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Support for Working Informal Carers Before and During the COVID-19 Pandemic

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Abstract

New Zealand's aging population, changing family and workforce dynamics have implications for working informal carers. Increased demand for informal care coupled with extended working life and governmental promotion of "aging in place" raises issues regarding appropriate supports and infrastructure to accommodate this expanding societal area of need. This qualitative research explores how working informal carers in New Zealand experienced support before and during the COVID-19 pandemic.

An inductive phenomenological approach was used to explore the support experiences of 10 adult working informal carers in paid employment while caring for a person aged 65 years and over. Semi-structured interviews were conducted online via video call or by telephone. The interview data was analysed using thematic analysis, from which several themes were developed. Salient themes included: invisibility and disinterest, disconnected services and difficulty accessing support; the importance of relationship and connection for the caring role and support systems; and the interconnectedness of support systems. The findings were explored in the light of existing research and considered societal, relational, and work supports as well as support implications caused by the COVID-19 pandemic.

The research findings are relevant, add value, and further, the literature regarding working informal carers support in Aotearoa New Zealand. As evidenced through this study and previous research, working informal carers are an essential cohort for society. Further related research could include raising awareness, growing knowledge on how to provide adequate services for all working informal carers, including diverse cultural groups, and engaging carers who do not self-identify as working informal carers.

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Glossary

Māori Word Definitions

The following definitions were directly sourced from Moorfield, J. C. (2011). In *Te Aka Māori-English, English-Māori Dictionary and Index* (3rd ed.). Pearson.

<https://maoridictionary.co.nz/>

Manaakitanga:

Hospitality, kindness, generosity, support - the process of showing respect, generosity, and care for others.

Tikanga:

Correct procedure, custom, habit, lore, method, manner, rule, way, code, meaning, plan, practice, convention, protocol - the customary system of values and practices that have developed over time and are deeply embedded in the social context.

Te Tiriti o Waitangi:

The Treaty of Waitangi.

Whakapapa:

Genealogy, genealogical table, lineage, descent - reciting *whakapapa* was, and is, an important skill and reflected the importance of genealogies in Māori society in terms of leadership, land and fishing rights, kinship and status. It is central to all Māori institutions.

Whānau:

Extended family, family group, a familiar term of address to a number of people - the primary economic unit of traditional Māori society. In the modern context the

term is sometimes used to include friends who may not have any kinship ties to other members.

Iwi:

Extended kinship group, tribe, nation, people, nationality, race - often refers to a large group of people descended from a common ancestor and associated with a distinct territory.

Hapu:

Kinship group, clan, tribe, subtribe - section of a large kinship group and the primary political unit in traditional Māori society.

Marae:

Courtyard - the open area in front of the *wharenui* (*meeting house*), where formal greetings and discussions take place. Often used to include the complex of buildings around the *marae*. Also, can refer to Kinship group, clan, tribe, subtribe - section of a large kinship group and the primary political unit in traditional Māori society.

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Figure 1: Support for Working Informal Carers Before and During the COVID-19

Pandemic

Table 1: Participant Contextual Details

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Chapter One: Introduction and Literature Review

As world populations age, there is an increasing emphasis placed on the corresponding impact on social and fiscal considerations at a societal, familial, and individual level (Elliott & Parker, 2012). An area of concern, specifically for the working adult providing informal care, is balancing work and informal care. As population and family structures shift and change, this highlights the importance of informal care and the need for appropriate support structures and attention to those who provide such care.

For many countries worldwide, informal care augments and complements governmental public health care structures (Phillips & O’Loughlin, 2017). This foundation of support contributes to reducing the public health burden in resource terms and has considerable benefits for care recipients as reflected by enhanced outcomes, lowering avoidable hospital readmission, and formal care placement (Elliott & Parker, 2012; Grimmond, 2014; Spillman & Long 2009). However, increased demand for informal care in tandem with extended working life and governmental promotion of “aging in place” raises employment, community, and family issues regarding appropriate supports and infrastructure to accommodate this expanding societal area of need.

Informal Care

Informal care is non-paid unofficial non-professional care provided by relatives, friends, and acquaintances to support a member with physical and or psychological health issues, disability, or old age fragility (Kia Piki Ake Welfare Expert Advisory Group, 2019). Informal care is grounded on the relationship between the carer and care recipient, which encompasses social and practical elements of daily life. However, informal care provision surpasses typical cultural relationship expectations (Centre for Policy on Ageing, 2015).

Informal care is characteristically multidimensional, which means its practical day-to-day care aspects should not be considered in isolation from its inherent relational ties (Cass et al., 2009). Pickard (2004) considers it crucial to understand the relational contextual aspect of informal care. This understanding is essential because obligation, reciprocity, and attachment may blur what constitutes and differentiates carer duties from standard relational patterns (Cass et al., 2009; Goodhead & McDonald, 2007). Such care is encapsulated in a normalised structure of accountability, commitment, and responsibility (Centre for Policy on Ageing, 2015). However, care is work, whether formal/informal or paid/unpaid, and distinctions between these intertwined facets are shaped by communal perception and government policy which is also not static (Cass et al., 2009; Goodhead & McDonald, 2007). It has been noted that providing informal care has far-reaching impacts and costs in both the public and private arenas of living. For example, caregiving can impact potential employment opportunities such as advancement, education, up-skilling, and social networking (Centre for policy on ageing, 2015).

The Informal Carer

Informal Carer Demographics

Demographically informal carers have a diverse representation; however, most are typically family members and frequently working-aged women (Kia Piki Ake Welfare Expert Advisory Group, 2019). Who undertakes an informal carer role is often determined by many factors such as established relationships, societal norms, accessibility, and proximity (Kia Piki Ake Welfare Expert Advisory Group, 2019). While there is often a primary informal carer within a family or caring network in most cases, many families share the load of caring, which is particularly relevant to note for some cultural contexts

(Ang & Malhotra, 2018). Situations can be very variable, with some providing intergenerational care (i.e., children, adults, and older adults), and or as well as working either full time or part-time (Kia Piki Ake Welfare Expert Advisory Group, 2019).

The Working Adult and Informal Care

Recent international research shows an increased number of older working adults provide informal care in tandem with rising higher intensity caring, resulting in subsequent impacts on their wellbeing and standard of living (Phillips & O'Loughlin, 2017).

According to Yeandle and Buckner (2017), many of the English caring cohort aged 50-64 years provide informal care while also in the workforce. Numerous studies suggest that most working informal carers would like extra support to help with their work/care balance (Arksey et al., 2005). Arksey and associates (2005) found that informal carers who had left work to provide informal care often regretted this decision. Moreover, many individuals solely providing informal care expressed the desire for a return to employment after caring duties eased or finished but thought this would be problematic (Arksey et al., 2005).

There can be many different caregiving scenarios for the informal carer, such as caring for someone living in another dwelling, caring for multiple persons across generations, providing care as a consistent arrangement, or providing variable care hours per day or week (Yeandle & Buckner, 2017). While it is common to care for parents, many care for other members of their family/friend networks such as a parent-in-law, partner, disabled adult child, sibling, neighbour, or a friend (Yeandle & Buckner, 2017).

This research project focuses on the working informal carer and their support experiences before and during the COVID-19 pandemic. The literature review covers various important aspects relating to this topic, such as cultural implications, gender, and

informal caring impact on work, finances, health, and wellbeing. It considers support systems in the family, friend, and work domains and considers government and workplace policy. Furthermore, it provides an outline of worldwide and New Zealand contexts regarding working informal carers. Finally, it includes a brief outline of the COVID-19 pandemic and its implications worldwide and for New Zealand.

Cultural Implications

National policy regarding informal carer support needs to recognise the entwined nature of ethnicity, cultural norms, gender, and the demographic diversity that influences the providing and receiving of informal care (Lapsley et al., 2019). Certain cultures have different standards and expectations surrounding informal care and support, and these can vary in salience between and within cultures. For example, the New Zealand 2013 census statistics revealed a markedly greater representation of women than men providing informal care, and this was consistent for both European and Māori New Zealanders (Grimmond, 2014). Other cultural contexts that highlight diversity in caregiving include Asian, Māori, and Pacific Island groups. For example, many Asian cultures consider family and family fealty foremost over the individual (Mehta, 2006). For Māori, whānau is central, with iwi, hapu, and the marae being significant for informal carer support, networking, wellbeing, and identity (Collins & Willson, 2008). Moreover, for some Pacific Island nations, the role of the family is paramount, and traditional family ideals mean that informal care provision is preferred over formal support provisions (Tamasese et al., 2014). It is noted that these are among some of the cultures represented in New Zealand's population's diversity. Hence, the range of cultural ideals may mean that different support methods may be more beneficial than others; for example, expressive social support may

be more welcomed over practical or formal supports (Ang & Malhotra, 2018). This could be due to work disruption by care duties as being perceived to be outside of one's control (Ang & Malhotra, 2018). However, while many factors contribute to good wellbeing and health, for indigenous people, it is observed that cultural identity is fundamentally important (Durie, 1999).

Lapsley and associates (2019) assert that while plenty of research has covered cultural differences surrounding family interaction, roles, responsibility, approach to sickness, aging, death and dying, there has been less focus on cultural diversity regarding informal caregiving and its effects. This dearth is also reflected in New Zealand literature regarding Māori caregiving, as there is more comprehensive research regarding whānau and relationships rather than caregiving (Lapsley et al., 2019). However, this could be because informal caregiving duties can easily be rendered invisible due to a cultural and societal view of family obligation and reciprocity that extends to the whole whānau and greater network (Collins & Willson, 2008). Due to differing saliency of needs, there can also be a contrast in caregiving approaches between Māori and European New Zealanders (Lapsley et al., 2019). For example, Māori caregivers assist with spiritual support, advocating, and broader family networking alongside typical caregiving duties (Lapsley et al., 2019).

New Zealand 2013 census statistics show the diversity of our nation concerning caregiving: For example, higher numbers of New Zealand European and Māori provided informal care against other ethnicities, Pacific Islanders have a greater tendency to provide informal care for household members but less so for non-family (maybe reflective of family structure and culture), other ethnicities including Asian, were shown to provide

informal care less often. However, when doing so, men were higher represented than women (Grimmond, 2014).

As shown by various studies, a universal issue for all informal carers is the dismissal of the caring role as important and disregard for its influence on the care recipient when seeking associated services, dealing with health organizations, and public agencies (Collins & Willson, 2008). It has been noted that concerning caregiving, Māori generally have well-established support networks (Collins & Willson, 2008). This could be because such roles are culturally important, and caregiving is commonplace across generations (Collins & Willson, 2008). For informal carers of all ethnicities, formal support systems, such as respite care, play a strong role in reducing overburden and providing assistance (Kia Piki Ake Welfare Expert Advisory Group, 2019). However, accessibility and culturally appropriate delivery are issues for Māori and other minorities in New Zealand (Kia Piki Ake Welfare Expert Advisory Group, 2019; Collins & Willson, 2008).

Gender

In contrast to other worldwide research, and while a small sample representation, New Zealand studies have found that men combining employment and informal care had worse psychological health than their counterparts (Alpass et al., 2017). This effect could be due to societal perception surrounding gender role norms, which may cause men to hesitate to identify as a carer because of diminished recognition in this typically feminine typecast role (Greenwood & Smith, 2015). This lowered recognition of their care role could lead to less support seeking (an effect already noted) or impact support availability and relevance for men fulfilling such roles (Greenwood & Smith, 2015). However,

international research points to a greater extent of disadvantage and negative caregiving impact and paid employment experiences (both perceived and real) on women who are working informal carers (Dentinger & Clarkberg 2002; Henz, 2006).

For the older working adult informal carer, caregiving has different impacts for men and women regarding retirement considerations (Alpass et al., 2017). A sizable portion of working women informal caregivers experience conflicting demands due to multiple roles, which can lead to reducing work hours or leaving the workforce to accommodate care (Evandrou & Glaser, 2003). Previous research notes the greater likelihood of women informal carers occupying lesser ranked positions, earning a lower income, experience greater employment history interruption than men, and ending paid employment when working in less qualified positions (Henz, 2006). For both genders, providing informal care while working has a high chance of progressively affecting health and financial status, particularly for women through present disparities (Goodhead & McDonald, 2007). In New Zealand, non-means-tested government superannuation is available to older working adults at age 65, which may help decrease the financial disparity between the sexes (Alpass et al., 2017).

Research shows several gender differences for working-age carers. For example, research shows that women are more likely than men to provide informal care, be the primary caregiver, assist with personal assistance and daily life activities, experience higher intensity care, work more care hours, and provide informal care for multiple people (Bernard & Phillips, 2007). It was found that men more often cared for one person at a time (Singer et al., 2010; Bernard & Phillips, 2007). However, while women tend to provide caregiving duties more than men throughout the life cycle, this appears to start

even out in older age, with more men providing informal care when over 65 years of age (Vlachantoni et al., 2013). The research also appears to support that population aging may change the gender dynamics of informal caregiving as more older men take up the care of aging family members (Phillips & O'Loughlin, 2017).

Other gender differences between men and women for working adults providing informal care included women tending to leave the workforce when caring for a partner (Carr et al., 2018). Also, upon beginning intensive caregiving, women are inclined to work less because of caregiving needs (Carr et al., 2018). It has been suggested that participation in caregiving and the above behaviours are shaped by societal norms surrounding gender, family, and work roles (Carr et al., 2018). However, previous research has found there may be gender differences in reaction to the caregiving burden; for example, older men tended to postpone retiring in order to meet caring financial demand while women provided at-home care for the person with care needs (Dentinger & Clarkberg, 2002). Numerous studies have found that working-age women in full-time employment may find informal care both physically and psychologically draining; hence family/work support is essential for women to avoid burnout (Juratovac & Zauszniewski, 2014).

Longitudinal research on aging in New Zealand showed that women provide more care than men (Lapsley et al., 2019). This balance may be attributed to societal norms around gender and role expectations, women living longer than men, and tending to be younger than their male partners (Lapsley et al., 2019). The 2013 New Zealand census showed the following: Informal carers tend to be older than the average adult, the average carer age is growing faster than the national average age, the ratio of women carers is more than double that of men (63%), and that European and Māori provide the most family

caregiving (Grimmond, 2014). These statistics are supported by research in New Zealand, Australia, England, and Canada, which showed that more women than men provide informal care, which is also reflected in contribution levels (Goodhead & McDonald, 2007).

Working Informal Caregiver Work/Care Impact and Support

Work/Care Impact

Working Informal carers have the extra challenge of simultaneously balancing care and work domains that impact time, resources, and capacity and can cause conflict in both arenas (Gordon et al., 2012). There has been an association between work/family discord and imbalance with poorer health for working informal carers (Yildirim & Aycan, 2008; Alpass et al., 2017). This interconnection and disequilibrium between work and care are also reflected in the work domain, with many carers working fewer hours, having more absence days, or discontinuing work altogether (Heitmueller & Inglis 2007; Longacre et al., 2017). Also, it is common for working informal carers to experience problems in professional advancement, training, and work opportunities (Centre for Policy on Ageing, 2015). These employment effects are worse for women than men due to unstable career direction and lower earnings (Centre for Policy on Ageing, 2015). Furthermore, other research points to a possible need for more support for those working carers who live with their care recipient, as it was shown they experience higher adverse effects than those who do not (Carr et al., 2018). These effects could be due to more intense caregiving duties and less choice regarding care provision as living in the same residence (Carr et al., 2018).

Impacts of informal caregiving on work depend on the type of employment. Some positions may have more flexibility than others due to the nature of the industry and level

of employment. For those in shift work, hospitality, and lower-income positions, care/work juggling can be problematic (Bernard & Phillips, 2007). Work timetable inflexibility and pressures impact informal carers and increase the need for solid support systems (Longacre et al., 2017). Research shows that many working informal carers tended to use allotted sick leave, annual vacation leave, or take unpaid leave to cover their care responsibilities (Goodhead & McDonald, 2007). Bernard and Phillips (2007) found that while informal caregivers acted to reduce care impact on work, it had more significant consequences for their social life.

The options of flexible hours, working at home, or opportunity to manage workflow coupled with formal structures such as work policies that cater for work-life balance and arrangements to facilitate carer's needs can provide much needed support for working informal carers (Goodhead & McDonald, 2007; Bernard & Phillips, 2007; Kia Piki Ake Welfare Expert Advisory Group, 2019). These can also benefit organizations with less absenteeism, higher productivity, and employee retention (Bernard & Phillips, 2007). Canadian and US research has pointed to the need for community support services, and workplace supports surrounding informal care to be cohesive and in partnership (Bernard & Phillips, 2007).

Workplace and corporate culture are not always cohesive with workplace policies and or practices that promote life balance, for example, long working hours, time equated to productivity, little regard to family concerns, work pressure, and outward appearance of coping (Bernard & Phillips, 2007; Sahibzada et al., 2005). Such work culture can limit working carer's support seeking and promote sharing a personal caring situation to employers only when in crisis (Bernard & Phillips, 2007; Sahibzada et al., 2005). In their

study, Bernard and Phillips (2007) noted that this suppression of sharing to employers about elder family care contrasted to sharing about childcare.

Research has found that for some informal carers, instead of work promoting further stress, it served to mitigate overburden due to the caring role (Arksey, 2002; Fuller & Raman, 2019; Eurofound, 2015). However, according to research by Bernard and Phillips (2007), this may apply to carers who did not need to work but who were able to choose to continue working while providing informal care. Also, it was noted that these working informal carers voiced that through their jobs, they had learnt valuable coping mechanisms, which in turn were beneficial in their caring role (Bernard & Phillips, 2007). While working benefits the working informal carer financially, it can also provide opportunities for networking, job satisfaction, and personal growth (Plaisier et al., 2015; Asksey, 2002). Moreover, when both roles do not interfere with each other, work can bolster the informal carer (Plaisier et al., 2015; Asksey, 2002).

