was just us"*.

Lily's account reflects the lack of support felt by caregivers during the pandemic, particularly over lockdown periods. Figure 2 shows the interconnectedness of themes to the core theme (continuing support during the pandemic) as voiced by caregivers in this study.

Figure 2:
The central theme from participants accounts and related categories



This figure shows that the core theme of continuing support in the pandemic is connected to areas identified in this research, such as formal domains, support that is accessible and wanted by caregivers, health systems and emotional social support. This core theme is embedded in multiple areas and the interactions across these areas. These links show us that caregivers are asking for support to continue during the pandemic, and these areas can improve aspects of their lives during the pandemic. For example, by continuing support in a pandemic, caregivers will have access to formal domains and health systems, support that is accessible to them and provides them with additional support that is wanted, needed and assessable to them.

Chapter 5: Conclusions

This chapter will first discuss implications for practice through the ideal of checking. This ideal looks to provide support to caregivers in real-time through the use of technology and work within or alongside pre-existing supports. Next, I will discuss the implications for future research and the limitations of this study. Finally, I will conclude with an overall summary of the study.

5.1 Implications for practice

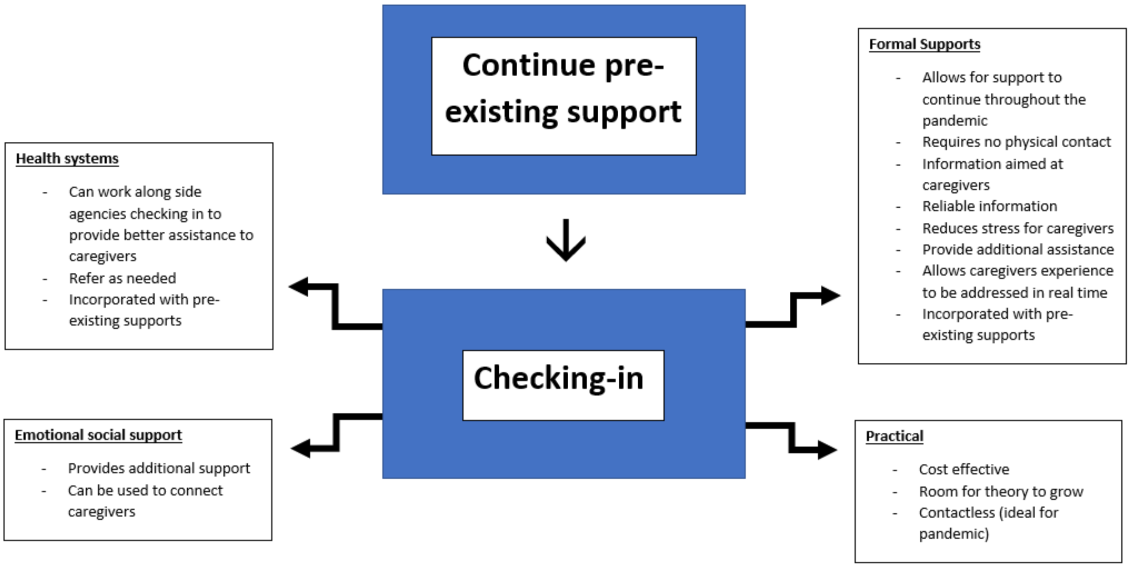
Here I will discuss my suggestions on implications for practice. Based on the experiences, wants and needs to be voiced by participants in this study the need for alternative practices to better support caregivers are needed. Despite the connectedness of themes and overarching themes of negative experiences and the need for support to continue, participants lacked suggestions on how to address these. Therefore, I will propose the idea of what I term checking-in here. I will discuss how checking-in incorporates technology to better support caregivers, improves emotional, social support, how it addresses the lack of communication, prevents misinformation and how screen tools can be as part of checking-in to better tailor support to meet older caregivers' needs.

5.1.1 Checking-in and technology

Checking-in is a way for formal and informal support can stay connected with caregivers. This can be done by contacting caregivers at regular intervals throughout the pandemic. For example, weekly or fortnightly checking-in incorporates the use of technology and can work alongside the pre-existing support caregivers have asked to continue during the pandemic. Participants voiced that they often declined support when it was available due to physical contact and the severe risk of Covid-19 associated with the care recipient. Therefore, for support to be practical, alternatives to physical support must also be provided during the pandemic. This is why I propose the idea of checking-in as it incorporates the use of technology, allowing for support to be offered via phone calls, emails and online platforms such as Zoom but can also be provided in the form of physical face-to-face visits if caregivers prefer. This would allow caregivers to be able to access both physical and non-physical support during a pandemic. I propose that agencies that are already supporting caregivers incorporate this approach as caregivers have been working alongside these agencies for longer periods and have already built rapport. However, this can be provided by formal domains of support, health systems and community support groups. Figure 3 below shows the needs of caregivers that checking-in address, and that can be incorporated into pre-existing supports that were available before the pandemic.

Figure 3:

Checking-in and core themes it addresses



In addition, the pandemic has provided a platform for technology as a form of support to be explored, as caregivers often rejected support that involved physical contact to avoid health risks. This means that alternatives to physical support, such as technology, need to be explored due to the pandemic. Participants in this study expressed not being able to access online shopping options due to high demands; however, by checking-in, agencies could be used to organise support workers to deliver shopping when alternative online shopping when it is unavailable. Community support organisations such as the Student Volunteer Army (SVA) have operated in a similar manner, providing an online contactless pharmaceutical and grocery delivery service to vulnerable people who were unable to shop for themselves (Carlton et al., 2022; Foodstuffs., n.d). Research on disasters has shown that volunteer organisations are an important resource for relief and contribute to psycho-social recovery for communities (Twigg & Mosel, 2017; Whittaker et al., 2015). Carlton and colleagues' (2022) study showed that the student volunteer army provided additional support such as childcare for essential workers, assisted professional cleaners, assisted with police and on phone lines. SVA reported that half the grocery orders they delivered came from the group contacting people who had been referred to them (Tindall Foundation, 2022). However, despite this movement growing, the student volunteer army was only able to operate at specific locations (Foodstuffs, n.d). The feedback for volunteer groups like this has been positive during the pandemic and is looking to expand (Carlton et al., 2022; Mills, 2020). This would allow for support to be provided to caregivers while the risk of Covid-19 could be reduced as caregivers no longer have to do their shopping. Care agencies such as those employing support workers can make referrals to volunteer groups such as this to provide additional support for caregivers. The idea of checking-in has the potential to be expanded further, allowing for online consultations and has the potential to be developed into many other areas to provide increased levels of support to caregivers. However, two caregivers in this study expressed their preference to do their own shopping as it was the only break from their caregiver role. Lily’s account shows this: *“The shopping gave me the little breather that I really needed, I have to say”*.