Much research has shown that employers and working informal carers tend to be solution focused regarding work and family balance (Bernard & Phillips, 2007). New Zealand research has found that many working informal carers considered their employers to be generally accommodating regarding their caregiving circumstances (Bernard & Phillips, 2007; Alpass et al., 2017). While it is noted that many working informal carers have difficulty in maintaining work/care balance, many consider their employer, manager, work colleagues to be flexible and understanding (Bernard & Phillips, 2007). In considering this, Plaisier and associates (2015) also noted that when working informal carers felt supported in their working situations, there was a greater chance of better work

results. Plaisier and associates (2015) recommended that organizations show explicit consideration and awareness of their needs and caring situations.

Financial Impact

Working informal carers can face financial repercussions and additional stress due to care duties disrupting work which can result in the following: missed professional advancement and opportunities, leave without pay, lost employment benefits, reduced life earnings and resources, as well as the need to retire ahead of time (Neal & Wagner, 2002; Longacre et al., 2017). For 2013, census statistics showed that the average New Zealand informal carer was aged 49 years (Grimmond, 2014). As most people are established in their working careers by this age, providing informal care at this age has implications for earning and saving power (Neal & Wagner, 2002; Longacre et al., 2017). Furthermore, 2013 census statistics also showed that household earnings of informal carers were on average 10% lower than their counterparts despite both showing similar inclinations regarding paid work, qualification, and occupation skill levels (Grimmond, 2014). However, these statistics also showed that the informal carer had a higher propensity to work part-time (Grimmond, 2014).

Health and Wellbeing

Due to the dual roles of work and informal care, the working informal carer has a higher risk for negative psychological, emotional, and physical health consequences (Kia Piki Ake Welfare Expert Advisory Group, 2019). The New Zealand Longitudinal Health, Work and Retirement Study found that greater caregiving intensity was associated with worse psychological health for carers, especially regarding depression and anxiety (Alpass et al., 2017). Qualitative studies have called attention to the physical impact caregiving can

exert on carers and outlined less healthy living styles resulting in tiredness, low energy, poor eating, and exercise habits as a factor (Goodhead & McDonald, 2007). For the working carer, psychological and emotional issues have been shown to increase as their care duty intensifies, pointing to the negative effects of caregiving accruing as time passes for people in these dual roles (Longacre et al., 2017).

Support

Social support has been defined as the actual or perceived provision of care, assistance from other informal (family and friends), and formal contexts of support networks, groups, or relationships (Gottlieb & Bergen, 2010; Seeman, 2008). This care can be emotional, instrumental, or informational (Gottlieb & Bergen, 2010). These types offer different support aspects. For example, emotional support can help with feelings of being loved, understood, and bolster self-esteem (Gottlieb & Bergen, 2010). In contrast, instrumental support is the more practical and tangible help (i.e., getting the groceries). Lastly, informational support refers to the passing on helpful knowledge or facts (Gottlieb & Bergen, 2010). The expression and appraisal of social support are determined by cultural, contextual, individual factors (Gottlieb & Bergen, 2010).

Support – Family and Friend Networks

The multiple supports of family and friend networks and workplace support all have their place in impacting the working informal carer's functioning, health, and wellbeing (Ang & Malhotra, 2018). According to Shiba and associates (2016), social networking with family and friends as individuals separate from their caregiving duties is vital for the informal carer. This acknowledgment of the carer for who they are as a person is important and lends credibility to any support provided for them regarding the care they

provide (Shiba et al., 2016). As balancing work and care can both be intense, both social and emotional support and practical help from family/friends and workplace networks can be influential in protecting the working informal carer from overburden (Shiba et al., 2016; Ang & Malhotra, 2018).

It has been suggested that when circumstances are perceived as out of one's control, that emotional support is more salient than a practical approach (Ang & Malhotra, 2018). Ang and Malhotra (2018) suggest that work disruption from care duties may be seen as outside one's control because the caring role can be inconstant and unpredictable regardless of planning. As this appears to be culturally bound, it could be reversed for some cultures, hence with work perceived as being less controllable than the care duties (Ang & Malhotra, 2018; Utz et al., 2012). A lot of the literature surrounding social support for the working informal caregiver suggests that emotional, expressive support has a more direct beneficial effect on mental wellbeing than other social support types (Utz et al., 2012). Shiba and associates (2016) found that informal social support was linked to significantly less caregiver stress, whereas formal support forms were not so much. They observed this effect between family and friend networks, and in some formal networks, notably from the general practitioner, which likely points to the significance of relationship. Research has shown that the positive influence of social support from family/friend networks seemed to be irrespective of whether the carer had formal social support or not (Shiba et al., 2016). Possibly this could be due to using professional services or assistance primarily for information or practical help without expecting expressive support (Shiba et al., 2016). However, research on family and work roles by Gordon and Rouse (2013) suggested that these roles can differ in importance to the carer. This differing

importance may mean that interference with the prominent role is likely to cause greater distress than for the other (Gordon & Rouse, 2013). Hence the context and type of support will depend on how effective or helpful it is perceived to be (Gordon & Rouse, 2013).

Support and the Workplace

Much literature focuses on workplace working informal carer policy and practices that aim to decrease work/family conflict, for example, flexible working hours, alternate modes of work, working from home, time off in lieu, and annual leave (Ang & Ang & Malhotra, 2018). However, there is much less research about social support in the workplace (Ang & Malhotra, 2018). However, while organisations have these practical provisions, they can cater more for workers with children and less so for those informally caring for older adults who have a higher probability of work/care clash (Gordon & Rouse, 2013). Studies have shown that many working informal carers only utilise a small range of available organisational support, which may be due to hesitancy to highlight their caregiving situation to their employer (Bernard & Phillips, 2007).

However, the working informal carer may also find further social support at work, such as information sharing from colleagues or access to therapy which could help bolster and enhance their caregiving role (Sahibzada et al., 2005). It is suggested that organisations factor expressive support into their support policy and practices support as many working informal carers have a high need for this alongside formal assistance (Ang & Malhotra, 2018). Research regarding respite care by Utz and associates (2012) pointed to the need for flexible organizational policies that consider caregiving duties and allow time out for reconnection with family and recreation.

Aside from organizational policies surrounding leave and flexibility, aspects that can help the working informal carer are work-related help, supportive managers, colleagues, and good working relationships (Kim et al., 2011). Work obstacles for the working informal carer include being short-staffed, excessive workload and demands, unaccommodating work colleagues, and work travel distance (Bernard & Phillips, 2007). Outside the workplace, supportive family and friends can help alleviate care stress; however, unsupportive family attitudes further add to pressure for the carer (Bernard & Phillips, 2007). Conversely, Lapsley and associates (2019) found that New Zealand working informal carers generally regarded informal caring to be positive and felt privileged to provide such care. Their research showed that facilitating work and care balance for working informal carers involves a combination of informal and official support and a practical, psychological, and emotional influence (Lapsley et al., 2019).

The Working Informal Carer and Policy

Due to population aging effects, such as a projected increase in informal and formal care needs alongside reducing workforce participation, many countries are looking to implement policies that promote aging in place and extend working life (Schofield et al., 2006). Such policy is centred on the concept of ‘positive aging’ and ‘aging in place,’ where individuals head into old age and are encouraged and supported to live in the community (Phillips & O’Loughlin, 2017). Most older adults prefer this option, and it is also a government preference as it can alleviate the economic burden of public care services (Phillips & O’Loughlin, 2017).

Due to New Zealand’s aging population, one effect is that there will be older aged working informal carers (Alpass et al., 2017). According to Phillips & O’Loughlin (2017),

a fundamental concern is that even with extended working life, how does the older working adult support the projected increase of those older adults with health needs, old age frailty, or disability? Research has found that working informal carer governmental and organizational support policy tends to largely focus on workers with young families and be less relevant for those caring for older adults or adult children with disabilities (Bernard & Phillips, 2007). Research confirms that working informal carers can face earning and professional advancement opportunity costs (Goodhead & McDonald, 2007). In addition to this, carer leave policy is usually inadequate, especially if care duties are continual and interminable (Goodhead & McDonald, 2007).

Despite differing societal and political nuances, investigating other countries' responses to the issue of working informal carer support may inform policy design and implementation for more effective response (Phillips & O'Loughlin, 2017). International research has shown several common care themes, for example, the central influence of family, the relevance of gender norms regarding care, and noting national standards of living to be relevant (Phillips & O'Loughlin, 2017). Concerning the working informal carer, policy response and implementation vary between countries, as shown by the following examples: For example, democratic countries such as New Zealand, Australia, and the United Kingdom offer a carer benefit and flexible work options (Goodhead & McDonald, 2007); Singapore has foreign domestic worker legislation to arbitrate family fealty and help support family care provision (Mehta, 2006); caregivers in China have a high reliance on family as there is minimal governmental and organizational support (Pei et al., 2017); and finally, as mentioned earlier, some Pacific countries centre around

traditional family ideals and rely on family support over formal arrangements (Tamasese et al., 2014).

Research confirms the need for policy and procedures (i.e., occupational supports, improved grants) and more formal support resources and services available communitywide to lessen pressure on working caregivers (Phillips & O’Loughlin, 2017). As support needs differ, such caregiver support needs to reflect individual, family, and paid employment situations and pay attention to those at risk of inequality due to pre-existing disparity or over-representation demographically (Carr et al., 2018).

Context

International and General Context

Population aging is occurring worldwide due to improved life expectancy and mortality rates, health care innovations, improved welfare and living standards, impacting employment age populations (Carr et al., 2018). While it is a fine accomplishment for populations to experience increased longevity, which is also projected to continue to grow, this presents significant implications for societies worldwide (Phillips & O’Loughlin, 2017). There is an increased expectation for older working adults to informally care for family members as governmental policies seek to extend working age due to anticipated reduced employment base as population demographics change (Carr et al., 2018). It has been noted that the demands of informal care responsibilities and paid work often compete and can place much pressure on family relationships, social networks, finances, and psychological/physical health, quality of life, and wellbeing (Phillips & O’Loughlin, 2017). According to research, there has been growth in higher intensity informal care and an increase in older working age adults providing informal care (Yeandle & Buckner,

2017). However, research also shows that as informal care grows, this leads to decreased supply of older aged workers Carr et al., 2018). Governmental policy is increasingly looking at options and incentives to counter the effects of population aging. These measures include: having older workers extend employment, flexible work policy, increases in government pension age entitlement, support of self-financed superannuation plans, over-reliance on government superannuation, and promotion of consumer managed age care services (Gill and Cameron 2015; Chomik and Piggott 2012; Phillips & O'Loughlin, 2017).

The New Zealand Context

According to Statistics New Zealand (2019), New Zealand's approximate population is 4.9 million, and ethnic demographics sit at approximately 70.2% European, 16.5% Māori, 15.1% Asian, and 8.1% Pacific (Statistics NZ, 2019). Census New Zealand 2018 statistics also showed that those aged 65 and over constituted 15.2% of the total population and that the working age represented 65.1% of the population at this time (Massey University, n.d.). By 2036, it is estimated that people aged 65 and over will be represented by one in 4.5 persons of the population, approximately a 77% increase from 2016 (Ministry of Social Development, n.d.). This trend of increasing older age is shown by further predictions that the 65 and over age group (calculated at 15.2% in the NZ Census 2018) will approximately double by 2046 and be approximately 23% of the total population (Ministry of Social Development, n.d.).

The implications of New Zealanders having a longer life expectancy include the associated prevalence of older age chronic illness, disability, and fragility (Alpass et al., 2017). Previous studies note that the ratio of older New Zealand adults entering formal care

is decreasing (Boyd et al., 2011). Those who do are older and have higher needs than previously, which impacts informal carers (Boyd et al., 2011).

Further statistics show that many New Zealand carers are family members with a high representation of working age females (Grimmond, 2014). According to New Zealand 2013 census results, 13% of New Zealand's adult populations were informal carers with statistics for this group as follows: proportionally 63% were female, the highest representation was for the 50-53 age range, and the median age was 49 years, and approximately 65% informal carers are also in paid employment (Kia Piki Ake Welfare Expert Advisory Group, 2019). With the proportion of older workers in paid employment expected to continue growing over the next 20 years, there will be many people still working and providing informal care as they also age (Alpass et al., 2017).

The rise in New Zealand's aging population, as shown by the above statistics, coupled with other trends like changing family dynamics, increasing female employment, and predicted decline in the working age population, could mean fewer available informal carers (Kia Piki Ake Welfare Expert Advisory Group, 2019). At the same time, demand grows. These factors, alongside public policy promoting aging in place, extended working life, and later superannuation, likely will lead to the expectation of combining employment with informal care duties (Kia Piki Ake Welfare Expert Advisory Group, 2019). Informal care provided by family networks will be more commonplace, which gives rise to concern that the increased societal burden of care placed on people and their families may not be supported by adequate formal resources and services (Maidment, 2016). Of note is the impact this may have on specific sectors of society, for instance, those already facing

disparity and inadequate service accessibility, the disabled, and gender-wise for women informal carers as they have the highest representation.

The COVID-19 Pandemic

The beginning of 2020 saw the World Health Organisation announce COVID-19, a coronavirus disease caused by the virus SARS-CoV-2, at pandemic status on 11 March 2020 with over 4000 deaths and 114 countries impacted (World Health Organisation, 2020; Cascella et al., 2020). A pandemic is a widespread disease outbreak that is pervasive, with regional or global impact (Ministry of Health, 2017). This current coronavirus, thought to originate from the wildlife trade, was discovered in Wuhan, China (Cascella et al., 2020). It was classed as a Public Health Emergency of International Concern in January 2020 (Guo et al., 2020).

COVID-19 is a viral disease belonging to the coronavirus cluster (also known to cause disease in animals) along with influenza, Middle East Respiratory Syndrome (MERS), Severe Acute Respiratory Syndrome (SARS), and the common cold (Cascella et al., 2020). It is very infectious with a high risk of transmission for all. However, it appears to have a higher rate of morbidity and mortality incidence for older people and those with compromised health status or pre-existing conditions (Guo et al., 2020). It usually presents with symptoms like influenza, typically with a mild gradual beginning however some may contract it and be asymptomatic (Ministry of Health, 2020). While most recover without specialized care, some are severely affected by respiratory difficulties and complications (Cascella et al., 2020).

New Zealand's Initial COVID-19 Pandemic Response

New Zealand declared lockdown on 25 March for four weeks (longer if required) to contain and eradicate COVID-19 (New Zealand Government, 2020). Without such measures, including self-isolation/quarantine, social distancing, or working from home, the outbreak would have been exponentially worse considering the impact seen in other countries such as Italy who had experienced high rates of infection and death (Ministry of Health, 2020). The lockdown aimed to help flatten the curve and prevent severe overloading of the countries health system and resources by slowing down and hopefully eradicating COVID-19 (New Zealand Government, 2020).

Impacts of the COVID-19 Pandemic on the Working Informal Carer

For working informal carers, the impacts of COVID-19 and the subsequent lockdown pose new hardship and exacerbate existing difficulties and stress. Informal care duties can be challenging even in usual circumstances. This pandemic can negatively impact caregiving duties and the subsequent wellbeing of themselves and their charges in numerous ways. Some areas include intensified pressure and frequency of daily duties, managing work/care duties, access to needed resources, higher stress, isolation, and limited connection (Schulz & Eden, 2016; Phillips et al., 2020). Due to the nature of caregiving and the fact that many aspects of it cannot be automated or outsourced, COVID-19 has intensified and increased the workload of informal carers (Phillips et al., 2020). The pandemic and its subsequent lockdowns have impacted the informal carers' workload. It has influenced and limited previously available support options such as respite care or assistance now deemed not essential or unavailable due to lockdown or short supply.

The Covid-19 pandemic further highlights the gaps regarding care in our society and policies pertaining to eldercare. Such experience due to an outbreak is unprecedented in modern society; nevertheless, informal carers carry out care duties as they did previously. However, with less formal support and assistance than the demand for care, statistics show and government policies advocate for ‘aging in place’ show increasing numbers needing care and trends for this to grow and the working care pool to shrink as population aging increases. Informal family carers increasingly provide this care and the private sector as government policy and investment in this area fails to meet demand. Nonetheless, there are still benefits of ‘aging in place’ where older adults and vulnerable members of society remain with their families and community until it is no longer possible. Families and informal caregivers can have some control in attempting to prevent COVID-19 infection; they can limit contact where needed. However, it becomes an issue when these carers and family cannot manage.

This research sets out to explore how working informal carers in New Zealand have experienced support before and during the COVID-19 pandemic. It specifically investigates the support experiences of the participants involved who were working and providing informal care to a care recipient aged 65 and over.

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Chapter Two: Methodology and Method

Methodological Approach

This project used a qualitative perspective and applied an inductive phenomenological approach to inform understanding. It is grounded in interpretative ontology and epistemology, which covers what may be known about the world and how this may be recognised (Mayan, 2009). Phenomenology is orientated toward human perception and experience, and it seeks to understand the personal experience of the world as seen and described by an individual (Dew, 2007). In considering several working informal caregivers' first-hand experiences of support, this research aimed to gain insight into how they perceive, describe, make sense of, and remember their experiences. The phenomenological approach frequently uses thematic analysis as a method to uncover meaningful patterns (themes) throughout a set of qualitative data (Mayan, 2009). Its design seeks to make known a phenomenon's meaning and its ramifications through the person's distinct experience of it (Grant & Giddings, 2002).

Method and Procedure

Participants

The participants were adult informal caregivers who also were in paid employment, either full or part-time. If their work situation had changed due to COVID-19 disruption, they were still eligible to participate in this project. Another criterion was that the care recipient was aged in the 65 and over age group or have serious underlying health issues in which COVID-19 could have caused severe consequences. Participants were required to live and work in Aotearoa/New Zealand and be comfortable with the English language.

Since New Zealand's population is aging, this research focused on working caregivers caring for persons aged 65 and over. This age bracket was chosen to reflect current population demographic trends while noting that there will be more in this age group requiring care as the population ages in Aotearoa New Zealand. Regarding the COVID pandemic, this age group, especially those aged over 70 years of age, were considered high-risk. Old age frailty, existing medical conditions, or disease further compounded risk.