This is a concept that can aid the checking-in process and needs to be explored further if it is to be implemented alongside checking-in. The use of checking-in can lead to care recipients' health declines being addressed sooner as caregivers will have the ability to communicate the issues they are having to outside support systems and professionals. By recognising these signs earlier through incorporating checking-in on caregivers, many of the negative experiences of caregivers may be avoided, and the need for support recognised sooner.

Recent research by Buonsanti et al. (2020) has shown that the use of online platforms and checking-in has bought people closer together. One participant's account in their study (Buonsanti et al., 2020) showed how checking-in was an effective way to form bonds with the agency or community support group you are talking to. It allowed for a mutual understanding between people. In contrast, it is unclear how this will work for those who are not highly competent at navigating technology. The use of checking-in can provide caregivers with additional resources such as access to counselling services, provide information and where to find information aimed at caregivers.

5.1.2 Checking-in and emotional social support

Checking-in can be used to provide additional support from formal domains and informal domains to connect caregivers across New Zealand together, which would increase caregivers' social interactions and provide additional emotional social support. Lightfoot and Moone (2020) have also discussed the benefits of caregivers creating their social support groups through social media during stay-at-home periods of the pandemic and found it to be beneficial. In this study, support from other caregivers was shown through the sharing of mediation, as the following account shows:

> But because the majority of us with children with the syndrome are in contact. I had stockpiled. I always stockpile a little bit of that one anyway. So, we got through, but we had to borrow some weeks' worth of medication from another family *(Phoebe).*

Checking-in can provide caregivers with social interaction outside of their household and additional emotional social support, which caregivers valued as important in this study. Emotional social support was seen as vital by caregivers during the pandemic. This will help counteract feelings of isolation experienced by caregivers. A focus of checking-in from agencies should be to provide emotional social to caregivers as disaster situations are stressful. I proposed that checking-in can be used to provide support and solutions to problems in real-time. This would allow for the caregiver's experiences to be explored as they happen, and appropriate support would be provided while the experience of a pandemic is present.

5.1.3 Checking-in and communication

A lack of communication and planning from agencies was reported by caregivers. As shown by the following accounts from Bella and Ted: *“it's just that sense of being the decision making and aloneness really big”* and *“I could get a bit of support when I needed it. And almost overnight, everything stopped...”*.

Lack of communication can be addressed by formal and informal services checking-in with caregivers. This can work alongside pre-existing supports that caregivers have suggested should continue during the pandemic. Checking-in can be achieved via phone calls and online meeting platforms like Zoom and Skype. Work by Aksoydan and colleagues (2019) found that caregivers' stress was reduced, and improvement in the quality of care they provide was found when support interventions were used by caregivers, including phone calls, emails, psychotherapy, and medication. Caregivers in this study did talk about their limited ability to use technology; therefore, phone calls may be the best way of communicating with older caregivers during the pandemic.

Furthermore, studies have shown that a reduction in caregivers' distress was obtained from mindfulness medication interventions, the use of telephone contact, psychotherapy and the use of multi-component educational programs (Chiu et al., 2015; Oken et al., 2010). It is believed that this can be beneficial to caregivers in a pandemic situation. Support such as telephone calls and online platforms like Zoom and emails to check-in may help reduce stress and anxiety for caregivers and act as a mediator for additional support to be provided to caregivers in a pandemic situation when needed. This will help resolve some of the feelings of lack of support displayed by caregivers in this study.

This approach can help deter misinformation and confusion around information that has been reported in previous disaster situations (Lewandowsky et al., 2012) and more recently in research on Covid-19 specifically (Modi et al., 2021; Tasnim et al., 2020). This would mean that those checking-in would need to have access to accurate information; therefore, it is likely this support will come from formal domains of support such as government sources. Checking-in would allow information to be provided from reliable sources and information that is directed at caregivers. In this study, participants called for clear communication and for information to be aimed at caregivers. It is important to note here that in the event of a disaster, the emotional support provided by checking-in would likely be valuable to caregivers (Towle et al., 2019). The University of Michigan has suggested ways in which family members can check-in on caregivers showing its value (Rice-Oeschger, 2021).

5.1.4 Checking-in and screening tools

Moreover, checking-in, which incorporated the use of a screening tool for children and adolescents associated with significant risk and stress of psychosocial problems, was found to be time-efficient and effective (Wiener et al. 2022). Wiener et al.'s (2022) work found that caregivers and patients rated the screening tool highly with accounts such as “easy” and “very easy to complete”, showing this when checking-in specific questions could be asked to provide caregivers with appropriate support for their situation. For example, some caregivers may require minimal support while other caregivers may require a higher level of support due to health concerns of care recipients and many other contributing factors. Checking-in can be used to provide caregivers with appropriate support for their situation by incorporating a screening tool or simply having a couple of set questions which are asked to understand caregivers' situations and needs. The use of technology and online methods for support can grow beyond checking-in by agencies. However, more research would be needed in this area to see if this is what caregivers want.

I have shown that caregivers needed more support; however, caregivers in this study were unclear on what support could specifically be provided. Caregivers commented on the need for support that was available prior to lockdowns to continue but, at the same time, reported not accessing these forms of support when they were available during the pandemic due to care recipients' risk of Covid-19. Participants discussed the use of online alternatives to aid them, such as getting shopping delivered. Caregivers felt their need for support was not met during the pandemic and called for better communication with formal and informal support during the pandemic. Checking-in allows caregivers to voice their challenges and for information to be provided to caregivers in real-time. This support can be provided on its own and incorporated within pre-existing supports, which caregivers have asked to continue in this study. Checking-in incorporates the use of technology, making it practical for a pandemic situation, and addresses areas participants identified as needing more attention, such as the delivery of shopping, communication and information related to caregivers. This suggestion was developed based on participants' accounts in this study.

5.2 Implications for future research

Future research is needed to better understand caregivers’ experiences of the pandemic. Many factors impact one’s experiences of the pandemic, and differentiating these can be difficult. Here, I discuss the benefits of focusing on specific points in time during the pandemic, the need to explore the use of technology to support caregivers, and the need to further explore what support caregivers want.

This research found that the care recipients' health and cognitive declines impacted the caregiver’s experiences during the pandemic. This interaction needs to be explored as care recipients’ health declines, specifically over lockdown periods where support was at its lowest for caregivers is likely impacting caregivers’ experiences. One way to address this issue Is for future research to explore specific points of time during the pandemic, as this would allow for an understanding of how experiences in the pandemic changed throughout the pandemic and the interactions between these experiences. I believe that focusing on specific points in time will allow researchers to explore how the pandemic exacerbated pre-existing factors which led caregivers in this study to have negative experiences. By reporting on these relationships, I believe that support can be improved for caregivers. This would allow for relationships between the pandemic, caregiving, and declines in care recipients' health to be explored.

Future research also needs to explore the use of technology to better support caregivers in a pandemic situation. This study has highlighted that the use of technology to check-in can be beneficial for caregivers. One area that needs attention is the possibility of respite being provided through technology that is accessible to caregivers and useable by care recipients. Recent research has begun to focus on incorporating technology into caregiving, and this is an area that needs to continue to grow. This study found that caregivers valued respite but were often reluctant to access it due to the risk of Covid-19; therefore, there is a need to explore the use of technology to provide support to caregivers such as respite. This is one area that has been identified as important, as caregivers in this study often declined physical support. I encourage research in this area and hope that it continues to grow as technology is an essential part of our world today and can be used to assist caregivers.

Finally, future research should explore what caregivers believe should be done to address the dominant negative experiences of caregivers found in this study. This study found that participants had minimal suggestions on how to improve caregivers’ experiences and what types of support caregivers wanted during the pandemic. It is clear that issues of accessible respite, isolation and anxiety need to be addressed by improving the support available to caregivers during a pandemic. More research is needed to address these issues, and should be a focus of future research.

5.3 Limitations of this research

This research had a small sample size of 7 participants that were used in the data analysis process. To address this limitation, this study's data will be used in an ongoing larger-scale project. Studies with larger samples should include greater diversity in participants. This study only had one

Māori participant; however, the literature has identified that Māori and Europeans have a greater tendency to undertake a family caregiver role in New Zealand. Therefore, the ethnic diversity of participants is a limitation of this study, and future research should include a greater disparity of ethnic groups, particularly Māori, in future research (Grimmond, 2014). This means the findings of this study cannot be generalised to the wider population of older aged informal caregivers. However, this is not a goal of this research or qualitative research in general. More studies incorporating larger sample sizes should be conducted. The larger country-wide study will help provide more insight into caregivers and their experiences of the pandemic in New Zealand and address the limited sample size and ethnic diversity in this study.

Participants lacked suggestions on how to best address the issues and central themes identified in this study, meaning more research is needed to confirm what caregivers want and need during the pandemic. This study has identified areas that need to be improved to better support caregivers; however, it can only provide speculative suggestions on how to address these areas, as participants lacked suggestions outside of pre-existing support to continue during the pandemic. Therefore, more studies are needed for theories to emerge that can be incorporated into all pandemic situations to address caregivers' needs.

A limitation of this study was the impacts of Covid-19 which meant not all interviews could be conducted face-to-face due to the high risk of Covid-19. This means that data in this study were collected in multiple ways: Zoom interviews, phone interviews and face-to-face interviews. The different methods of data collection can impact the richness of the data. For example, I found face-to-face interviews easier to build rapport which can result in more in-depth interviews with participants. However, despite the method of data collection, the overarching theme of negative experiences was present and the core theme of the need for pre-existing support to continue during the pandemic for caregivers. It is important to note that the collection of data on caregivers’ experiences during the pandemic can be beneficial as the experiences are fresh in participants' minds.

As I have already highlighted in my introduction, the theory selected can help explain contradicting findings in research. Therefore, I believe it is appropriate to discuss the limitations of grounded theory employed in this study. The many benefits of this approach were discussed in the methods section. One disadvantage of grounded theory recognised in the literature is that the data analysis process of grounded theory produces an abundance of data (Saunders et al., 2012). Therefore, this process is time-consuming, which can be problematic for researchers. As this research was conducted as part of a master's thesis, the time-consuming process of grounded theory is not ideal; however, this did not impact the findings of this study.

Additionally, the literature yields mixed views on researcher bias within grounded theory (Saunders et al., 2012). The idea of grounded theory used in this study is that participants and researchers co-construct meaning through interviews to understand better the underlying processes and structures that led to caregivers' experiences during the pandemic (Glaser, 2007). It is believed that this process helps find new knowledge within the data (Glaser, 2007).

El Hussein et al. (2014) recognise that reviewing the literature without developing assumptions can be difficult and is recognised as a limitation of ground theory. This study's co-construction of meaning and understanding occurred during the interview process between myself and the participants. This meant that I was able to check with participants to see if I was understanding their experiences the same way they experienced the pandemic. Additionally, I engaged in reflective practices such as memoing to reduce the likelihood of bias occurring within the data.

Finally, due to the time that passed since the occurrence of Covid-19 and the experiences of Covid-19 lockdowns, it is unclear whether some aspects of participants' accounts reflect caregivers' experiences of caregiving during the pandemic or are rather general issues related to the caregiver role. In this study, caregivers were aware that the nature of the things they were dealing with, regardless of Covid-19, would have had some impact on their experiences during the pandemic. For example, a participant may already be stressed, worried, or anxious about something outside of the pandemic, and the pandemic leads to additional stress, worry, and anxiety. The problem here is distinguishing between the impact of Covid-19, pre-existing stressors and the deterioration of care recipients. The impact of these should be considered in future research.

5.4 Conclusion

The present study has found that informal caregivers’ experiences of the pandemic in New Zealand are predominantly negative. However, this idea was not reflected in past literature, which yielded contradictory results.

Participants' accounts are complex and indicate interplay across experiences. Common themes identified in caregivers' accounts are experiencing anxiety, the impacts of isolation, having difficulties receiving support, having difficulties with medication, and impacts on caregivers' health. These factors combined led to an overall negative experience for caregivers in this study.

Caregivers reported a lack of support and having to navigate the pandemic on their own, as information on how to manage the pandemic was not aimed specifically at caregivers but rather general in nature. This, combined with the high risk of care recipients who were often immunocompromised and faced other health difficulties, meant caregivers felt additional stress to protect the care recipient, as it was a matter of life and death for them. Caregivers implemented their own policies over the pandemic, such as not letting anyone outside of immediate family enter their home to protect the care recipient. This led to a loss of friendships and further isolated caregivers. Here we start to see how caregivers' experiences are intertwined and interrelated.

Furthermore, caregivers experienced a lack of support from pre-existing supports during the pandemic. They have asked for pre-existing support to continue to operate during the pandemic and have expressed that this would be the biggest help for them. Despite this finding, caregivers reported declining support during key moments in the pandemic due to the physical nature of the support offered. For example, support workers come into their homes and taking care recipient to access respite.