At the time of interviewing, all participants were in paid employment with six working full-time, four part-time (20+ hours a week), two self-employed or working flexible hours, and three on paid leave (government subsidy) for most of the initial COVID-19 lockdown. The lockdown timeline was as follows: New Zealand was put into COVID-19 alert system level 4 national lockdown (virus likely not contained) on March 25, 2020, and this was downgraded to alert system level 3 (high-risk virus not contained), with partial restriction on April 27, 2020, and further downgraded to alert system level 2 (limited community transmission and clusters), with the aim to reduce on May 13, 2020. New Zealand's COVID-19 alert system ranged from alert system level 1 to 4 (See Appendix A).

The majority of the participants were in the mid 40s – mid 50s age bracket, with one exception who was in the 70s age bracket. A range of ethnicities was represented, which included Māori/European, English, Pacifica, Indian, Seychellois, and five with New Zealand European heritage. Eight of the care recipients were family, and two were friends, and all were in the 65-85 age range. Six participants cared for a parent, one for a spouse, one for a sibling, and two were providing care for a friend. Half of the participants had

school children. One person cared for his father while also providing care for his spouse and had three school-aged children. Four participants lived in the same residence as their care recipient, while others provided care for a person living in the community at another residence. Three participants had health complications or vulnerabilities of their own, which also put them in the vulnerable high-risk group for COVID-19. Care recipients' conditions included old age frailty, dementia, heart and blood pressure issues, and limited mobility.

Recruitment and Participant Selection

Participants were recruited through advertisement (See Appendix B) on appropriate caregiver websites, newsletters, magazines, blogs, and social media communities. These networks, agencies, and communities (e.g., Carers NZ, Dementia New Zealand, and Aged Concern) were approached for permission to advertise in their channels and provided with information regarding the project (See Appendix C). In addition, a Facebook page was set up solely to recruit participants using the same advertisement, which was targeted to people who were working and informally caring for older care recipients. Potential participants were able to contact the researcher independently and confidentially. When a potential participant showed interest, they were emailed a copy of the information sheet (see Appendix D). Any further questions or concerns regarding the research and its procedure were also answered. When a person agreed to participate in the research, and before their interview, it was ascertained that they understood the project details and were happy to continue. Oral consent was obtained at the beginning of the interview (See Appendix E).

The sample size was 10 participants. For the size of this project, approximately 10 participants were considered an ideal number to obtain a comprehensive understanding, insight, and conceptualisation of the subject matter (Braun & Clarke, 2006).

Ethical Considerations

Ethical concerns included: Consideration of Te Tiriti o Waitangi (the Treaty of Waitangi); informed consent; confidentiality/privacy; manaakitanga (the showing of hospitality and respect for others); autonomy; nonmaleficence/beneficence; information provision about harm; and possible lockdown distress. See Glossary for Māori word definitions.

Te Tiriti o Waitangi and Māori cultural principles (i.e., tikanga, whakapapa) were considered with the support of a cultural advisor. The advice provided me with a greater understanding of tikanga (the correct customary system of procedures, practices, and protocols within Māori culture). In this instance, as interviews were required to be conducted online or over a telephone call, the importance of introduction, acknowledging whakapapa (the genealogy and ancestry of the participant and their whānau), as well as making room for extended whānau (family) and support to be present was especially considered. Also, regarding showing cultural respect, it was important not to assume and be informed by the participant regarding what they were comfortable with concerning their cultural needs.

Potential participants were informed about the research project by an information sheet (See Appendix D). Any further queries were answered, after which they could decide if to consent to take part. Participant informed consent for participation, recording, transcript release was obtained orally at the beginning of the interview recording.

Attending to confidentiality/privacy involved digital information being password protected, maintaining participant and employer/workplace confidentiality, using pseudonyms instead of real names, and identifying information not to be transcribed. Transcripts were stored in a secure location.

Manaakitanga (showing of hospitality, respect for others, including meeting face to face) was difficult due to COVID-19. However, zoom conference and telephone calls still offered the opportunity for korero (conversation) and building of whakawhanaungatanga (the forming and strengthening of relationship through working together). Providing time to build rapport, gain acquaintance, read transcripts together, and the provision of the research summary conveyed consideration, respect, and care for the participants. The opportunity was also provided for the inclusion of a support person/s in the interview.

Consideration of participant autonomy was shown by providing study details in layperson terms, which outlined the research goals and its process, and by answering any related questions to ensure clear understanding before their commitment to participate in the interview. Regarding nonmaleficence/beneficence, there was no harm anticipated. However, if participants wished to or found it beneficial, they were offered appropriate support services information in the research information sheet (See appendix D). Consideration was also given to lockdown effects, and if participants had experienced any distress, appropriate support service information was offered.

Interview and Data Collection

Type of Interview. A semi-structured interview was used to gain insight into the participant's experience of being a working informal caregiver, and enabled the participant to express their feelings and ideas relating to the topic and their experiences. This interview

type was chosen to promote depth and richness in interviews and encourage attentive listening and communication that flows two ways (Josselson, 2013; Anderson & Jack, 1991). Part of this is due to open-ended questions that allow participants to express and explain their answers (Willig, 2008). A flexible interview schedule (See Appendix F) was used that facilitated open-ended queries and subsequent follow-on questions and comments to elicit deeper understanding and clarification (DeJonckheere & Vaughn, 2019; Willig, 2008). Particular care was given to relationship and rapport so the participant could express themselves as needed while being gently guided on the topic (DeJonckheere & Vaughn, 2019). While this interview type allows for the collection of open-ended information and a deep understanding of experiences or phenomena, it is recognised that results may not be able to be generalised to working informal carers outside this study (Braun & Clarke, 2013).

Due to COVID-19 restrictions and for participant safety, interviews were conducted online via Zoom or as a telephone call. It was recognised that there were some benefits and disadvantages in using a virtual medium. Some benefits include: the convenience of scheduling a phone or zoom call over a face-to-face meeting, it makes proximity a non-issue, and it can afford a sense of control and a measure of anonymity which can make it easier and more comfortable for participants to share (Braun & Clarke, 2013). However, there can be downsides, such as it may be harder to establish a good rapport, one may miss subtle nuances of body language, and involvement may be limited to those who can afford to be online (Braun & Clarke, 2013). In this instance, concerning any internet-based participant interviews, security was considered (Braun & Clarke, 2013).

Timewise, the interview and participant interaction were on average approximately 1.5 hours, with the pre-interview conversation at approximately 20 minutes, 30 to 50 minutes for the interview, and reading the transcript with the participant approximately 20 to 30 minutes. A draft of the interview transcript was emailed to the participant for editing and feedback with further discussion as required. Participants were not expected to spend more than 2 hours of their time on the project.

Prior to the interview, time was spent with each potential participant to build rapport, discuss the project, answer queries, and ascertain any cultural needs. Attention was paid to participant cues and to making the video view welcoming and safe. For telephone-based interviews, it was ensured that these were conducted in a quiet environment with no interruption and that privacy and confidentiality were respected. If the participant was undecided about participation, a time frame for deciding was negotiated. All participants had the opportunity to have a support person/s with them for the duration of the research process. Most of the participants preferred interviewing via telephone call; however, three participants shared their experiences via Zoom video/audio conferencing, which has built-in recording facilities. Interviews were participant-led and conversational, with minimal questions asked and only if needed to open new directions within the conversation. The telephone interviews were recorded with a mobile phone voice recorder application. Formal verbal informed consent (including transcript release of use) was obtained at the beginning of recording (See Appendix E).

Interview Procedure. Prior to the interview, time was spent with each potential participant to build rapport, discuss the project, answer queries, and ascertain any cultural needs. Attention was paid to participant cues and to making the video view welcoming and

safe. For telephone-based interviews, it was ensured that these were conducted in a quiet environment with no interruption and that privacy and confidentiality were respected. If the participant was undecided about participation, a time frame for deciding was negotiated. All participants had the opportunity to have a support person/s with them for the duration of the research process. Most of the participants preferred interviewing via telephone call; however, three participants shared their experiences via Zoom video/audio conferencing, which has built-in recording facilities. Interviews were participant-led and conversational, with minimal questions asked and only if needed to open new directions within the conversation. The telephone interviews were recorded with a mobile phone voice recorder application. Formal verbal informed consent (including transcript release of use) was obtained at the beginning of recording (See Appendix E).

Data Analysis

Transcription

Recorded interviews were transcribed with the assistance of the Sonix program. While this software was not always consistent in translating the New Zealand accent, it made the task quicker. It was beneficial to have the audio connected directly to its transcription. This feature aided with both checking for accuracy and nuance while analysing the interview data. When completed, the interview was sent to the participant to read, discuss, and provide feedback. They were given two weeks to respond, upon which, if no response, the transcript was deemed in order. Participants were able to withdraw at any point of the research until the release of transcripts. If they had any reservations about participating after reading their transcript, again, a time frame was negotiated with them to allow the opportunity to decide.

Reflexive Thematic Analysis

Reflexive thematic analysis was Reflexive thematic analysis was used to distinguish relationships or associations of meaning that helped provide a greater understanding of working caregiver experiences before and during the COVID-19 pandemic. Due to its flexibility, this form of thematic analysis is particularly suited to inquiries about an individual's experiences, perceptions, or views on a particular phenomenon (University of Auckland, n.d.). Hence it worked well with the phenomenological approach used in this research as it is intentionally designed specifically for work within a qualitative paradigm (Braun & Clarke, 2013). The objective of the analysis was to deliver a cogent and persuasive interpretation that was centred on and in the research data (Braun et al., 2018). An inductive approach was used to allow the interpretation of salient themes. In this context, themes were the patterns of meaning found in the data as interpreted by the researcher to capture the essence of an idea relevant to the research question. Therefore, the use of an inductive approach allowed for analysis to be guided by the participant's experiences and what was important to them. Taking this approach meant the interference of any bias or supposition was reduced along with any other influences such as the researcher's preceding ideas regarding the subject (Braun & Clarke, 2006).

This reflexive thematic analysis process involved thorough familiarisation with the data set to code, develop, and revise categories and subsequent themes guided by the data content to answer the research question. As a method of analysis, it was acknowledged that the integral active involvement of the researcher in code making, and theme development influenced the subsequent output. It was recognised that the interpretation was coloured by

the researcher's ideology and theoretical approach, cultural background, belief systems, and social status (Braun, et al., 2019). The importance of researcher self-awareness (i.e., personal perspectives and positioning) and reflexivity regarding data interpretation were highlighted.

The research data, which consisted of the interview transcripts, was handled according to the thematic analysis framework as developed by Braun and Clark (2006). Firstly, to get familiar with and know the data as fully as possible, it was read numerous times, and any subsequent early ideas or thoughts were noted. The next step involved noting down any interesting or relevant ideas related to the subject and grouping them as they appeared throughout the entire dataset. In this manner, the data was systematically coded to describe the content as directed by the researcher's interpretation of salient patterns throughout the data set related to the research focus. Hence these patterns, also known as themes, were established within and across the data set with relevant codes grouped accordingly. Then, these potential themes were reviewed and amended as necessary to ensure that they made sense and that the coded data followed through for each theme and the interview data as a whole. Finally, the themes were established, named, and described in preparation for the last step of reporting.

To assist in the coding of the interview data, NVivo 12 software was initially used to help structure and systematically code the interview data. It was helpful in that the transcripts and coded data were stored in one place and easily reviewable, accessible, and that the information was kept secure. However, as the research progressed, the codes became manually considered, grouped under broader themes, crosschecked, and regrouped, if necessary, as analysis progressed.

On completion of the research, participants were provided with a summary of the project findings. Participating and interested networks, Carers NZ, Dementia New Zealand, and Aged Concern were offered a summary of findings and presentation of the final report.

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Chapter Three: Results

Brief Description of Participants

Details of the participants' living and caring arrangements are provided in Table 1. All 10 participants were middle-aged or older, with the majority in the early 50s age range. Seven participants were women, and three were men. It must be noted that any identifying details, such as occupation, have been omitted.

Three of the participants, Ava, Freda, and Isla, were employed full-time; two, Ben and Cole, were self-employed; and the remaining five, Dora, Emma, Grace, Helen, and Jack, were employed in part-time work. Their living arrangements varied. Four participants, Ava, Ben, Grace, and Jack, lived with a spouse; one, Isla, lived alone; four, Cole, Dora, Emma, and Helen, lived with their spouse and school-aged children; and one, Freda, lived with her spouse, school-aged children and two other family members.

The care recipient living arrangements were as follows: Four of the participants, Ava, Ben, Freda, and Grace, provided live-in care in their home; five, Dora, Helen, Isla, and Jack cared for a person who lived in their own dwelling nearby; and one, Cole cared for a person who lived in their own dwelling out of town.

Six participants, Ava, Ben, Cole, Emma, Freda, and Helen, cared for a parent; two, Dora, and Jack cared for a friend; and one, Isla, provided care for a close family member. The care recipients' ages ranged from 65 to 88 years of age. Their conditions ranged from: old age frailty; onset, moderate, and advanced dementia; stroke; and frailty resulting from a medical condition.

Table 1*Participant Contextual Details*

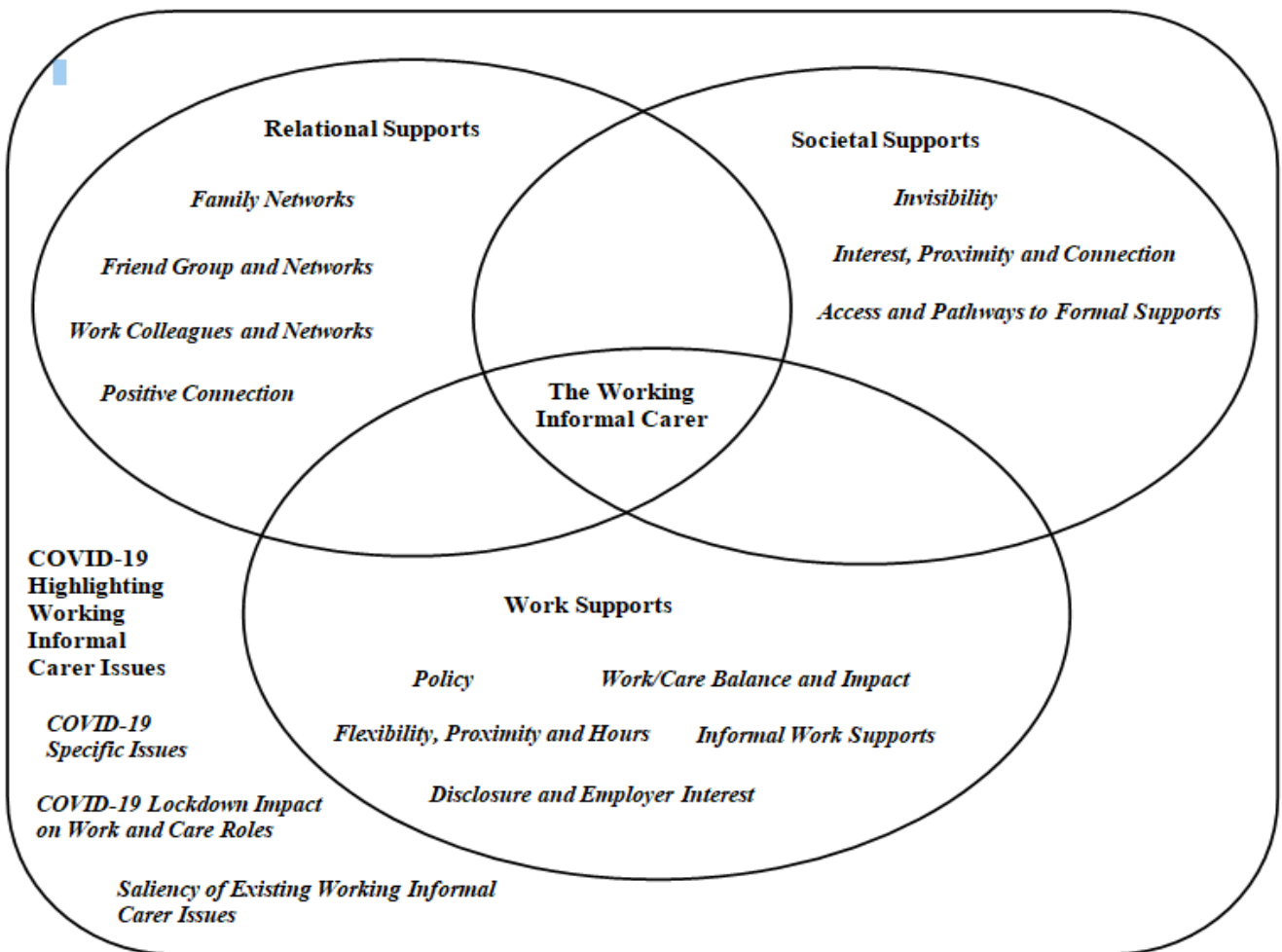
Name (Pseudonym)	Living Relationship	Care Recipient Details	Care Recipient Condition	Care Living Arrangement
Ava (female) Full-time	Husband	82 years old Mother-in-law	Advanced Dementia	Same abode
Ben (male) Self-employed	Wife	82 years old Mother	Advanced Dementia	Same abode
Cole (male) Self employed	Wife 3 school aged children	88 years old Father	Old age frailty	Own dwelling, out of town
Dora (female) Part-time	Husband 2 school aged children	Mid 70s age Friend	Medical condition and frailty	Own dwelling, same location
Emma (female) Part-time	Husband 2 school aged children	82 years old Father	Old age frailty Onset Dementia	Own dwelling, same location
Freda (female) Full-time	Husband, 5 school age children 2 other family	77 years old Mother	Old age frailty	Same abode
Grace (female) Part-time	Husband	75 years old Husband	Advanced dementia	Same abode
Helen (female) Part-time	Husband 3 school age children	Mid 70s age Father	Moderate Dementia	Own dwelling, same location
Isla (female) Full-time	Single	65 years old Family member	Stroke	Own dwelling, same location
Jack (male) Part- time	Wife	82 years old Friend	Old age frailty Onset Dementia	Own dwelling, same location

Overview

Ten interviews were analysed. While each participant's experiences and situations were unique, several recurrent and key themes were identified in the thematic analysis process. These key concepts were considered fundamental to understanding the experiences of working informal carers regarding support and throughout the COVID-19 pandemic. These themes were: 'Societal supports', 'Relational supports', and 'Work supports'. Further consideration was given to the way the COVID-19 pandemic highlighted existing issues for working informal carers. It is noted that some facets of the participant responses weave across these themes. Similarly, some of the themes had aspects that intersected with different avenues of life, such as work, family, social networks. This highlights the overarching relational interconnected aspect of informal caregiving, which was seen in the interview data. Hence themes and their sub themes for this project were structured to consider both the interconnected impact on life domains for the working informal carer, the family and community contexts in which they are involved, as well as policy and support issues from a societal perspective. Regarding the carer specifically, the impact of balancing work and caregiving on different life domains such as health, family and personal relationships, social life, and work/career was considered. As shown in Figure 1, this analysis recognises the interconnectedness of societal, relational, and work supports for the informal working carer and how COVID-19 impacted and highlighted carer issues.