Caregivers had to make challenging and difficult decisions during the pandemic. In this study, I have discussed the interconnectedness of themes that occurred and how these all link under one overarching theme, which is labelled "the negative nature of caregiving in a pandemic". I have shown how this theme is embedded in many other themes and accounts and how these elements link together to create a bigger picture of how caregivers experienced the pandemic. This experience was prominently negative for caregivers.

Just like outside the pandemic, caregivers are solely responsible for the care recipient in many cases and take on the majority, if not all, of the workload related to caregiving themselves. During the pandemic, participants felt that family was there to assist them if needed; however, the logistics of Covid-19 it was difficult for family members and friends to be of any assistance with caregiving duties. Participants did feel family was a great form of emotional and social support, and they trusted them to be there if they were needed.

In addition, health care support, which refers to institutions that provide medical care, medications, or both, excluding support agencies such as rest homes, care homes, and support workers for this study, was found to be valuable. Caregivers that accessed ambulances and hospitals during the pandemic felt it was a positive experience. The participant felt the staff were great and more than willing to assist. However, the majority of participants in this study had concerns about whether the health system in New Zealand would have the resources and staffing during the pandemic to be able to assist them and provide them with support if it was needed. For the few caregivers in this study that accessed health care support, it was a negative experience due to protesters, non-mask wearers, and the nature of the reason caregivers had to access the hospital.

Although the experience of how healthcare professionals handled care was positive, the overall experience of caregivers' access to healthcare during the pandemic was negative.

Formal care support, which was defined as the providing of support to caregivers through professionally trained services such as agencies that employ support workers, rest homes, and care homes for the purpose of this study, showed caregivers who had their care recipients in care homes often had a more positive experience during the pandemic. It was difficult for caregivers to access care homes during the pandemic if they were not in this care prior to the pandemic. This positive experience may be because challenges such as medications, providing care, and managing health declines were managed by care home workers rather than the participant. This was an interesting finding of this study.

Caregivers in this study engaged in self-care habits but, despite this, had a negative experience during the Covid-19 pandemic. Caregivers voiced the need for respite to continue; however, when respite was available, caregivers often declined due to the immunocompromised status and risk to care, recipients.

Practical ways of providing care were explored. Participants had minimal suggestions here other than for pre-existing supports to continue and how forms of technology have assisted them in getting groceries. Many caregivers were unable to get groceries delivered through online platforms due to high demand during the pandemic.

Therefore, with the idea of practicality, I proposed the concept of checking in to work within and along with pre-existing supports in the pandemic. For example, caregivers may decline support from support workers during the pandemic, but support workers can be used to deliver groceries when delivery services are unavailable. The concept of checking in allows for caregivers' experiences to be reported in real-time and for solutions and support to be provided as these experiences occur. Checking-in has room to grow and should be explored in future research, along with other uses for support through technology for caregivers.

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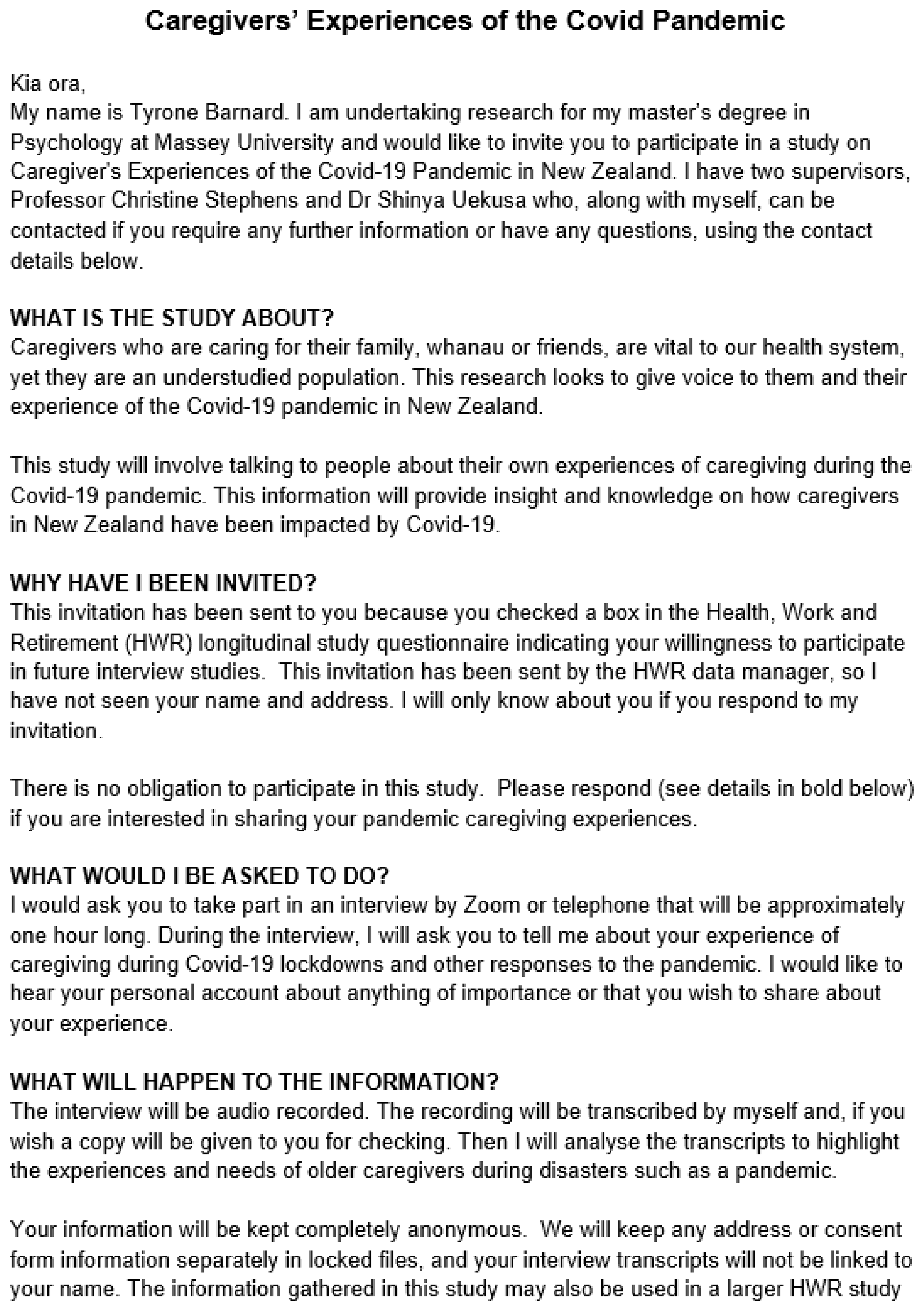
Appendix

Appendix A: Information sheet page 1



Caregivers' Experiences of the Covid Pandemic

Kia ora,
My name is Tyrone Barnard. I am undertaking research for my master's degree in Psychology at Massey University and would like to invite you to participate in a study on Caregiver's Experiences of the Covid-19 Pandemic in New Zealand. I have two supervisors, Professor Christine Stephens and Dr Shinya Uekusa who, along with myself, can be contacted if you require any further information or have any questions, using the contact details below.