Figure 1

Support for Working Informal Carers Before and During the COVID-19 Pandemic



Societal Supports

A strong theme was societal supports. This theme encompassed the community context in which the participants lived, the support available, and how it impacted their circumstances. Some subthemes were labelled: 'invisibility', 'interest, proximity and connection', and 'formal supports' within this theme. The 'invisibility' subtheme was concerned with societal expectations, perception, and attitudes regarding providing informal care as well as the participants' perception of their care giving role and how this was valued. 'Interest, proximity and connection' focused on such aspects as

acknowledgment and interest of the caring role and societal assumptions regarding informal care giving. Finally, regarding formal support in the community, there were several relevant issues such as: risk; regulatory mechanisms, and responsibility; rural versus city supports which covered issues surrounding opportunities and resources; and finally, disjointed and fragmented services, which looked at knowing the system, access, and reliability.

Invisibility

An important subtheme was the invisibility of the caring role, which included the implications of societal attitudes and recognition of the caring role, for example, the value of housework; carer role incongruence; implications of not being paid; and understanding of care giving.

Societal Attitudes and Recognition of Care Role. Unpaid work such as caregiving (attending to practical, physical, and emotional care needs) and particularly housework is not always appreciated or recognized as valued work. An element of this was seen through the interviews in how participants spoke concerning their care duties. It seemed that attending to household chores such as vacuuming was viewed as not a big deal. For example, regarding the mundane everyday aspects of care, one of the participants, Jack (pseudonym) mentioned, “But what I do for him actually is simple things. Yeah, just mopping floors, vacuuming. Just I mean, all of that stuff is very simple”. While these comments reflected the willingness to care, such comments were interpreted as the participants seeing these tasks as trivial. However, in congruence, participants also pointed out the necessity and value of some of their care tasks for the care recipient. This was seen in the following comments from Jack when further outlining what he did for his friend:

Jack: But I also take him to the doctor when required... I was taking him to those appointments and getting groceries. It's really important because he has no car... I just help him out. It is as simple as that.

The overarching impression was the care the participants afforded their family and friends they were caring for. It was important. Some of the tasks were viewed as 'simple', but the accumulation of care and making sure their loved ones were safe, warm, clean, and happy was important.

The societal expectation that family looks after family was highlighted in the data as a common sentiment throughout the interviews. For example, Cole stated simply, "It is what you do". He went on further to say, "So it does impact on work and income and all that sort of thing. But you know, he is your dad, so you do what you do".

In many instances, the participants appeared not to consider the care giving tasks they were providing for their loved one equating to work: They are doing what anyone would do for a person they care about or simply as part of a family. The overarching impression was the care the participants afforded their family and friends they were caring for. It was important. Some of the tasks were viewed as 'simple', but the accumulation of care and making sure their loved ones were safe, warm, clean, and happy was important.

The Implications of Not Being Paid. Relevant to this theme of invisibility was the lack of acknowledgment and recognition afforded to the informal caring role as it was unpaid work. Regarding this one participant mentioned it specifically:

Isla: In normal events, and obviously I can't say categorically, is that in a lot of cases, clients or family or whānau accept a person who's doing it [caring role] because they're paid with a little bit more respect.

Understanding. One notable concept was the reference to first-hand experience and understanding of what it was like to provide informal care. This reference came up in many of the interviews as well as across contexts. The lack of others understanding the dynamics of care appeared to come up in many of the interviews and across contexts. For one of the participants, who cared for his mother, who had advanced dementia, this lack of understanding was evident when discussing care arrangements with others. When talking about deciding to have his mother come live with him and his wife, Ben spoke of how people were surprised they had not done this earlier: “So everyone is saying you should have done it six months ago. But she wasn't in a place to come in her own free will without dragging her here”. His comments illustrate how other people did not quite understand some of the dynamics of care, such as the autonomy of the care recipient and how care needs can be progressive in nature.

Several participants stated that unless another person is involved in providing informal care in a similar circumstance, they just do not know what it was like. For example, concerning other people's understanding, Cole said, “We are just kind of at this stage; we are just doing it ourselves. I don't think people understand. You can tell your friends or whatever about the back issue, but no one can really understand”. Further comments regarding friend networks showed there was the assumption that friends could not fully understand the experience. Ava who was caring for her mother-in-law at home spoke of having friends over and of the proclivity to shield her due to lack of awareness:

Ava: Well, our friends are really lovely, and they are very good with her. But the thing is. I know really her well now... So, yeah, I find myself being a little bit

protective of her actually, with other people around... They don't really understand the situation fully. And we don't expect them to as they are friends of ours.

It seemed typical that some of the participants just did not expect their friends to understand fully. The expectation for friends and others to understand when they had not experienced informal care was low. As with Ava, Grace highlights this in her comments:

Grace: I think people if they are not actually living with the person, they don't really understand. And one of Walter's supporters took him on holiday. And she could see what he was really like. If you are not really in that situation, you don't really understand.

Three of the participants worked in the health and care profession and they mentioned how providing informal care was different to providing formal paid care:

Isla: In my case because I am in the primary health sector, there were things that I automatically knew, because I'm dealing with it every day. But nevertheless, when you suddenly become 'that person' yourself, that takes it to a whole different level.

Even with knowledge of the caring role, it was found to be different if in that position yourself first-hand:

Isla: Both from a theoretical position and also checking those things out for many of the clients that we have passing through our organization... It's a whole different matter when you are an informal carer for one of your own family.

At work, having managers who understood or had experienced a comparable situation was valued as it also could translate into tangible work support. Having a manager who understood what it was like to care for a parent in a rest home was valuable. For example, Ava talks about her manager, who had recently been involved in caring for her father as he was declining. She felt that because her manager had been through this experience, that her manager would have empathy for her if she required extra support at work, such as unplanned leave:

Ava: So, she was often out visiting him through the day when he was awake and things like that. So, it would be 100 percent fine if I needed to shoot out and do something, I would totally have the ability to do that.

Interest, Proximity and Connection

A common theme that overlaps different life domains with implications for the public, work, family, and social arenas is interest, proximity, and connection. This subtheme refers to the societal aspects of relating that the participants noticed regarding their caring roles. How people showed support or interest depended on familiarity, living distance (same or different city/town), and how well acquainted they were with the care recipient. If a family member, friend, work colleague, or other did not have a relationship with the care recipient or were not involved, there was less interest or acknowledgement of the caring role. It appeared that interest was linked to the strength of the relationship with the care recipient. One participant, Ava, found that one of the hardest things was a lack of family interest and corresponding support. She and her husband had recently taken in his mother, who needed more hands-on care. It had been a few months, but his siblings had not

contacted their mother or enquired how she was doing or if it was working well having her live with them. They had not heard much from them at all. Ava had not expected the low interest considering it was their mother, was unaware that they were so distant, and was saddened:

Ava: They have not rung her to see how she is or rung us to see how she is or kept in touch. It's just horrible really. They are just so shocking.

Rachel [researcher]: I have heard that can be a big issue, like between siblings.

Ava: Yeah, like trying to do the right thing by her. And it just puts things in not a very nice light really.

For some participants, a lack of interest could also be seen in friend and acquaintance networks. For example, when Jack was asked about the response people had regarding him providing care, he said: “Well nobody really... except for like his [Fred’s] immediate neighbours”.

The informal caregivers also talked about societal assumptions regarding informal family care in the home, which may be specific to their own limited experiences. For example, when Ava was asked if there were people who understood her situation, she said, “I think so. I mean, we are pretty unusual, really, in the sense that most people don't actually bring their elderly parents into their home”. However, this participant considered it normal for older frail members of the family who needed care to be in facilities such as a rest home.

Access and Pathways to Formal Supports

There was much discussion surrounding formal support and the participants’ experiences of navigating the system, access to services, communication issues, reliability,

and the usefulness of these support services. Topics seen in the interview data set included: risk management and regulatory mechanisms; rural versus city support options and access; issues with the system being fragmented, which highlighted issues around knowing the system, poor referrals, access, and reliability.

Responsibility, Risks, and Regulatory Mechanisms. The participants reflected the weight of their responsibility in caring for their loved ones. It was easy to feel alone in it; however, it made a significant difference when there was support. Several of the participants found that sharing of the duties and responsibility helped. For Ava and Emma, informal teamwork made a difference. However, when there was strong formal support, it made a notable difference. For example, another participant was relieved that district nurses called to check on his friend as this provided 'another set of eyes'. Likewise, other participants worried about what they would find upon returning from work and for their loved one's safety. For Isla, a primary concern was the risk and regulatory mechanisms regarding the responsibility of informal care giving. She was the principal carer for a member of her family while also working full time. Her comments below highlight her disquiet:

Isla: And, you know, having oversight of a huge amount of primary health services which involves, you know, checks and balances, and health and safety, with all of those ramifications, compliances/accreditations, keeps me alert, to risk.

Rachel [researcher]: When you're doing it as an informal carer...

Isla: You do not have that exact accountability. And for me, that is a great concern on behalf of not just what I was doing, but I really saw first-hand why informal carers become very worn down very quickly.

Isla: And there were issues for me as an informal carer, that when I shut the door and rushed off to work, I always felt a sense of less than satisfaction. If it had been under the auspices of a registered home help arrangement, then there are checks and balances. Informal care is actually in my view, totally exposed.

Rachel [researcher]: Yes.

Isla: And that concerned me greatly...If you are an informal carer, you are carrying all the responsibility.

Rural Versus City Supports. Another issue that came up across interviews was that access and available support services for informal caregiving were dependant on location and catchment area size. Helen comments on this below:

Helen: Different health catchment areas have more opportunity for groups, for support and things like that, where we don't. And I think we lack that. But it is because we live in a smaller area. I think sometimes it would be nice if there were more support groups. But there are just not.

Rachel [researcher]: Yes. So, it is different to be in a rural town compared to a city town, is what you are saying?

Helen: Yeah, pretty much. I mean, it's just that there's more money in the big centres. And there more support available really right across the board for all aspects really, of health and education.

However, Helen considered the services provided to be mostly adequate, “I think that it probably is as much as anybody really gets”. This could also be interpreted as because it was provided by the public health system, expectations were low. Another participant also mentioned that rural locations may have less access to resources, agency intervention and support:

Isla: So, there are all kinds of little aids and things which, you know, today, in terms of health and disability resources, they are sparse. Particularly in a predominately rural region, very sparse. So again, an informal carer is faced with sorting all those issues out yourself. You don't necessarily have agency intervention, support, or meaningful facilitation.

Another issue Isla mentioned that was an issue for rural locations versus central city locations was travel distance. When asked if her experience providing care in a smaller locality was different to a larger central locality, she said “Oh, without a doubt. Without a doubt, because the travel alone has been a major problem for many of the [paid] carers”.

Disjointed and Fragmented Services. A theme that showed across the interview data was how fragmented and disjointed the system was in New Zealand and how it was challenging to navigate if not familiar with it. Two factors were highlighted: knowing the system, and inadequate referral and misinformation.

Concerning information and service channels, a couple of participants found that knowing someone who knew the system did help a lot. Regarding initial inquiries into support options, Emma mentioned: “Kind of helpful to have someone that is a bit onto it”. For others such as Isla, who was familiar with the health system, it was easier with this

knowledge. When asked if her work experience had helped, she replied, “Yes, absolutely. I knew what was absolutely within the realm of possibility. I could ensure that that happened by going directly to the agencies ... thus saving huge time and effort”.

A few participants had found that some of the information they had received was inadequate or not relevant for their situations. For example, Grace had experienced poor referral and misinformation. It was hard to hear Grace outline her experience of trying to get help to keep herself safe when her husband (diagnosed with dementia) had exhibited violent behaviour. It was concerning that she was referred to Womens Refuge as dementia issues would be better dealt with at a specialised dementia support facility.

Grace: I did, actually I did get a bit of help from the women's centre. Because [my husband] did get violent toward me and I was terrified.

Grace: And the GP referred me to the Women's Centre.

Rachel [researcher]: Yes.

Grace: But, you know, they did connect me with a social worker, but she didn't help me at all. She just made everything worse.

Rachel [researcher]: Just made it harder?

Grace: Yes.

Navigation, Access, and Reliability of Formal Systems. A common issue was navigating the system to get support. Lines of communication was one issue as described by Isla below:

Isla: I have noticed a lot of people have said that they don't know where to go.

They don't know. It's so just fragmented. They go to a certain person, say their GP,

and they just not referred on to different parts. The system seems overloaded.

People don't know what is available to them or where to go and sometimes even how to begin to find supports.

Access to formal supports was also an issue. If a person was not familiar with the agency and its responsibilities, there could be great difficulty in accessing supports.

Isla: And I really feel for people who because they're not familiar with the various agencies or neither the agencies responsibility, get left to, you know, sort of try and source resources that actually should not be difficult to resource. But they are having great difficulties... nothing is easy to access.

For those who had formal support to assist with the caring duties, a major issue was reliability. This ranged from the formal carers being late to not being advised of schedule changes or absenteeism. Ava, who has her mother-in-law living at home with assistance, considers it fortunate that her husband is at home because the formal care support is unreliable:

Ava: The carers come in; well, they are supposed to come in three times a day.

They are not very reliable, to be honest. And so sometimes they come, and they come late... They obviously get busy or get caught up. We are lucky that [my husband] works from home.

This reliability issue extended to the services that were meant to be provided. Ben speaks of his concern regarding formal carers not being reliable while he is working out of town or away:

Ben: Especially if I'm away, especially if you want me to put all her medication in a lockbox that Mum can't access and I can't access, and that carer doesn't turn up!

Now the medication is not critical, but that's not the point.

Furthermore, Ben goes on to express his concerns regarding the care provided, that it cannot be relied on and points to systemic issues:

Ben: If I was not home, I would have great concerns about Mum, or a patient kept up with them...So the carers are great. The people are great. The system is letting them down.

Ben: The service is great. It's admirable, but certainly, I wouldn't rely upon it. It's only because I've got Mum at home with me.

Ben: But if you didn't have the choice, if you're both working, and your mother was in a different city...

Rachel [researcher]: You wouldn't choose that. It would not be enough?

Ben: No, not. The service we are getting is too irregular. Not good enough. There are too many holes in it.

Relational Supports

Personal relationships and connections make the experience of informal caring different to providing care in a formal paid capacity. The relational aspect of informal caregiving was strongly apparent in the interview data. Particular areas of note included impact of caring on relationships, teamwork, duty and priority, interest, and connection.

Family Networks

In family networks, care role dynamics impacted interactions between the carer and their care recipient as well as with other members in the family.

Relationship with Care Recipient. It was found that caring duties could subtly alter the carer's relationship with their care recipient. It could be hard to maintain relationship balance because the carer was also doing another role for their family member. This caring, while necessary, was not always an interaction that the care recipient wished to have. Also caring needs could lead to more demands on the carer which could strain the relationship. One of the participants, Isla, who worked in health, mentioned that clients in her workspace spoke about the relationship difficulties of providing informal care. This made her aware of how providing informal care can alter and change relational dynamics. This is highlighted below when she described her relationship with her family member for whom she was caring:

Isla: I was very, very aware... aware to do whatever I could do, but not to be pushed into doing what was just too much, given my working life as well... I really wanted to make sure that for this point in time, COVID would inevitably come to a place of normality, hopefully, and relationships, did not diminish.

The ever-evolving nature of informal caring due to the care recipient's condition deteriorating and the impact of this on relationships was another factor that could be hard to come to terms with. This was shown by Grace who was caring for her husband who had dementia. She spoke of the changes and loss, "But you do feel lonely because obviously

before you lost that person, you know, that you married. And now you have got this person that you are really, caring for”.

Other Family Relationships. Providing informal care could also cause complications in other family relationships. For many of the participants, any conflict or resolving arguments with other members of the family could be problematic. Ava’s comments about having family disagreements at home while her Mother-in-law was living there highlighted this, “But had to have an argument in front of her... cannot argue really. Just don't want to make a horrible, horrible atmosphere. I think to shut your mouth! (Frustrated laugh)”. Other participants also spoke of this difficulty, and this is reflected in Freda’s comments about her mother “She can be unhappy if I have to tell off one of my children. For me, it's a big change for me when I'm staying with her... You know, dealing with that is very hard”.

Ava spoke of how caring for her mother-in-law at home made her and her husband aware of other family dynamics and how lacking coherence the family was regarding the caregiving, and this was shown her comments, “And now we have got her here with us we can see just how disjointed that actually is. Because they[siblings] just don't contact her. It's really sad... Hmm”.

The caring role also highlighted differences in the family such as priorities, partner differences in approach. It also comes with a sense of duty and obligation. The relational aspect is significant; people want to see their care recipient happy, well supported and enjoying life regardless of their needs. These aspects were seen in Ava’s comments when she was talking about her husband’s approach to caring for his mother at their home:

Ava: But [my husband] said we are not going to change our lifestyle because of it.

It is important that we keep doing what we were doing, but in some ways, you have to adjust, and you have to adapt because she's our priority right now.

As a positive note regarding support and family relationships, a few of the participants spoke of family teamwork in meeting the caring needs of their care recipient. It was seen that for some, a working out of schedules and care together made a difference to how supported the participant felt. This sharing of the caregiving load can be seen in the participants following comments when talking about other family members' involvement in the care tasks. For example, Ava talks of her husband's support regarding caring for her mother-in-law: "My [husband] is really connected and involved as well. So, if I feel like I need to get away, I just go by myself. But one of us will stay generally with her". Emma reflected this support regarding family teamwork in providing caregiving, when she spoke of how it was great when her sister was back from living overseas, "But when she came back it was great to have an extra pair of hands. Between the two of us, we help each other out". And lastly, Helen describes the juggling her and her husband's work schedules with her father's care needs.

Helen: It's never sort of been an issue because quite often my husband and I are like ships on the night, a little bit. So sometimes I'm working and he's not. So, he sort of picks up and helps where he needs to as well.

Friend Group and Networks

Relationship and Reciprocity. Relationship and reciprocity were seen to be motivating factors for providing care. When asked why she was happy to provide care,

Dora who cared for a family friend spoke of relationship and past help, “When I first came to Auckland, I was alone. And since we knew them from back home, I stayed with them for quite a while. I really got along and so yeah. They helped me quite a lot!” Emma who cared for her aging father mentioned calling in favours while in lockdown, “Yeah. It's not too bad. I've got a good support network out there of people who I have obviously helped in the past. Oh! I am cashing in all my favours over COVID!”

In facilitating informal care, carers also created networks around their care recipient. These networks helped lighten the burden by providing more support, information, and monitoring. In talking about her father's neighbours, Emma said “And I know the people on either side of him... I can talk to them "hey have you seen Dad?" Or "can you explain what this is?", if Dad is sketchy on the details”. For others it was helpful to know that other people were looking out for the person they were caring for. This could be seen in Jack's comments regarding the involvement of Fred's neighbours, “They've been helping him. That's really good. It's great because it is another set of eyes. ... They are there a few times a week”.

Friendship Networks. For some of the participants, working and providing informal care meant changes in socialising, loss of friends, or difficulty in making friends. A few of the participants did mention how providing care changed the way they interacted with their friends and vice versa. Ava talked of these changes and the corresponding difficulty when she spoke of socialising with her friends.

Ava: I would prefer to go out than have people come here now. I mean, we do have a big friend network and a lot of them come, and it's really lovely. But I wouldn't want to make a big habit of that because it's just hard on her.

Others found that existing friends visited less or did not contact at all. Grace who was providing care for her husband, who had dementia, found this to be hard and isolating. She talks of these changes in contact with friends and acquaintances below:

Grace: A lot of people that you think you might have come around, like friends or acquaintances don't anymore.

Rachel [researcher]: I guess some people find it awkward?

Grace: I think they must do. Because they don't come around and they don't ring up.

Participants spoke of a need to connect with people who understood and were going through similar care giving experiences. Grace again found it was hard to keep sharing with friends the difficulties or nuances of care, "Your friends... You don't want to just keep on going on about your things that are happening. They are your friends!" Grace as well as other participants spoke of a need to connect with people who were going through similar care experiences. Working while also providing informal care also meant it was hard to meet other people in comparable circumstances. Grace's comments below show this struggle:

Grace: I'm desperately trying to find someone who is similar to my age, in a similar situation and working... someone like me, you know, and it just makes you feel so much better. It's very difficult to meet anybody... Because people are working, they are working, aren't they!

Work Colleague and Networks

Regarding work colleagues and networks, to have someone who could be relied on, understood made a substantial difference. Hence work colleague relationships seemed to be a key factor regarding feeling supported at work as shown by Emma's comments below:

Emma: And I know that if I had a problem, [Immediate Manager] has always said family comes first and you just need to say the word. And I know that she, if I got sick, she probably would be there to help.

Positive Connection

Many positive aspects were noted by participants regarding their caring and the satisfaction they received from being able to help their friends and loved ones. They enjoyed helping and enjoyed the person they were caring for. Jack when asked if got on well with Fred said "Yeah, he's a grumpy sod, but he's also incredibly charming and I enjoy his company. So, yeah, I mean, I look forward to Thursday". Likewise, Ava spoke of spending time with her mother-in-law and how she liked it:

Ava: I like sitting on her bed in the sun. We open the curtains in the morning and lie on the bed and have a little chat. She holds my hand, and she tells me I'm such a treasure.

This pleasure was also shown in Dora's comments concerning her family friend, when she would first see her for the day:

Dora: The most enjoyable thing was whenever I see her smile as soon as I turn up...She would give me a lovely smile and say, "Oh my, you are here!" And that just made me think, "Oh this is going to be a good day!"

Others also spoke of their enjoyment of caring for their care recipient, for example Freda started "But for me to have her in here, it is a gift, not only for me but for my children. My children so happy, I'm so happy to have her with them".

Work Supports

A critical area for working informal carers is how their workplace supports them and enables them to balance their roles of work, informal caring, and family. Work supports include tangible formal and informal supports such as work policy, flexible working arrangements, the ability to be in contact with their care recipient while working, and the workplace being carer friendly in attitude and interactions. Sub themes included: Absence or unawareness of formal policy; carer friendly workplaces and training; flexibility, proximity, and hours; work/care/family balance and care impact on work; informal work support; disclosure and employer interest.

Policy

Absence or Unawareness of Formal Policy. Apart from the self-employed participants, all were unaware of any official policies concerning support for those providing informal care at their workplace. As a result, the work support received was informal. This was reflected by Emma's comment, "Yeah. There is nothing formal set-in place. But I know that there'll be someone who's got my back... which is kind of nice,"

and by Helen's comment, "They don't have formal policies. It would be more at an informal level".

Carer Friendly Workplaces and Training. In discussing workplaces' general attitudes, most participants thought their organisations were reasonably carer friendly and informally supportive. However, some comments showed that it was an area that had scope for growth. For example, Isla highlighted the need for development and training:

Isla: I do wonder if the background training that goes in. And I just think that it's an arena of considerable need for a probably greater capacity for training and development.

Rachel [researcher]: You think that employment policy, but also caring policy is heading in the right direction?

Isla: I think it's slowly inching toward better conditions, better remunerations, you know, greater training, and facilitation. But it's inching so slowly, that... the needs are overriding... And I think that because it's such a slow-moving sort of response that there's a lot of falling on the way.

The lack of formal or informal support was seen in some cases. In particular, Grace wanted to schedule time off to attend a regular afternoon dementia meeting with her husband and was made to take annual leave for any such leave requests, "They made me take, let me take annual leave". She spoke further of the difficulty in arranging time off work to support her husband:

Grace: We put in a request for a regular appointment. And this is what I have done...and it could take six weeks to process. Why does it take them so long? ...

No one got let down because of me. I still did my job. Uh, the union really has got no power.

Flexibility, Proximity, and Hours

Several participants were employed part-time in order to fit caregiving into their weekly schedules. This made it easier for them to be available to provide care when needed. Cole, who was self-employed, considered he was lucky to have the flexibility to be able to take time off or schedule work around his caring role:

Cole: Yeah, you do what you do. And he doesn't ask for it. I guess we're fortunate enough to be able to do it really. That is one thing that I guess there probably a lot of people out there that aren't in a position to be able to stop work or don't have jobs where they can do that sort of thing.

The proximity of work was an important consideration for many of the participants. Many of them used their breaks to check on their care recipients or to do jobs to facilitate their care role. It was peace of mind to be able to check on their care recipient if needed and to be close by in case of emergency. In talking about proximity and flexibility, Ben said, "Well, my job is semi-flexible. So, when she was in her own home. I could pop in when I wanted to. Probably two or three times a week probably". When Ben's mother could no longer cope even with assistance at her home, she came to live with them making caring for her easier.

Ben: When I was going through the COVID lockdown, as I say, I was at a period of time with work that I could pop in two to three times a day. But I will be coming into my busy period in about another three months' time.

For some participants like Cole, this meant only accepting work which facilitated him caring for his father, “So have been lucky. So, I haven't taken on any jobs that or anything like that, that would require me to be there for all the time. It's just not really possible”. The caring role was made possible by ensuring they worked nearby or could schedule time for caring when needed.

Having the flexibility and being able to structure work around caring and vice versa was an important consideration for many of the participants. Emma speaks of how flexibility in her job made it much easier to care for her father:

Emma: You know, the good thing about my job is I have that flexibility. Although I work six days a week, I can structure my working week around other commitments. So, you know, if Dad's got an appointment at the doctors, I can just move my appointments around to fit that in.

One way of making it possible to have time off work when needed was to have a strong work ethic and be a team player. Dora's comments about how she approached work show this.

Dora: So, it wasn't an issue at all. And I always filled in when others were away. I always pitched in. If they needed me for a few extra hours... They knew that and if there was anything I needed, they were really supportive. Although I never mentioned I was looking after someone.

While it appeared many workplaces could accommodate working informal carers, others were not so fortunate and had difficulty as their managers and the organisation, in general, was not carer friendly. Grace, who worked in the care industry, preferred work assignments that were close as her husband had dementia and it was a worry to work further away. Grace spoke of her struggles with her work, “I have had people threaten me on the phone because I have said no, I can't go there, it's too far away”.

Work/Care Balance and Impact

Care Impact on Work. It was noted that providing informal care while also working could have ramifications for participants in their workplace or work role. This was shown by several of the participant's comments. Furthermore, the changing dynamics of caring for a person in the older age group as their needs change could be a factor. For example, Ben's work had busy seasonal periods, which meant reorganising the current arrangements to accommodate care for his mother. Below he speaks about his busy work season and managing and planning care for his mother, who had advanced dementia:

Ben: Got a couple of things up my sleeve. My wife might quit her job in about two months' time...Mum may crank up another notch and require hospital care. She's heading in that direction. But how fast we're going to get there, I don't know.

One option to balance his family care needs and work needs was for his wife to leave work to be at home and present for his mother. Here Ben commented, “In the worst case, she's still at home. My wife still works full time. We'll give it a month and then we'll assess it then”.

For others, it was not so much the care impact on work but the emotional repercussions, which were hard. Other factors were the hustle with time and consideration of their care recipient's safety, needs, and wellbeing. Below, Isla comments on the impact of caring for her family member and balancing this with her work demands:

Isla: Yes. But I would not say it impacted my work because I'm really like a radar, conscious of my work all the time. But emotionally, I would say that it took a toll. You know, took a toll because I always had the timing of Martin's needs in mind, always. And if I had any reason to go to a distance to attend meetings, or whatever, then I would be really racing against the wind to get things prepared and to make sure that Martin would be safe while I was away.

The work/care balance and its impact on the care recipient weighed heavy for some participants. Isla spoke of this and emphasised that these were her concerns, not her care recipients:

Isla: You really realize that the other person, Martin, did not share any of those concerns. And I am glad that was the case. But for me, for reasons of safety and Martin's well-being, they were always to the forefront of my mind.

At times, the caring role encroached on work. It was common for both the carer and care recipient to worry. For example, Grace found it affected her work at times because she worried about her husband, who had dementia, and he worried and fretted about her:

Grace: ... he worries about me. He always wants to know where I'm going and when I'm coming back. And obviously it is very difficult to know when I am coming back.

Rachel [researcher]: How does he take that if you can't say an exact answer?

Grace: If he thinks it is too long, he might ring up and he does get worried.

Rachel [researcher]: And it's okay for you to talk to him while you are at work if you need to?

Grace: Obviously, you can't if you're showing someone, you can't really...

Rachel [researcher]: Yes true!

Grace: He can sometimes manage to text, but you know, you just survive.

... the times when my husband was here on his own, you know, I was very worried.

I actually only go to people in my neighbourhood so I can actually be close. It is a worry. He has good days, bad days... you know spells.

For others, to reduce the caring impact on work, keeping professional and private life separate helped, but it was still tiring at times. This was a strategy that Dora used.

Dora: I don't actually mix my personal with my professional. But sometimes ... if she was really sick and needed to be admitted into hospital and stuff, um it was draining. Like I was tired the next day when I turned up for work but after a few coffees and being there was usually okay. Up for the game.

Work/Care/Family Balance. A major issue for participants that came up across the interviews was work life care balance. Isla, who worked full time in a demanding role while being the primary carer for a family member, described it as being intense:

Rachel [researcher]: So, how have you found it balancing both care and work?

Isla: Balancing both things was actually very intense. Not the least of it because you're conscious as the informal carer that the person that you're looking after informally, is actually waiting for you. To come back and do dinner. Get those shoes off.

In order to maintain work schedules and balance care needs many of the participants prepared in advance or utilised work breaks. Isla explains this succinctly.

Isla: I couldn't afford to run late for work, for instance. I couldn't. So, by always making sure that I had everything sorted the night before, and then I'd rush and do the breakfast and what have you and get going.

Isla: If it was something that was so important that he would fret because it wasn't done, I would quickly do it. But if it was something that could wait until that night, so that I didn't get held up on the road and be tempted to speed and then put myself at risk.

Informal Work Supports

In the workplace, informal support regarding their care giving role was the primary type of support that participants had access to. It was apparent that relationships play a role at work regarding the working care giver feeling supported. This support could be tangible, such as time off for appointments, provision of information, or that their close managers and work colleagues were empathetic and understanding. Below Emma mentioned that being part of a team and that her immediate manager was family oriented helped:

Emma: I am part of a team ... And I know that if I had a problem, [My manager] has always said family comes first and you just need to say the word. And I know that she, if I got sick, she probably would be there to help.

Others found that having flexibility at work helped balance work and care and were confident their employer would support them if they really needed it. Regarding this Helen said, “Yeah. Yeah. I do think they would actually. Yes, I do think so. I do have a little bit of flexibility in some respects so I think they would if I really needed it”. For Freda, that her manager understood equated to her manager being supportive, “Now, my boss is a good boss because she can understand”.

Disclosure and Employer Interest

Most participants did not disclose their informal care role to their employers or management. There could be many reasons for this, one being work /personal boundaries or workplace culture. Dora mentioned how management did not seem interested or even ask. She chose not to say anything, “Actually the management doesn't have any idea as to what I am doing during my personal hours. And well, they never really, uh well no one really cared to ask”. Those employed at workplaces that were less supportive or flexible were hesitant to disclose on the off chance it would cause problems at work. For example, Grace had a difficult employer, and she thought it would be detrimental to disclose to management. She did not expect that they would support her as a working informal caregiver and was afraid of the consequences of sharing such information.

Grace: I think they don't know. Some people will know in the organization but not the coordinators. I don't think they do.

Rachel [researcher]: Would you want them to know?

Grace: No, not with the way that, you know, they have treated us. A lot of people have left... They have lost a lot of good people.

Grace: I think they would probably use it against me. Actually, I can't see they would support me in any way at all.

Rachel [researcher]: So that makes it really difficult, very stressful.

Grace: Yes.

She also mentioned how the union could help her but thought they were too overloaded to be of much assistance:

Rachel [researcher]: Do you think the union could help in this case, like the people as yourself who are caring for others?

Grace: Yeah, I think they could. I think they have far too much on their plate.

Rachel [researcher]: How are the immediate work people that you deal with, your supervisors and managers? Are they good in regard to your situation?

Grace: Only when I have contacted the union.

In contrast to the above experience, Helen had no problem with her employer knowing about her father needing care. However, she did mention that she worked part-time, “Yeah. I mean, it's not exactly a secret that my dad has dementia. That's what it is. And I guess for me, because I've only sort of ever worked two or three days a week”.

COVID-19 and the Highlighting of Informal Carer Issues

The experience of the COVID-19 pandemic and the subsequent lockdown presented their own issues. It highlighted several existing issues for the participants as they

navigated work, care duties, and family over this time. Specific to COVID-19 was the increased awareness of their own wellbeing and their care recipient and families. COVID-19 also had impacts on work and care, which are outlined in some of the examples below. Overall, the main feature of participant's experiences during the COVID-19 was how it made existing work/care issues more salient, such as work/care/family domain balance, wellbeing, and worry for the future, and highlighted existing care/work issues.

COVID-19 Specific Issues

Wellbeing of Carer. Changing routines meant that some self-care did fall to the side, however, the need for self-care was seen as important due to the uncertainty of how the pandemic would affect life and living. Regarding coping over COVID-19, Emma said “That was another thing with COVID too, I did not exercise as much as I would have liked. That was another hard part I didn't mention”. Emma, who had an underlying health condition, realized that she needed to make sure she was safe and was looking after herself, “For the first time, I had to stop and think about and put me first. This need to take care of yourself was a common sentiment as many of the participants were the sole carer for their care recipient.

For many of the participants, the COVID-19 pandemic and subsequent lockdowns increased work pressure and stress. This was particularly relevant for those providing essential services, such as Helen, who commented, “Leading into the build-up for going into level four I had a hell of a lot of stress at work. As you can probably imagine”.

The unknown aspect of COVID-19 did have an impact on many of the participants. It affected every domain. Participants spoke about the challenges of dealing with their own issues, staff and work, changes for family and kids, husband's work situation, schooling (if

children were of school age), and ensuring their care recipient was safe and well cared for. A common theme was that participants recognised it was hard but that the only thing to do was to keep moving forward and make the best of it. This is shown by Grace's comment, "You know, you've just got to carry on. And that's what you have to do". Other participants echoed this sentiment. For example, Helen explained how she coped with COVID-19 and lockdown:

Helen: Well, it is what it is. The whole situation. The whole COVID, everything. I kept thinking it is what it is. And it was just something that we were going through, and we can't change. For everybody. And you just kind of have to roll with it a little bit and just sort of make the best of it.