WHAT IS THE STUDY ABOUT?

Caregivers who are caring for their family, whanau or friends, are vital to our health system, yet they are an understudied population. This research looks to give voice to them and their experience of the Covid-19 pandemic in New Zealand.

This study will involve talking to people about their own experiences of caregiving during the Covid-19 pandemic. This information will provide insight and knowledge on how caregivers in New Zealand have been impacted by Covid-19.

WHY HAVE I BEEN INVITED?

This invitation has been sent to you because you checked a box in the Health, Work and Retirement (HWR) longitudinal study questionnaire indicating your willingness to participate in future interview studies. This invitation has been sent by the HWR data manager, so I have not seen your name and address. I will only know about you if you respond to my invitation.

There is no obligation to participate in this study. Please respond (see details in bold below) if you are interested in sharing your pandemic caregiving experiences.

WHAT WOULD I BE ASKED TO DO?

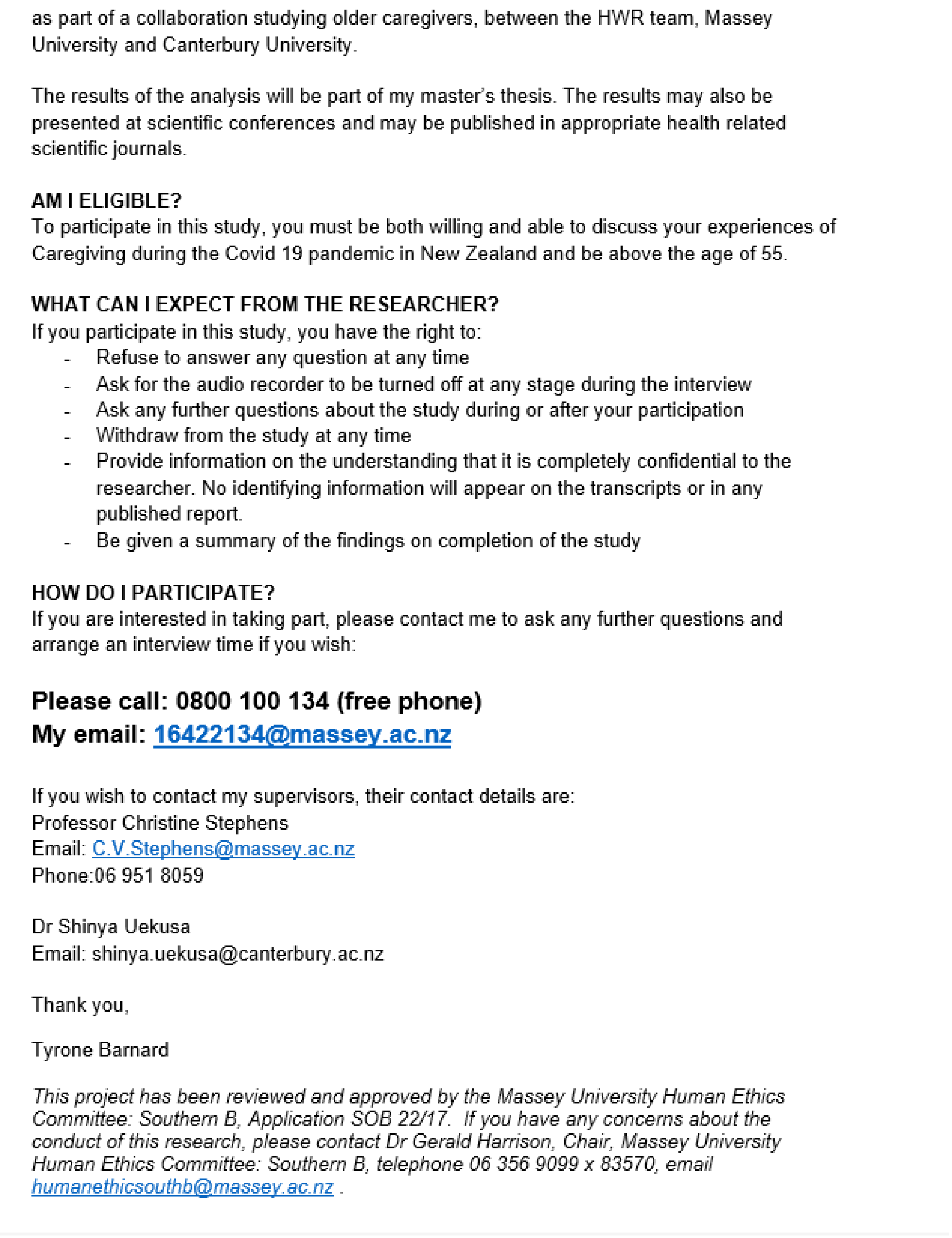
I would ask you to take part in an interview by Zoom or telephone that will be approximately one hour long. During the interview, I will ask you to tell me about your experience of caregiving during Covid-19 lockdowns and other responses to the pandemic. I would like to hear your personal account about anything of importance or that you wish to share about your experience.

WHAT WILL HAPPEN TO THE INFORMATION?

The interview will be audio recorded. The recording will be transcribed by myself and, if you wish a copy will be given to you for checking. Then I will analyse the transcripts to highlight the experiences and needs of older caregivers during disasters such as a pandemic.

Your information will be kept completely anonymous. We will keep any address or consent form information separately in locked files, and your interview transcripts will not be linked to your name. The information gathered in this study may also be used in a larger HWR study

Appendix A: Information sheet page 2



as part of a collaboration studying older caregivers, between the HWR team, Massey University and Canterbury University.

The results of the analysis will be part of my master's thesis. The results may also be presented at scientific conferences and may be published in appropriate health related scientific journals.

AM I ELIGIBLE?
To participate in this study, you must be both willing and able to discuss your experiences of Caregiving during the Covid 19 pandemic in New Zealand and be above the age of 55.