Wellbeing of Care Recipient. The COVID-19 pandemic increased participants' concerns for their care recipient since they were at an age to be at higher risk from COVID-19. For some, it was a very present and real worry. Regarding the risk, Freda said, "It's really, you know. I think it is very hard aye. And plus, with this disease, you cannot see it. So, it is hard for health and safety". A main concern was that their care recipients were vulnerable to COVID-19 as they were older, frail, or had underlying medical conditions. Cole spoke of this worry, "Well, yeah, well, I had major concerns about COVID because of his age and vulnerability. Yeah. It was a worry, that's true". Others, such as Helen, mentioned that they were careful with procedures and social distancing and expected others to be the same. This was reflected in her comments regarding other people, "I just kept saying to people, just wash your hands, just wash your hands". Participants were also concerned for their care recipients' wellbeing as they had less social interaction

due to lockdown and because some services were stopped over this period. Some spoke of how it impacted their care recipient:

Grace: I think he has declined a bit because of the lack of social interaction. A lot... He was just starting to get into activities and that was all stopped. And he couldn't understand why people weren't coming or getting in touch with him. He didn't really understand at all.

COVID-19 Lockdown Impact on Work and Care Roles

Care. COVID-19 lockdown brought much disruption for the participants' daily lives, which was very evident across life domains such as work and family life.

Adjustments were needed both for their caring roles as well as their work demands. Ava found that working from home and being at home more helped with adjusting to having her mother-in-law living with them, "During lockdown, it was good because it was a transition time for me and her". Others had extra care duties due to assisting family and friends who were in the high-risk group for COVID-19. To cope with this, some of the participants like Helen, made time available to assist, "I just made time to do the neighbour's groceries whenever they wanted stuff".

Work. COVID-19 and the lockdown meant changes regarding work. A number of the participants were working at home during this time. This worked out well concerning their caring role but could make it difficult with disruptions while working. Ava found this when on work calls or in meetings with colleagues:

Ava: I was up in my office because our office is upstairs. And every time I was on a work call, she would think I was talking to her so she would be calling out to me.

Tricky as (laugh).

Others who were essential workers and out in the community had concerns and fears regarding COVID-19 infection for themselves as well as for their care recipient. Grace spoke about personal protective equipment (PPE) and how it was frightening to work during COVID-19, “Well, we never had PPE which we should have had. And it was frightening going into a stranger's house”. Furthermore, when Grace spoke about the pandemic and continuing work while looking after her husband, her sentiments echoed other participants who were in similar positions, “Well, definitely not good at all. In any shape or form or in any way. Not a good time to be doing this job”.

Supports. Throughout lockdown, networking and reciprocity did play a part in helping some of the participants cope. Emma mentioned having a good support network and being able to ask for return help was beneficial, “Yeah. It's not too bad. I've got a good support network out there of people who I have obviously have helped in the past. Oh! I am cashing in all my favours over COVID!”

Saliency of Existing Working Informal Carer Issues

Highlighted Work/Care Juggle. The juggling of care and work was still an issue for many. Some had to adjust after having different schedules during lockdown:

Jack: When COVID happened, I had his meals delivered to my place... frozen.

Then I would take them down after heating them up at my place. But of course, we came out of lockdown. That became an issue because I had to go back to work.

Others found the changes to work due to COVID-19, such as working from home, did make it easier to facilitate the caring role. Ben found it much easier to ensure his mother was doing well, “During COVID, I was at home, so it was easy to do that”.

Lockdown and social distancing impacted some families by highlighting how busy their usual pre-COVID-19 schedules were. It emphasised how busy working informal carers are due to the multiple roles they have in their lives. Helen’s comment below reflects this:

Helen: So honestly, [my husband] and I probably found it was a little bit of a breather, a little bit of a break from our normal hectic schedule... You know it is a bit like Energizer Bunnies. You literally just keep going and going.

For others involved in essential work, previous care/work issues that existed before COVID-19 lockdown were the same or more intensely felt. Grace, who was caring for her husband, who had dementia, found it particularly worrying regarding safety for herself and her husband, “It was very frightening. Because we knew there were cases in the Hutt Valley”.

Worry for Own Wellbeing and Future Welfare of Care Recipient. Many of the participants spoke of concern for the future regarding the welfare of their care recipient if they were unable to provide care. This was also an existing concern, but the COVID-19 pandemic further accentuated it. Emma, who had underlying health issues and was in the vulnerable at-risk group for COVID-19, spoke of how the pandemic brought home this issue:

Emma: For the first time, I had to stop and think about and put me first...All of a sudden it was like, you know, hang on, if someone brings this virus home to me, I could be dead.

Rachel [researcher]: And then what happens then?

Emma: Yeah, ... What happens to Dad?

Highlighting of Existing Carer Issues. A number of existing care issues were exacerbated by the threat of COVID-19 and the impact of lockdown. Because the caregivers provided care for family members or friends, there was continued concern about caregiving changing relationship dynamics. COVID-19 lockdown was intense for many, emotionally, psychically, and mentally challenging. Isla speaks of her relational concern, “And then I wanted to make sure that the relationship that he and I always had, as family would just be really, great...would not be damaged by COVID-19”.

For others, the change of work status or working at home afforded them more time and attention for caring for their care recipient. It was a worry that once life returned or started to return to normal, that the person they were caring for would struggle with less contact. For example, this is seen in the excerpt below where Jack worries about his care recipient becoming over reliant on his care and losing what independence he had:

Jack: Oh yes. As soon as the main lockdown was over, I was able to go straight back to work. The only thing that I was concerned about the lockdown and seeing him so frequently was that he'd become too reliant on me.

Concern about settling back to a more normal life routine after COVID-19 lockdown highlighted how it could be problematic in sourcing support and advocating with

providers. Despite it being the responsibility of the relevant organisations and government bureaus to ensure families were supported in their caregiving, accessing support was an ongoing issue. Isla describes this experience succinctly when asked how it had been when she needed further support with caring for her family member:

Isla: Very difficult. Very difficult. We had to have the other person that I talked about who really stepped in big time to help me over the COVID time. And she was marvellous. And she knows her way around. And we had to, you know, like, really, really drive it quite hard in order to get attention from the providers in Northland. That this was a case that required a response, and it was their responsibility to get that response because that's the bureau that they are... But they are the designated bureau for that purpose.

Isla, when asked if she thought there was a difference in obtaining or advocating for support before the COVID-19 pandemic and subsequent lockdowns, had found that it was harder to obtain services. She thought it was due to the fear of COVID-19 risk and agencies being short-staffed:

Isla: I think that it was harder after COVID. Because many people who were doing caring before COVID, chucked it in over COVID. You know, for some people it was very frightening. But basically, I think that the agencies are struggling with staff.

The COVID pandemic also served to highlight existing workplace issues for some. Grace, who struggled with work conditions previously to the pandemic, thought the issues

were the same before and during the COVID-19 pandemic and lockdown, “There is no change I do believe. It is really not that much different”.

Summary of Results

In summary, the experiences of these 10 participants showed the importance of their informal caregiving to their care recipient, for themselves and their families, and New Zealand society. It specifically focused on support for working informal carers providing care for a care recipient aged 65 and over and their experiences before and during the COVID-19 pandemic. Four major themes were evident: ‘Societal support’, ‘relational support’, ‘work support’, and ‘COVID-19 and the highlighting of informal carer issues’ as shown in Figure 1 above. These findings and their important points are outlined briefly below:

‘Societal supports’ explored recognition, invisibility, and access issues concerning the carer role both to the person caring, their family, and society. It could be seen that social attitudes and surrounding unpaid work, understanding of the caring role, family roles, and duty influenced support received and how the carer perceived that support. At a practical level, access and pathways to formal support showed issues around responsibility, risk, and regulatory mechanisms for informal carers, rural versus city supports, and disjointed, fragmented services which affected navigation, access, and reliability.

In examining ‘relational supports,’ it was seen that providing informal care is highly dependent on relational dynamics and connections, as seen in many participants’ responses. This covered family, friend, and acquaintance, and work colleague networks. Regarding family support, impacts were seen in changes in dynamics in the relationship with their care recipient due to the carer role and other family relationships. Friendship

networks again highlighted relationship and reciprocity and the importance of networks, and the support gained. Regarding work, it was noted that supportive colleagues, teamwork, understanding, and reciprocity were important. Furthermore, the positive aspects of providing care for a loved one were seen throughout the participant interviews, which again highlighted the importance of relationship and connection when providing informal care.

‘Work supports’ covered a range of support concerns, as seen in Figure 1 above. Regarding policy, it was noted that there was an absence or unawareness of formal policy for the participants involved. Of importance was carer friendly workplaces and training. Work mechanisms of support that were helpful were: flexibility, proximity of work, and hours. Some found self-employment and opting for part-time work helped with balance. Issues that impacted the carer included work/care balance, which showed that care duties impeded on work and conversely for work/care/family balance. Alongside flexibility, proximity, and hours, informal work supports were significant for those working. However, it was found that several participants chose not to disclose their care duties and also that for some, there was a lack of employer interest.

Finally, COVID-19 brought with it further issues specific to the pandemic and subsequent lockdown. Regarding COVID-19 specifically, there were issues around the carer's wellbeing and that of their care recipient. COVID-19 and lockdown did impact both work and care roles for the participants, and this was seen in disruption in care duties and support systems. In addition, it was found that COVID-19 increased the saliency of existing issues for working informal caregivers in this sample. In particular, it highlighted the work/care juggle, worry for the participant's wellbeing and future welfare of their care

recipient, as well as highlighting existing working informal carer issues such as changing relationship dynamics, changes in work status, and communication.

Chapter Four: Discussion

This qualitative research explored how working informal carers in New Zealand experienced support before and during the COVID-19 pandemic. It looked at the support experiences of the participants involved who were in paid employment while providing informal care to a care recipient aged 65 and over. This discussion explores the results in light of existing research and examines the implications for working informal carers by considering societal, relational, and work supports. It further discusses the repercussions of the COVID-19 pandemic on working informal carer support. In closing, the limitations of this research project and opportunities for further research are outlined.

Societal Supports

Societal Attitudes and Recognition of Care Role

Social attitudes surrounding unpaid work, understanding of the caring role, as well as family roles and duty, influence support received and how the carer perceives that support. Of importance is how society views those who have health issues, disabilities or are elderly. Attitudes, social norms, and past health policies appear to influence how people view those who require care and how this impinges on the people caring for them. According to Shannonhouse and associates (2002), covert ageism towards older persons is a particular problem when systematised in governmental policy and the health sector. Such research complements other research which points to a societal focus on ‘aging well’ with connotations of success and failure depending on how able and healthy one is as they enter older age (Hooyman, 2003; Holmes, 2006; Phillips & O’Loughlin, 2017). Furthermore, ageism towards the elderly is associated with a societal fear of infirmity, deterioration, and death (Shannonhouse et al., 2002). The above research supports the results from this paper

as a lack of interest, less involvement, or contact from others was an issue for some of the working informal carers in the sample. It was particularly noticeable when the recipient had advanced dementia. Research notes that older people aged 65 years and older are comparatively invisible in Western society, and even more so if infirm (Bai, 2014). These current results appear to reflect that underlying societal attitudes regarding health, infirmity, and older age can reverberate to impact those who are informally caring. After all, they provide a service to those who need support due to illness, old age frailty, or disability. However, other societal attitudes do come into play concerning informal caring, for example, perceptions surrounding unpaid work, work that is not easily measurable, or work that is not recognised due to it being embedded in the relational aspect of caring.

Providing informal care and what it entails is often hard to fully measure (Berentson-Shaw, 2019). It transcends financial and time value. It involves relationship, time, finance, and attention to physical, emotional, and spiritual wellbeing (Maidment, 2016). It has been noted that acknowledging the cost of informal care does not fit well into the egalitarian framework, which has guided policy in this country and many other western countries (Maidment, 2016). This focus on marketable worth and economic value can detract from the intrinsic importance of caring (Berentson-Shaw, 2019). While more attention has been drawn to working informal carers in recent times, as a subpopulation of society, they can be statistically lost in other areas such as old age or disability sectors (Kia Piki Ake Welfare Expert Advisory Group, 2019; Synergia, 2019; Goodhead & McDonald, 2007). In Western society, paid work has a higher value than informal care (Mandel, 2009; Berentson-Shaw, 2019).

While it is touted that informal carers are needed and even more so due to an aging population and a decreasing workforce to support the elderly, there is a lack of recognition concerning their contribution to society (Jorgensen et al., 2010; Plaiser et al., 2015; Singer et al., 2010). This can be seen in the lack of acknowledgement of carers and carer rights (Goodhead & McDonald, 2007). These underlying attitudes seem to run through society, permeate family circles, formal services, and workplaces (Samman et al., 2016). For working informal carers to be effectively supported, their role needs to be seen, recognised, and acknowledged. Furthermore, when forming and implementing support policy, societal perceptions, expectations, and discourse surrounding informal care needs to be considered; these factors can impact how effective support systems can be (Samman et al., 2016).

Dissonance could be seen in some instances regarding the participant's perspectives on their care duties. Some duties were viewed as 'simple' or 'no big deal' in some comments, while in other comments shown as 'important' because the care participant needed this help. Other times, it appeared that the relational aspect made the lines between relational duty and what was considered work to be indistinct. These effects have been described in previous research. Commonly, unpaid work such as caregiving (attending to practical, physical, and emotional care needs) and particularly housework is not always visible, highly valued, or recognized as work in many societies (Chartered Institute of Personnel and Development, 2016). However, informal care is work, and regarding it as such increases its visibility. Viewing informal care as work has implications for how society views informal carers and what support and policies are available (Kia Piki Ake Welfare Expert Advisory Group, 2019). Jobs that are involved in providing informal care

can also be seen not as work as they can blur into relational and family duty (Phillips & O'Loughlin, 2017; Knowles et al., 2016).

The expectation 'family looks after family' was a common view seen in the current study results. It was also well supported by existing informal carer research regarding societal family norms and roles (Goodhead & McDonald, 2007). This reciprocal duty regarding the family role and informal care duties was further highlighted in the data as a common sentiment with such statements as "It is what you do". While the informal care role involves tasks beyond typical family-related patterns, this role is inherently relationally bound, which can render this work invisible. Consequently, it seems that boundaries between what constitutes the caring role and sets it apart from what is perceived as normal relational functioning are indistinct (Cass et al., 2009). Thus, caregivers can struggle with validation and recognition of their role, which was seen in the current findings supported by previous research (Goodhead & McDonald, 2007).

Formal Supports

At a practical level, the current results showed issues about access and pathways to formal carer support. These included concerns about responsibility, risk, and regulatory mechanisms for informal carers, rural versus city supports, and disjointed, fragmented services which affected navigation, access, and reliability. This study's results concerning formal support issues such as accessibility, geographically available support, and service fragmentation, and bureaucracy were well supported by existing research.

Other studies show that navigating formal support systems to access relevant information, allowances, and appropriate services can be daunting (Kia Piki Ake Welfare Expert Advisory Group, 2019). Access is impeded by fragmented and poorly coordinated

government support services, and current provisions require the informal carer to recognize and classify themselves as an informal carer (Maidment, 2016). However, carer and care recipient circumstances and contexts can differ greatly. The Ministry of Development acknowledges this diversity in their 2021 care document outlining general support information and department contacts. It also points to the fragmentation among government departments. It states that support criteria and even definitions of what constitutes an informal carer can range between different agencies (Ministry of Social Development, 2021). Other studies point to insufficient information about the availability, range, and accessibility of services as commonplace (Goodhead & McDonald, 2007). These factors were noted in this current research and were also relevant concerning diagnosis, information, and understanding of the care recipient's disorder. This disconnection can leave informal carers feeling alone and frustrated while trying to advocate for the person they are providing care for. For those living in rural or smaller centres in New Zealand, access and availability of appropriate services can be an issue that may increase the burden of care (Kia Piki Ake Welfare Expert Advisory Group, 2019). There appears to be a lack of uniformity across services, which can be keenly felt for those in small town New Zealand. This can disadvantage many of those in informal care situations. It is noted that, as seen in this research, other studies show that many carers do find the formal supports on offer, such as respite care options, to be unsatisfactory or irrelevant to their situation (Synergia, 2019). This highlights the necessity for services to be tailored or re-evaluated to be relevant for carer needs.

According to Goodhead and McDonald (2007), informal carers looking after an older aged recipient need supports that are flexible, well interfaced, and uphold dignity. In

this respect, care recipient needs, and characteristics drive what assistance the carer requires (Maidment, 2016). While formal and respite services can lessen carer strain, it is also important to consider the full caring context inclusive of carer needs (Kia Piki Ake Welfare Expert Advisory Group, 2019; Goodhead & McDonald, 2007). This is so that support systems are relevant, and care remains manageable (Maidment, 2016). In addition, longitudinal research has indicated that if home care, meal, or respite services were not accessible, there was a higher chance of work exit to sustain their care role (Pickard et al., 2018).

Policy

As the demographics of society alter and change with population aging, evolving family structures, and the shrinking workforce, this has placed much pressure on working informal carers. It has been lauded that this cohort is providing a vital service and is a significant resource for the country (Jorgensen et al., 2009). However, regardless of the contribution that working informal carers provide to society, policies around work and formal supports still seem to be lacking. A crucial point to note is that support can be made available for those informal carers only if they recognise their caring role (Knowles et al., 2015). However, it is a role that is inhomogeneous, may not be viewed as work or important work, and a role that may blend into family relational ways of being (Knowles et al., 2015; United Nations Economic Commission for Europe, 2019). Informal carers need to be acknowledged and seen as an integral part of society. They need communities that will value and pull together to support them. However, how can people understand or support the working informal carer if they cannot see what this role entails? If this role blends into others, is ill defined, how can support be relevant? How do communities pull

together to support and value this sector of society? The first steps could be made by increasing the visibility and acknowledgement of working informal carers and their role in the public arena and public discourses. Such visibility around working informal carers could mean that they can be less hidden within other sectors of society such as disability/old age and mean more opportunity for informed and hopefully effective policy regarding support (Goodhead & McDonald, 2007).

Much research highlights how providing informal care, especially while also working, is a challenging role (Jorgensen et al., 2009). The informal carer must balance different life demands such as work and family and find a balance regarding physical health, spiritual, social commitments, and personal growth. It is usually a role that is thrust onto a family through circumstance, especially when caring for older friends or family members, and can be challenging (Knowles et al., 2015; Plaiser, 2015). In addition, informal care is usually required when a member needs more support due to old age frailty or encroaching health issues. As such, it is not a static role, and demands can vary depending on the recipient's needs or condition. That it is not a static role separates it from other caring obligations such as child rearing and care which can be more linear and structured (Plaiser, 2015).

Worldwide research (including New Zealand) shows that informal carers are instrumental in enabling persons to be able to live feasibly in their own residence for a longer duration (Maidment, 2016). This aging in place is encouraged through government policy as the financial and provision responsibility of extended care has become that of the family (Maidment, 2016; Phillips & O'Loughlin, 2017). This change to public policy has occurred over the last twenty years as there has been an emphasis on neoliberal economic

growth, impacting the health sector (Maidment, 2016). However, while informal carers bear the brunt of these policy changes, existing research notes that New Zealand legislation lacks in acknowledgement and recognition of carer rights and protection (Jorgensen et al., 2010; Rea et al., 2010). Moreover, New Zealand research shows that regarding governmental policy, there is a lack of discourse concerning the worth of informal care (Maidment, 2016). However, the focus on aging well in the community does have major ramifications for those providing informal care, especially when caring for people with high needs. Regarding carer policy and community attitudes, researchers have noted the tendency to assume that informal carers will be available to bear the burden of care for those vulnerable in our communities (Horrell et al., 2015). In this public climate where government and society rely on family informal carers to provide care, the needs of this cohort must be attended to. In addition to reducing the public health burden in monetary and resource terms, the value of informal care for the care recipient is reflected by enhanced outcomes, reduced avoidable hospital readmission, and formal care placement (Elliott & Parker, 2012; Grimmond, 2014; Spillman & Long 2009).

The current results showed that informal carers need access to reliable, appropriate, and flexible respite options, which is well supported by existing research (Jorgensen et al., 2010; Goodhead & McDonald, 2007). Awareness of informal carer needs at the policy level is a crucial starting point to ensuring adequate and relevant support for this cohort. Silverstein & Parrott (2001) found that personal knowledge of caregiving intrinsically shapes perception regarding resource provision and policies pertaining to carer support. In particular, public and employer policy needs to work in tandem for the working informal carer to ensure that this cohort is not disadvantaged financially or in other areas (Phillips et

al., 2020). This current research noted that working informal carers are mostly unaware of any formal provisions in their workplaces and tend to rely on more informal work support systems or take work leave to meet their caring obligations. Again, the need arises for acknowledgement and awareness of the carer role and the additional pressures and implications for those providing care while also in the paid workforce (Phillips et al., 2020). Recognising the social service contribution of unpaid informal carers is essential to ensuring adequate government entitlements, regulations (i.e., employment), and appropriate formal supports such as respite care (Centre for policy on ageing, 2015).

Relational Supports

Providing informal care is highly dependent on relational dynamics, and connections were evident in the participants' responses in this study and other research. The current results showed that relationship is pivotal to informal caring and that it also permeates supports, especially the informal family/friend/acquaintance networks. This factor is supported by other existing research on working informal carers, which notes the vital relational aspect of providing such care (Goodhead & McDonald, 2007; Pickard, 2004). The informal care role is tempered with the implications of relationship and a role motivated by love, cooperation, and moral obligation (Pickard, 2004). Despite complications of the pandemic, this relational aspect remains a strong feature regarding working informal carer support and perhaps even more so due to interrupted systems. This relational aspect threads through different avenues of assistance ranging from informal family, professional and formal, and workplace supports (Kia Piki Ake Welfare Expert Advisory Group, 2019). Hence, relationship is a key defining part of the processes

surrounding care provision and support for working informal carers (Centre for Policy on Ageing, 2015).

The participant's responses showed the evolving nature of the informal carer role, care dynamics, and subsequent effects on personal and family relationships. Reasons for providing care and some of the impacts raised were supported by existing research. For example, outside societal expectations, there are many relational prompts for informal carers to begin the role of caring, such as attachment, reciprocation, sense of duty, as well as concern for recipient wellbeing (Greenwood & Smith, 2019). As care needs change and evolve depending on the recipient's wellbeing, so does the care relationship dynamic alter (Goodhead & McDonald, 2007). These relational changes can bring grief for the carer and can also mean adapting to new aspects of care provision (National Advisory Committee on Health and Disability, 2010). Previous research shows that the carer and care recipient's pre-existing relationship status can negatively or positively affect carer perception of the caring role and its pressures (Goodhead & McDonald, 2007). It is also noted that more intensive care roles can increase the sense of burden (Jorgensen et al., 2009).

Positive Experiences

It is important to note the positive characteristics of providing informal care. Several studies observed that existing research tended to focus on informal care's problematic features and overlook the benefits provided to the carer. The positive aspects of providing care for a loved one were seen throughout the participant interviews, which again highlighted the importance of relationship and connection when providing informal care. It shapes why such care is undertaken and how it is administered (Horrell et al., 2015). Relationship underpins informal caring, and the attachment and consideration

involved in caring for another are both valued and satisfying (Centre for Policy on Ageing, 2015; Kia Piki Ake Welfare Expert Advisory Group, 2019).

Friendship networks again highlighted relationship and reciprocity and the importance of these networks, and the support gained. Connection is important for people in any circumstance. Lack of social connection has been shown to have adverse outcomes for wellbeing in any circumstance, let alone for those providing informal care where isolation can be a common side effect (Victor et al., 2020). This is worrisome as research shows that social connection and support can help negate negative consequences of care giving such as poor wellbeing and burnout (Victor et al., 2020; Goodhead & McDonald, 2007). This is particularly relevant for working informal carers who face time pressure and the juggling of commitments (Wiegelmann, 2021; Kim et al., 2011). It is hard to form new social connections when working and caring, and a common need is to interact with others in comparable circumstances (Victor et al., 2020). The strength of existing support connections can wane; for example, existing friends can be in contact less, and especially if the care recipient has a chronic deteriorating condition such as dementia (Victor et al., 2020).

Per existing research regarding work colleagues and networks, it was noted that supportive colleagues, teamwork, understanding, and reciprocity were important (Kim et al., 2011). Hence work colleague relationships are a crucial factor regarding feeling supported at work. Interaction at work has a strong relational aspect where connection, mutual understanding, and reciprocity take place. Work friendships also may provide other avenues of constructive resources (i.e., information sources or practical support) and can

facilitate the informal carer to remain in employment while also meeting caring obligations (Arksey, 2002).

Work Colleague and Networks

Consistent with existing research regarding work colleagues and networks, this study found that for the working informal carer to feel supported at work, the following factors made a significant difference: having supportive colleagues, good teamwork, understanding, and reciprocity (Kim et al., 2011). Regarding the workplace, several participants spoke of feeling supported and about practical support, which enabled them to do well in both their work and care roles. Hence, having strong and supportive relationships, clear communication patterns, and work dynamics can facilitate success in both work and care duties. Furthermore, as supported by previous similar research, participants did find that workplace friendships were also constructive in providing avenues of information sources or practical support, which could facilitate the informal carer to remain in employment while also meeting caring obligations (Arksey, 2002).

Work Supports

Work supports cover a range of important support concerns, and among these are policy, carer friendly workplaces, and training on work/care practices. Previous research substantiated this report's findings that work support mechanisms found to be particularly helpful were flexibility, proximity of work, and hours (Arksey, 2002; Phillips & O'Loughlin, 2017). Likewise, some participants found that self-employment or opting for part-time work helped with balance. Alongside flexibility, proximity, and hours, this research was further supported by previous findings that indicate that informal work supports are significant for working informal carers to facilitate both care and work

demands (Goodhead & McDonald, 2007; Phillips & O'Loughlin, 2017). This current study found that while work could offset care strain, it also may provide other pressures which impact other life domains, as seen in previous research (Gordon et al., 2012). Hence informal social, formal, and work supports all play a part for the working informal carer to sustain their care and work roles.

Work/Care Balance Strategies

Other research has noted that working informal carers use a range of methods to balance their work and caring commitments, such as: working nearby, making use of work lunch breaks and leave for care duties, taking unpaid leave, adjusting working hours around care role, accepting less challenging work, or reducing hours to part-time (Goodhead & McDonald, 2007). A number of these strategies were seen in this sample. An option that helped some participants with work/care balance was to be self-employed as one could tailor work to their needs and facilitate the caring role (Arksey, 2002). However, the present research showed that even when carers were self-employed, there were opportunity costs caused by issues of proximity, hours, and dependence on work processes or clients being able to be flexible.

Informal Workplace Support

This research confirmed existing findings showing that carer friendly workplaces had higher chances of successful work outcomes for staff with informal care responsibilities (Plaiser et al., 2015). Carer-friendly workplaces were supportive, had sympathetic and understanding managers and work colleagues, and promoted supportive family work culture and work conditions (Plaiser et al., 2015). Additionally, workplace methods that helped facilitate work and informal care included supports such as personal

telephone use, flexible working choices, and hours, leave options, and promotion of supportive work culture (Goodhead & McDonald, 2007; Plaiser et al., 2015; Carers NZ, n.d.). Previous research has found that if managers were supportive, for example: if they were accessible, could listen, had clear work expectations, and acknowledged good work, this greatly assisted working informal carers (Higgins et al., 2008; Kim et al., 2011; Plaiser et al., 2015). Studies have shown this management style aided in easing care/work overburden and care/work intrusions (Higgins et al., 2008; Kim et al. (2013). In fact, work/care concessions appear to be strongly reliant on manager and work colleague support (Kim et al., 2013).

Work as Respite

A number of the participants did find that their work role at times did help alleviate their caregiving pressure, as shown by existing research. For example, for many working informal carers, work can offer a break from their care role (Sahibzada et al., 2005; Carers NZ, n.d.). Several studies note that work and informal caring roles, when considered independently, are personally fulfilling, rewarding, and when both are in balance, can add to quality of life (Arksey, 2002; Eurofound, 2015; Carers NZ, n.d.). However, reconciling both these roles in tandem can impact both care/work roles and create much stress (Arksey, 2002; Fuller & Raman, 2019). Likewise, the balance of care/work was found to be difficult for some of the participants in this study, especially those with more demanding care duties.

Care Disclosure to Employer

The current study noted that some participants did not mind if their employer and work colleagues were aware of their care role, but others were reluctant to disclose. Those

who preferred not to disclose their care duties to their employer did so for various reasons, for example: to maintain personal/work life separation; due to fear of losing their job; due to lack of employer interest, or they considered it irrelevant to disclose. This hesitance was supported by existing research. For instance, Sahibzada and associates (2005) found that employees may not disclose their caring role to their employers, which meant their workplace might not know of staff members who also provide informal care (Sahibzada et al., 2005). Some working informal carers may prefer to keep their personal lives private or fear negative work repercussions and reduced work opportunities if their employer is aware of their care role (Tehan & Thompson, 2013; Phillips et al., 2020; Centre for Policy on Ageing, 2015).

It is important to note that the participants in this current study were generally unaware of their workplace policy regarding informal care. Conversely, it was unknown how aware their employers and supervisory staff were of their dual roles. These issues can be partly explained by workplace culture and societal norms, as these have been shown to influence employee's disclosure of their private life at work and take up informal and formal work support arrangements (Clancy et al., 2019). If fellow work managers/colleagues discouraged formal policy utilisation, this became an issue for working informal carers relied on work supports to alleviate care burden and facilitate their work/care balance (Sahibzada et al., 2005). That the employer appears unaware is supported by Plasier and associates (2015) as they found it was widely unknown as to how many companies approach informal care, and about the level of staff awareness of colleagues who are informal carers, or what their care role entails.

Work Policy

New Zealand employment policy stipulates that an employer is obligated to consider an employee's request for changes in hours, days, or where they work (Maidment, 2016). It was unsure how this legislation was supported in the workplace because, as with similar research, it was found that participants were unaware of their entitlements regarding flexible options, conditions, or work leave. Considering current aging population trends and the growing need for informal care, it was surprising that working informal carers would be unaware of formal supports. Research shows that functional organizational working informal carer policy can benefit both the workplace and the working informal carer. These benefits include assisting the organisation in decreasing productivity losses and enhancing staff retention while lessening employee income loss and enabling continued employment versus workforce exit (Lero et al., 2012; Plaiser et al., 2015; Bernard & Phillips, 2007).

COVID-19 Highlighting Issues

The COVID-19 pandemic has brought several existing issues for working informal carers to the forefront. Although an existing issue, isolation is a more significant issue for those providing informal care due to the pandemic. Recent research on the pandemic effects on working informal carers shows the pandemic had created more support barriers, closed avenues of support, limited respite services, or added strain to an already overburdened system (Wiegelmann, 2021; Phillips et al., 2020). This echoes the experiences of several of the participants of this study. For participants who worked in essential services during the lockdown or who had exposure to the public, this also posed a risk for themselves and their vulnerable care recipients. As one of the participants

mentioned, it was “not a great time” to be in the caring line of work. Sourcing and navigating the formal support systems has always been an issue due to fragmentation and unclear pathways (Goodman & McDonald, 2007). Added to this is the pressure of the higher risk that exposure to COVID-19 poses for an already vulnerable population.

COVID-19 brought with it further issues specific to the pandemic and subsequent lockdown. In particular, the COVID-19 pandemic has exacerbated issues for both the carer's wellbeing and their care recipient. As with many other people, the working informal carers in this study found that COVID-19 and lockdown did impact both work and care roles, and this was seen in disruption in both work and care duties and support systems. It was found that COVID-19 increased the saliency of existing issues for working informal caregivers in this sample which has been mentioned in many studies concerning working informal carers during the pandemic (Phillips et al., 2020). In particular, it highlighted the work/care juggle, worry for the participant's wellbeing and future welfare of their care recipient, and highlighted existing working informal carer issues such as changing relationship dynamics, changes in work status, and communication. This research showed that informal carers, while being regarded as providing crucial assistance to the countries' health and social care sector, are still experiencing disregard and lack of notice which has persisted throughout the COVID-19 pandemic (Phillips et al., 2020). They are a quiet essential service that has sat in the background and continued to do so through this pandemic even though they care for the vulnerable in the community who are most at risk of adverse effects from COVID-19 (Wiegelmann, 2021). In fact, Family Carers Ireland has been campaigning for informal carers to be classed as an at-risk cohort and given precedence for COVID-19 virus testing and protective gear (Laffery et al., 2021).

This current research is backed by other pandemic informal carer research. It has echoed the concern of other informal carers (both working or not) regarding their own risk of severe illness and potential exposure for their vulnerable at-risk care recipients (Health Service Executive, 2020). In a time where the risks are very high for those who are recipients of informal care, their carers are facing heavier loads of care alongside the need to safeguard themselves from contracting COVID-19 and subsequently passing this on to their care recipient (Phillips et al., 2020). The worry about the future for their care recipient should they not be able to care for them has been a recurrent informal carer concern even before the pandemic, as shown in this study and previous research (Laffery et al., 2021; Wiegelmann, 2021; Kia Piki Ake Welfare Expert Advisory Group, 2019). However, it has been a common theme during the pandemic regarding COVID-19 infection (Phillips et al., 2020). When care services and respite options are limited due to lockdowns, closure, and stretched services, informal carers are providing higher levels of care (Laffery et al., 2021). For some, as seen in the current research, they are providing care with fewer resources and reduced income (Laffery et al., 2021). Furthermore, because the older cohort is high-risk, there has been concern around cloistering and increased dependency of care recipients (Phillips et al., 2020). The concern is that this may lead to hastened deterioration, independence losses, and lowered wellbeing (Phillips et al., 2020). Such impacts would intensify the burden of care while informal carers are in uncertain times with less support (Phillips et al., 2020; Laffery et al., 2021).

The current findings showed that some of the participants found aspects of the initial New Zealand pandemic lockdown to be positive, which has been reflected by research worldwide (Phillips et al., 2020). For those caring for family members or friends

residing with them or close by, working from home meant they could reconcile both roles with more ease. Phillips and associates (2020) found that for families, it also meant that as other family members were available to help with care duties, this relieved pressure on the primary carer. Conversely, while working from home has its benefits, it could also mean interrupted workflow as caring obligations could intrude and result in increased pressures (Laffery et al., 2021). Despite this, flexible work arrangements are among the most helpful mechanisms to assist working informal carers (Kim et al., 2011; Lero et al., 2012).

Work/care role interference while working at home during the pandemic lockdown was an issue for some in this research, but overall, working from home did facilitate both roles easier. One of the positive aspects of the pandemic has been that employers have had to adapt, resulting in many being more open to flexible work arrangements (Phillips et al., 2020). While working informal carers need appropriate supports at the best of times, it is even more essential to ensure support services continue and are operational through the pandemic and subsequent lockdowns. Without this support, and especially during the pandemic due to increased burden, working informal carers could face adverse outcomes on their own welfare (Phillips et al., 2020).

The pandemic persists, bringing with it many new challenges as well as highlighting existing concerns for working informal carers. This means organizations and employers have an ethical duty to be conscientious and accountable in assuring their employee's wellbeing and facilitate space for tactful conversations about sustaining care/work/life balance and coping with work duties and responsibilities (Phillips et al., 2020). The pandemic offers opportunities for community, government, and formal supports as well as work organizations to step up. In considering working informal carers

who are caring for vulnerable persons and in the interests of diffusing disparity, Ehni and Wahl's (2020) following statement is relevant, "Especially in a crisis, it is important to preserve the basic values of our society and to protect the rights of individuals, especially the weakest".