WHAT CAN I EXPECT FROM THE RESEARCHER?
If you participate in this study, you have the right to:

- Refuse to answer any question at any time
- Ask for the audio recorder to be turned off at any stage during the interview
- Ask any further questions about the study during or after your participation
- Withdraw from the study at any time
- Provide information on the understanding that it is completely confidential to the researcher. No identifying information will appear on the transcripts or in any published report.
- Be given a summary of the findings on completion of the study

HOW DO I PARTICIPATE?
If you are interested in taking part, please contact me to ask any further questions and arrange an interview time if you wish:

Please call: 0800 100 134 (free phone)
My email: 16422134@massey.ac.nz

If you wish to contact my supervisors, their contact details are:
Professor Christine Stephens
Email: C.V.Stephens@massey.ac.nz
Phone:06 951 8059

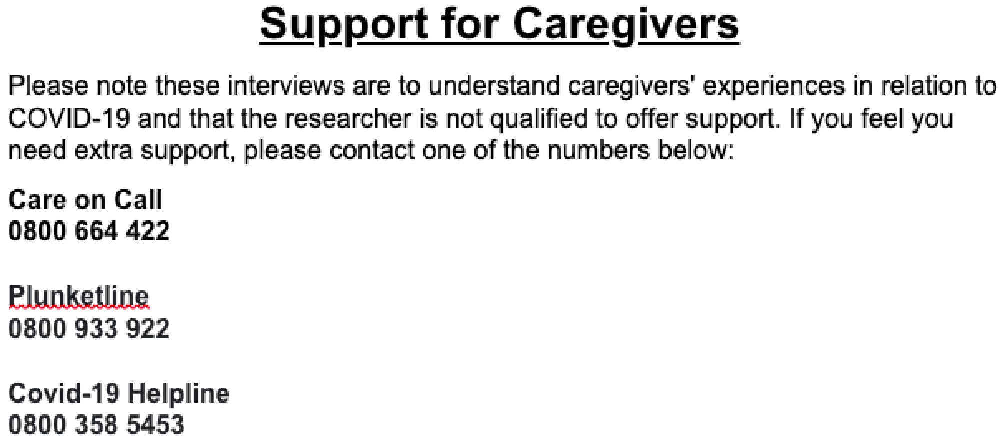
Dr Shinya Uekusa
Email: shinya.uekusa@canterbury.ac.nz

Thank you,

Tyrone Barnard

This project has been reviewed and approved by the Massey University Human Ethics Committee: Southern B, Application SOB 22/17. If you have any concerns about the conduct of this research, please contact Dr Gerald Harrison, Chair, Massey University Human Ethics Committee: Southern B, telephone 06 356 9099 x 83570, email humanethicsouthb@massey.ac.nz .

Appendix B: Help numbers



Support for Caregivers

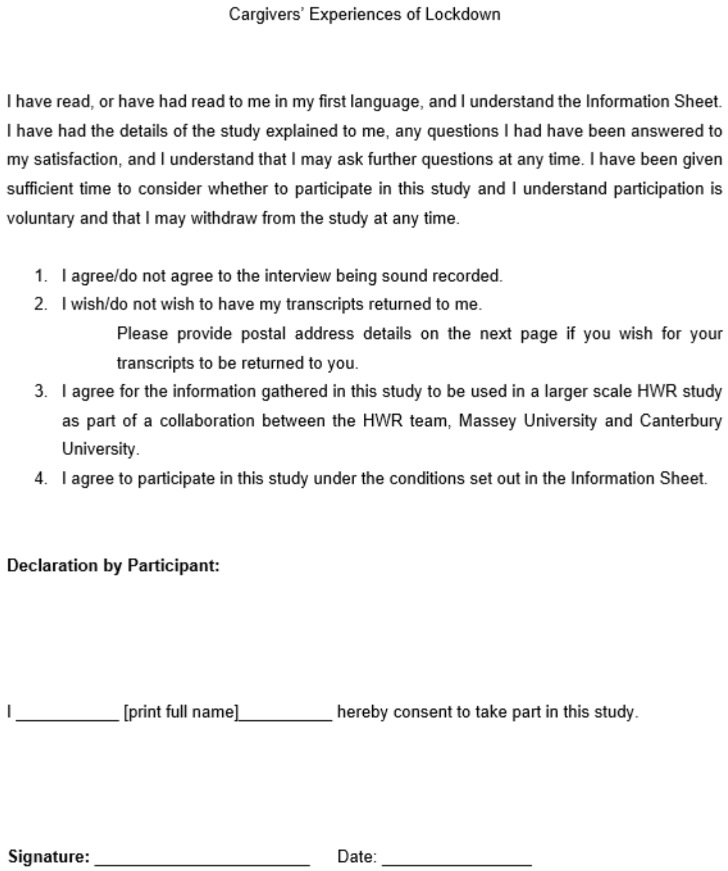
Please note these interviews are to understand caregivers' experiences in relation to COVID-19 and that the researcher is not qualified to offer support. If you feel you need extra support, please contact one of the numbers below:

Care on Call
0800 664 422

Plunketline
0800 933 922

Covid-19 Helpline
0800 358 5453

Appendix C: Participant consent form



Cargivers' Experiences of Lockdown

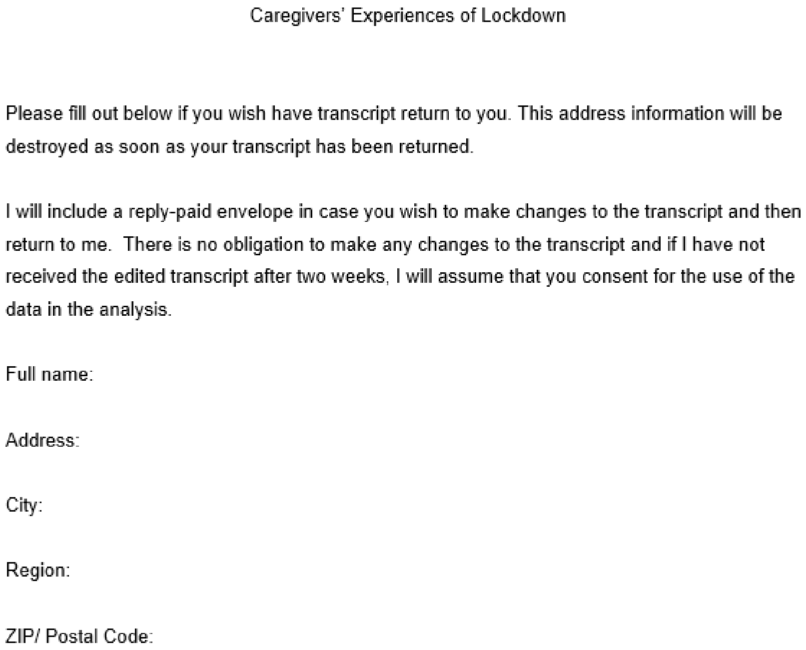
I have read, or have had read to me in my first language, and I understand the Information Sheet. I have had the details of the study explained to me, any questions I had have been answered to my satisfaction, and I understand that I may ask further questions at any time. I have been given sufficient time to consider whether to participate in this study and I understand participation is voluntary and that I may withdraw from the study at any time.

1. I agree/do not agree to the interview being sound recorded.
2. I wish/do not wish to have my transcripts returned to me.
   Please provide postal address details on the next page if you wish for your transcripts to be returned to you.
3. I agree for the information gathered in this study to be used in a larger scale HWR study as part of a collaboration between the HWR team, Massey University and Canterbury University.
4. I agree to participate in this study under the conditions set out in the Information Sheet.

Declaration by Participant:

I ___________ [print full name]__________ hereby consent to take part in this study.

Signature: ______________________ Date: _______________



Caregivers' Experiences of Lockdown

Please fill out below if you wish have transcript return to you. This address information will be destroyed as soon as your transcript has been returned.

I will include a reply-paid envelope in case you wish to make changes to the transcript and then return to me. There is no obligation to make any changes to the transcript and if I have not received the edited transcript after two weeks, I will assume that you consent for the use of the data in the analysis.

Full name:

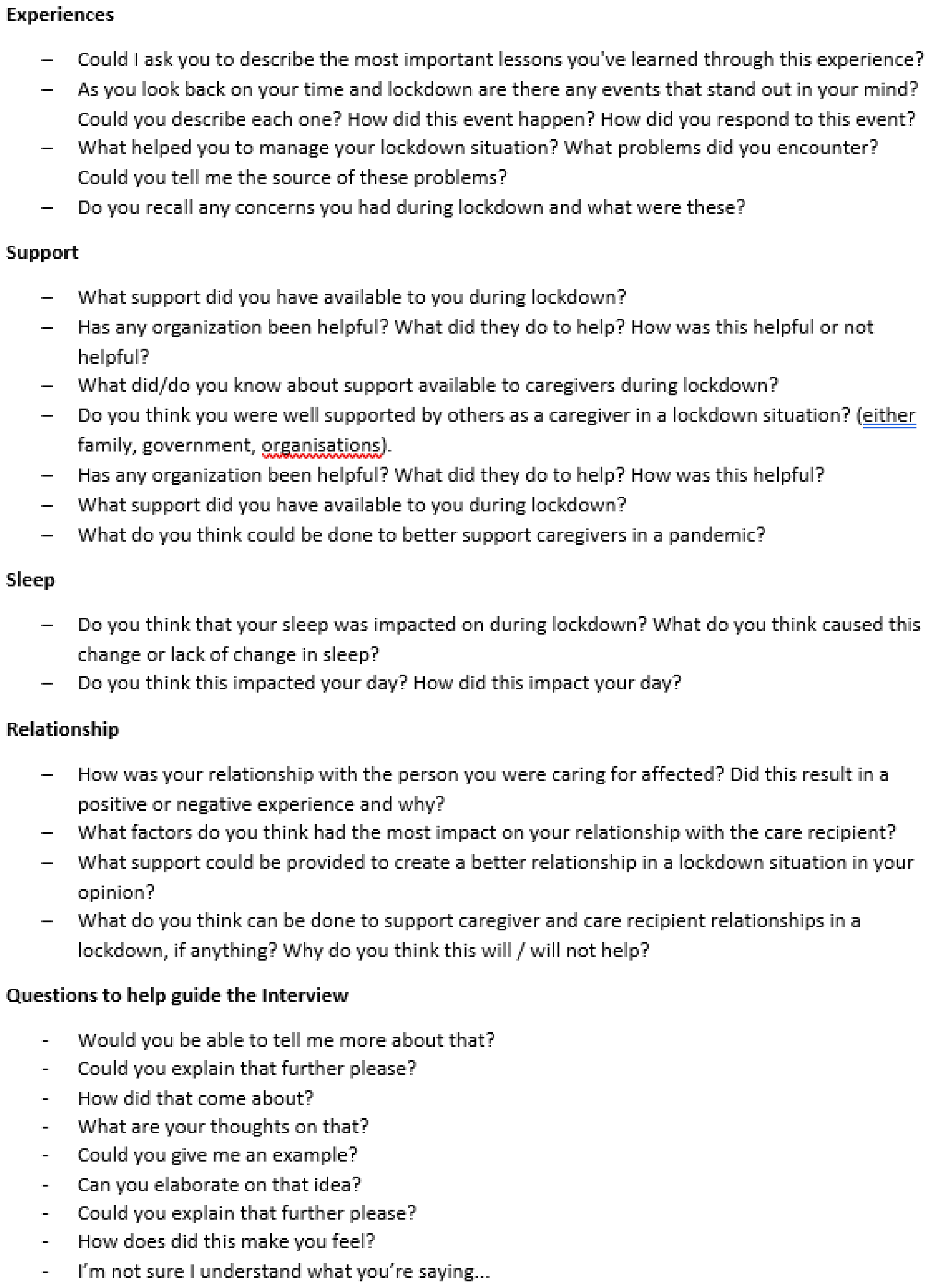
Address:

City:

Region:

ZIP/ Postal Code:

Appendix D: Interview questions and layout



Experiences

- Could I ask you to describe the most important lessons you've learned through this experience?
- As you look back on your time and lockdown are there any events that stand out in your mind? Could you describe each one? How did this event happen? How did you respond to this event?
- What helped you to manage your lockdown situation? What problems did you encounter? Could you tell me the source of these problems?
- Do you recall any concerns you had during lockdown and what were these?

Support

- What support did you have available to you during lockdown?
- Has any organization been helpful? What did they do to help? How was this helpful or not helpful?
- What did/do you know about support available to caregivers during lockdown?
- Do you think you were well supported by others as a caregiver in a lockdown situation? (either family, government, organisations).
- Has any organization been helpful? What did they do to help? How was this helpful?
- What support did you have available to you during lockdown?
- What do you think could be done to better support caregivers in a pandemic?

Sleep

- Do you think that your sleep was impacted on during lockdown? What do you think caused this change or lack of change in sleep?
- Do you think this impacted your day? How did this impact your day?

Relationship

- How was your relationship with the person you were caring for affected? Did this result in a positive or negative experience and why?
- What factors do you think had the most impact on your relationship with the care recipient?
- What support could be provided to create a better relationship in a lockdown situation in your opinion?
- What do you think can be done to support caregiver and care recipient relationships in a lockdown, if anything? Why do you think this will / will not help?

Questions to help guide the Interview

- Would you be able to tell me more about that?
- Could you explain that further please?
- How did that come about?
- What are your thoughts on that?
- Could you give me an example?
- Can you elaborate on that idea?
- Could you explain that further please?
- How does did this make you feel?
- I'm not sure I understand what you're saying…

Research Questions

For the reasons identified in the literature above I propose these research questions:

1. What are the experiences of older informal caregivers in a pandemic situation in New Zealand?
1. What are the needs of older caregivers in a pandemic situation in New Zealand?

Establishing rapport

Introduction

- Introduce myself
- Explain purpose of interview
- Ensure consent has been given
- Confirm that the interview will last for one hour
- Give participants the option to introduce themselves
  - What is their caregiving situation like?
  - How long have they been caregiving?
  - Were they a caregiver prior to the pandemic?

Initial opening questions

- When did you first experience caregiving during a COVID-19 lockdown?
- Did you experience caregiving in more than one lockdown?
- Who was with you during lockdown?
- Could you describe the events of caregiving during lockdown to me?
- Do you remember what you felt during the lockdown? Or how being in lockdown influenced you?
- Tell me about what happened in lockdown and how you came to cope?
- Did your view on caregiving change before lockdown compared to after and how may this have changed?
- What most contributed to this change for you?
- What contributed to challenges / stress you experienced during lockdown(s)?

Intermediate questions

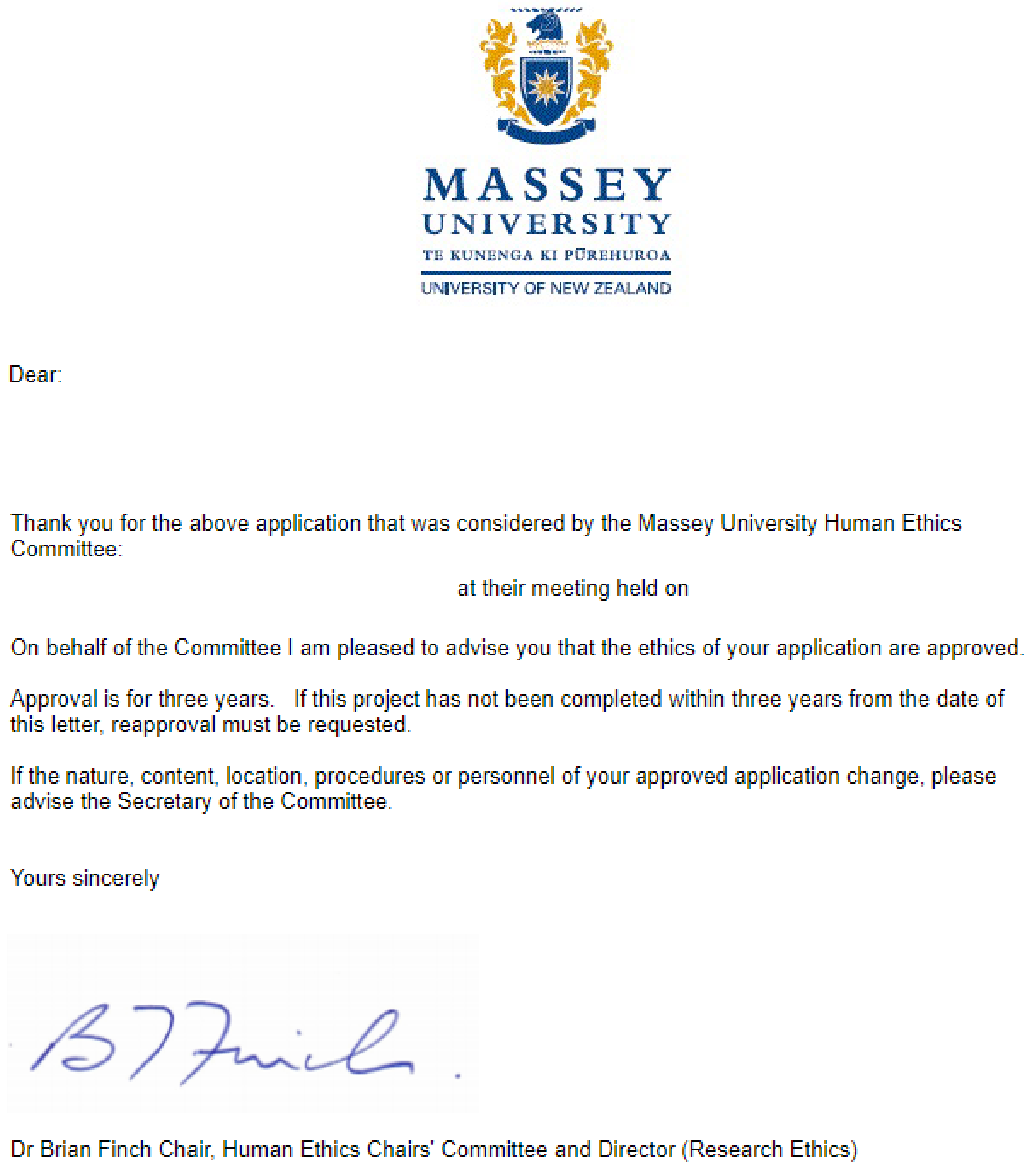
Daily Life

- Could you describe a typical day for you when you are in lockdown?
- How did your daily life change due to lockdown and what challenges did this create?
- If you recall, would you be able to tell me how you adjusted to a lockdown situation as a caregiver?
- What positive changes if any have occurred in your life due to caring in a lockdown situation?
- What negative changes if any have occurred in your life due to caring in a lockdown situation?

Ending questions

- Can you tell me how your views on caregiving may have changed since lockdown?
- Is there anything else that is important to understanding your experience of caregiving during COVID-19?
- After having these experiences what advice would you give somebody?
- Is there anything you would like to ask me?

Appendix E: Ethics approval letter



MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA
UNIVERSITY OF NEW ZEALAND

Dear:

Thank you for the above application that was considered by the Massey University Human Ethics Committee:

at their meeting held on

On behalf of the Committee I am pleased to advise you that the ethics of your application are approved.

Approval is for three years. If this project has not been completed within three years from the date of this letter, reapproval must be requested.

If the nature, content, location, procedures or personnel of your approved application change, please advise the Secretary of the Committee.

Yours sincerely

Dr Brian Finch Chair, Human Ethics Chairs' Committee and Director (Research Ethics)