Interconnections

A prominent and important aspect of the analysis was how the themes were interconnected. As shown in figure 1, the results show how interrelated aspects of life such as professional, public, and private life are for those involved in informal caring. This has implications for support systems for the working informal carer. It shows how understanding and attitudes are interrelated and contextual rather than isolated concepts (Kia Piki Ake Welfare Expert Advisory Group, 2019). Many of the common themes that arose had aspects that intersected with different avenues of life such as work, family, social networks, as reflected in other studies concerning working informal carers (Bernard & Phillips, 2007). Relationship was seen as fundamental for support across life domains, such as work, family/friend connection, and community level. As supported by other research, it was seen that balancing work and informal caregiving has significant impacts on different life domains such as health, family and personal relationships, social life, and work/career (Pickard et al., 2018). These domains are often evaluated when talking about life satisfaction, wellbeing, and balance. Additionally, and relevant when combining work and informal care, there was a frequent distinction between professional and personal life boundaries and what is considered acceptable crossover between these two life domains in the workplace, which was also seen in other research (McCartney, 2020). Governmental policy recognizes the distinction between work, formal and personal support systems.

There are specific policies for work covering such provisions as flexible work options, special leave, entitlements, and separate specific formal policies in place for medical, housing, and financial support provision (Ministry of Social Development, 2021).

Goodhead and McDonald (2007) note that informal caregiving for the carer holds a significant position in their life while also involving and creating interaction with others in a wider societal context. Hence, when considering supports, it is essential to consider the interconnected impact of caregiving on life domains for the working informal caregiver, such as the family, work, community contexts, and applicable legislation and policy. Previous research has highlighted the need for community support services and workplace supports regarding informal care to be cohesive and collaborative (Bernard & Phillips, 2007).

For working informal carers to remain in the workforce and to be able to attend to care duties, they require reliable and appropriate formal supports, strong informal networks as well as acknowledgement and inclusion in employment and health policy (Kia Piki Ake Welfare Expert Advisory Group, 2019). In fact, this finding is supported by longitudinal research conducted in England, which indicated that lack of care support services resulted in a higher probability of working informal carers needing to leave work (Pickard et al., 2018). Even just access to one basic support service such as home domestic and health care, respite services, or meal services greatly increased the chance for informal carers to continue working (Pickard et al., 2018). Numerous studies point to the benefits for informal carers to be empowered to remain in the workforce, with benefits such as increased mental and physical wellbeing, more robust social connections, and greater financial security (Jungblut, 2015; Stiell et al., 2006, as cited in Phillips et al., 2020).

Hence, the need for good formal support, governmental policy, and employment legislation and regulation, as reflected by these results and other related research (Phillips et al., 2020).

Limitations, Implications, and Future Research

This research has raised new awareness of how working informal carers have and are experiencing support in New Zealand and how the pandemic has highlighted long standing issues and new instances of need. It draws attention to the need to recognise and acknowledge working informal carers at the societal, workplace, and family levels so that effective, cohesive systems of support, legislation, and policy can be put in place to protect this growing cohort. The findings indicate that informal care is intrinsically relational and impacts all life domains, which means that the whole support network needs to be considered in order to provide relevant and effective support.

A strength of this study is that even though the sample of participants for this study was small, it did somewhat reflect how diverse the working informal carer cohort could be. For example, there was a range of different ethnicities, caring roles, care recipient characteristics and conditions, and workplace circumstances. Nonetheless, as with other research, this study has limitations that need to be taken into account when considering the results. Notable considerations are mentioned below:

The first limitation directly concerns the recruitment methods and the range and size of the sample. While the sample size of 10 participants was considered appropriate for the scope and size of this study, it may not be fully reflective of the diversity of caring circumstances or cultural diversity in the New Zealand population (Braun & Clarke, 2013). While there was some diversity in the range of participants (i.e., cultural heritage,

background, gender) and their caring circumstances, it was noted that the sample was predominately New Zealand European. Nonetheless, informal carers are a heterogeneous cohort with much range in living and care circumstances (Kia Piki Ake Welfare Expert Advisory Group, 2019). However, this research sought to investigate support systems for the broader working informal carer cohort caring for an older care recipient. Hence it did not focus on specific demographics or cohort subgroups such as women, men, Māori, other minority cultural groups, or specific care situations. Further research could explore the nuances of working informal carer support, specifically considering impacts for these subpopulations.

This research, as an inductive phenomenological qualitative study, has explored the working informal carer's personal experience of caring and support to understand its meaning and ramification (Dew, 2007; Grant & Giddings, 2002). While such a study is valuable in providing in-depth information and growing understanding, one must apply caution when generalizing the findings to outside contexts (Willig, 2008).

It was recognized that data was interpreted through the researcher's cultural lens, ideology, and theoretical approach (Braun et al., 2019). As the researcher was actively involved in the research process, this highlighted the importance of researcher self-awareness (i.e., personal perspectives and positioning) and reflexivity regarding data interpretation. While not necessarily a limitation, as it is a feature of qualitative research, it is something to be aware of when considering the findings.

Another limitation is that the recruitment methods may have limited involvement by specific sectors of society. Due to the COVID-19 pandemic, most of the recruitment was conducted online through social media advertising mailing lists and personal contacts.

This meant that only a particular cohort was reachable. Hence, others who did not use social media or were not involved with care organisations, who did not have or could not afford internet or mobile services, were excluded.

In considering exclusion, another notable limitation here is that while this research targeted working informal carers of older age recipients, many provide such care but do not recognize themselves as informal carers. It has been suggested that culturally specific family relational dynamics play a part in whether the role is seen as outside normal family bounds of relating and reciprocity (Knowles et al., 2015). Hence, a future direction could be how to engage those who are providing informal care but are not recognized by the system as they do not self-identify (Knowles et al., 2015).

This research raises important points about how working informal carers are experiencing support and has implications for future research. In addition to the directions mentioned above, there is much room to explore the interconnectivity of informal care support systems, within themselves and across sectors in New Zealand.

Conclusion

In conclusion, this qualitative study aimed to explore how working informal carers in New Zealand experienced support before and during the COVID-19 pandemic. It has been a unique opportunity to investigate this topic during a pandemic and its repercussions. As evidenced through this research, working informal carers are an important part of our society. This project provided a detailed overview of several relevant issues supported by previous research both here and abroad. The more significant findings are briefly summarised below.

Firstly, one of the most salient findings was that the caring role, in general, is not highly valued in Western communities, resulting in working informal carers being frequently rendered invisible and overlooked. This societal disinterest occurs despite working informal carers' contribution to society, the reliance of public health and social systems on their support, and the evidence of improved outcomes for care recipients. This 'invisibility' filters down through all support systems for working informal carers and raises the question, how can sufficient and effective services, supported by policy and legislation, be put in place if the informal care role is not fully recognised, acknowledged, or understood?

Another notable finding was the interconnectedness of support systems. These systems included informal networks, formal and community supports, government policy, and employers and organisations, all of which are encompassed by New Zealand society. As evidenced through previous research, relationship and connection were shown to underpin the informal caring role and the informal carer support networks in the community, family, and work settings. It could be seen that different avenues of support had meaningful interactions and complimented each other and hence empowered the working informal carer to balance work and care. This was further highlighted by the current findings, which point to disconnected support services and difficulty accessing such support and information. Although a general issue for all participants, this was particularly felt in smaller town centres and rural locations. This research has found that when the interaction between these support domains is cohesive, it is possible for working informal carers to succeed in their care and work roles. Finally, some of the positive aspects of providing informal care were apparent in carer satisfaction and fulfilment in

caring for their loved ones and ensuring their needs were met. This aligned with research that showed that attachment and consideration involved in caring for another are both valued and satisfying.

The findings of this research project are relevant, add value, and further the literature resource regarding working informal carers support in Aotearoa New Zealand. Furthermore, it is a timely topic regarding New Zealand's increasingly aging population. Implications and directions for further research regarding this topic include growing understanding of how to provide adequate services for diverse cultural groups and how to engage hidden carers who do not self-identify and miss the opportunity for much needed support.

In considering implications for practice, this research points to several opportunities for Aotearoa New Zealand to address long standing support issues for its working informal carer cohort. Firstly, it is important to acknowledge working informal carers' contributions to society and increase understanding of their role. This includes upholding the positive benefits and outcomes that informal care can provide for both carers and care recipients at a personal, familial, and societal level. Moreover, it would allow for dignity and respect for this cohort and the people they care for. Such awareness is essential to address negative underlying societal norms and perceptions that obscure the positive aspects of informal care and instead promote stigma and enable existing and non-identifying informal carers the opportunity for support. Secondly, to further support working informal carers, a viable approach is to educate and promote this group's cause in public discourse in the community, family, work, and policy arenas. For example, a coordinated educational campaign would raise community and employer awareness, assist in overcoming

stigmatisation, and provide opportunities for more people to identify as informal carers. Thirdly, it must be acknowledged that steps have been made toward better legislative support for working informal carers. However, with increased working informal carer cohort input and deeper understanding, there is an opportunity to implement relevant policy and effective, cohesive support systems that centre on and bolster these carers as they provide an essential service to this country.

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Appendix A: Outline of New Zealand's COVID-19 Alert System

New Zealand Government (n.d.). *COVID-19 alert system*. Unite against COVID-19.

<https://covid19.govt.nz/alert-system/>

New Zealand COVID-19 Alert Levels Summary			
<p>Alert Levels are determined by the Government and specify the public health and social measures to be in the fight against COVID-19. Further guidance is available on the Covid19.govt.nz website.</p> <p>Measures may be updated based on new scientific knowledge about COVID-19, information about the effectiveness of control measures in New Zealand and overseas, or the application of Alert Levels at different times (e.g. the application may be different depending on if New Zealand is moving down or up Alert Levels).</p> <p>Updated 14 Dec 2020</p>			
<p>Different parts of the country may be at different Alert Levels. We can move up and down Alert Levels.</p> <p>Services including supermarkets, health services, emergency services, utilities and goods transport will continue to operate at any level. Employers in those sectors must continue to meet health and safety obligations.</p> <p>Restrictions are cumulative (e.g. at Alert Level 4, all restrictions from Alert Levels 1, 2 and 3 apply).</p>			
MINIMISATION STRATEGY – New Zealand is working together to eliminate COVID-19			
Alert Level	Risk Assessment	Range of Measures (can be applied locally or nationally)	
Level 4 – Lockdown Only the disease is contained	<ul style="list-style-type: none"> Sustained and intensive community transmission is occurring. Widespread outbreaks. 	<ul style="list-style-type: none"> People instructed to stay at home in their bubble other than for essential personal movement. Safe recreational activity is allowed in local area. Travel is severely limited. All gatherings cancelled and all public venues closed. 	
Level 3 – Restrict The risk the disease is contained	<ul style="list-style-type: none"> Multiple cases of community transmission occurring. Multiple active clusters in multiple regions. 	<ul style="list-style-type: none"> People instructed to stay home in their bubble other than for essential personal movement – including to go to work, school if they have to, or for local recreation. Physical distancing of two metres outside home, or one metre in controlled environments like schools and workplaces. People must stay within their immediate household bubble, but can expand this to reconnect with close family/whānau, or bring in caregivers, or support isolated people. This extended bubble should remain exclusive. Schools (years 1 to 10) and Early Childhood Education centres can safely open, but will have limited capacity. Children should learn at home if possible. People must work from home unless that is not possible. Businesses cannot offer services that involve close personal contact, unless it is a supermarket, primary produce retailer, pharmacy, petrol station or hardware store providing goods to trade customers, or it is an emergency or critical situation. 	
Level 2 – Reduce The disease is contained, the risk of community transmission remains	<ul style="list-style-type: none"> Limited community transmission could be occurring. Active clusters in more than one region. 	<ul style="list-style-type: none"> People can reconnect with friends and family, and socialise in groups of up to 100, go shopping, or travel domestically, if following public health guidance. Keep physical distancing of two metres from people you don't know when out in public or in retail stores. Keep one metre physical distancing in controlled environments like workplaces, where practicable. No more than 100 people at gatherings, including weddings, birthdays and funerals and tangihanga. Businesses can open to the public if following public health guidance including physical distancing and record keeping. Alternative ways of working encouraged where possible. Hospitality businesses must keep groups of customers separated, seated, and served by a single person. Maximum of 100 people at a time. Sport and recreation activities are allowed, subject to conditions on gatherings, record keeping, and – where practical – physical distancing. Public venues such as museums, libraries and pools can open if they comply with public health measures and ensure 1 metre physical distancing and record keeping. Event facilities, including cinemas, stadiums, concert venues and casinos can host more than 100 people at a time, provided that there are no more than 100 in a defined area and the groups do not mix. Health and disability care services operate as normally as possible. It is safe to send your children to schools, early learning services and tertiary education. There will be appropriate measures in place. People at higher risk of severe illness from COVID-19 (e.g. those with underlying conditions, especially if not well-controlled, and seniors) are encouraged to take additional precautions when leaving home. They may work, if they agree with the employer that they can do so safely. Face coverings required on public transport and aircraft (but not inter-island ferries). School buses and children under 12 are exempt along with passengers in taxis and share services and people with disabilities or mental health conditions. 	
Level 1 – Prepare The disease is contained in New Zealand	<ul style="list-style-type: none"> COVID-19 is uncontrolled overseas. Sporadic imported cases. Isolated local transmission could be occurring in New Zealand. 	<ul style="list-style-type: none"> Border entry measures to minimise risk of importing COVID-19 cases. Intensive testing for COVID-19. Rapid contact tracing of any positive case. Self-isolation and quarantine required. Schools and workplaces open, and must operate safely. No restrictions on personal movement but people are encouraged to maintain a record of where they have been. No restrictions on gatherings but organisers encouraged to maintain records to enable contact tracing. 	

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Appendix B: Advertisements

Facebook Advertisement:

Carers for family/whānau, be a part of important Massey University research!

Are you in full or part-time paid employment and also providing care for a family/whānau member or friend with chronic illness or disability or is elderly or frail that is: Living in same household as you?
OR living or aging in place in the community?

Message <https://www.messenger.com/t/WorkingCarerResearchNZ> for full information about taking part or phone 022 320 7398 or email rachel.harris.nz@gmail.com



Newsletter and *Organisational* Advertisement



Understanding the Experiences of Working Informal Carers and Their Supports Before and During the COVID-19 pandemic

Massey University Master of Science in Psychology Research Project

Kia ora

Are you in full or part-time paid employment and also providing care for a family/whanau member or friend who is:

- Living in same household as you?
- OR
- Living or aging in place in the community?

Then I am interested to hear about your experiences.

Please note: If your work situation has changed due to COVID-19 disruption, you would still be eligible to participate in this project.

Are you interested to be a part of my research? To talk to me and obtain full information about taking part please contact me on:

022 320 7398 or at rachel.harris.nz@gmail.com

Ngāmihihui

Rachel Harris

Appendix C: Letter to Prospective Organisations



18 June 2020

Tēnākoe

My name is Rachel Harris, and I am currently undertaking a Master of Science in Psychology at Massey University. My supervisor is Professor Christine Stephens. My research is about the experiences and support systems of people in paid employment who also provide unpaid care for older adults (before and during the COVID-19 pandemic and lockdown in New Zealand).

I would like to know if it is possible to place a notice in your organisation's newsletters, bulletin or mailing list regarding recruitment for research participants (please see attached copy of the advertisement).

There may be a range of people who are working informal carers and I am looking for those in full or part-time paid employment who provide informal care for:

- a family member or friend who lives in same household

OR

- a family member or friend living, or aging in place in the community

If their work situation has changed due to COVID-19 pandemic disruption or lockdown, they would still be eligible for my study.

As there are many people who are in this situation, I am sure there are those who would be interested and perhaps also find it beneficial to talk about their experiences.

Interviews would be conducted over the telephone or internet via Zoom or Skype. The participants will be fully informed regarding study details, privacy, and information use as according to research protocols and the privacy act. Should they decide they no longer wish to be a part of the research; they can withdraw at any time. These procedures will be subject to ethics committee approval.

Thank you for your time and consideration. I look forward to hearing from you and your organisation soon.

Ngā mihi nui

Rachel Harris

Appendix D: Research Project Information Sheet



Support for Working Informal Carers Before and During the COVID-19 Pandemic

INFORMATION SHEET

Kia ora,

I am Rachel Harris, a Master of Science in Psychology student at Massey University. With my supervisor, Professor Christine Stephens, I am researching the experiences of working informal carers and their supports before and during a pandemic.

What is the research about?

Aotearoa/New Zealand and communities around the world are currently dealing with the Covid-19 epidemic. There is a gap in research regarding how working informal carers are impacted by these circumstances. We are particularly interested in their experiences and any changes the lockdown has brought about regarding caregiving and support.

What are you being asked to do?

An interview by telephone or Zoom/Skype will be conducted. It will be a conversation with me about your experiences (before and after lockdown) of caregiving and support, while also in paid employment, and will take approximately an hour.

What will happen to your information?

For the duration of this project, all information will be securely stored and only available to the researcher and supervisor. The interview with the researcher will be audio recorded and transcribed. You will have opportunity to review and amend your interview transcription. All audio recordings will be destroyed when the project is completed.

Your name and any identifying information will not be included in any final report.

The findings will be described in my MSc thesis and presented to interested organisations in New Zealand. The results may also be published in international journals.

What you can expect from the researcher?

- I will be in contact to arrange an interview time.
- Following transcription, I will be in contact again for a follow-up catch up and to review your interview transcription.
- Once the project is complete, I will send you a summary of the findings.

What if you are struggling with the current situation and or with providing informal care while also working?

For support with grief, anxiety, distress, or general wellbeing, you may call or **free text 1737** at any time to speak with a trained counsellor.

You may also contact Lifeline: 0800 543 354 (0800 LIFELINE) or free text 4357 (HELP).

For more information about ways to manage being in lockdown, visit:

<https://covid19.govt.nz/individuals-and-households/health-and-wellbeing/>

Your rights

You are under no obligation to accept this invitation. If you decide to participate, you have the right to:

- Decline to answer any question;
- Withdraw from the study at any time until you have approved the transcript;
- Ask any questions about the study at any time during participation;
- Ask for the recorder to be turned off at any time during the interview;
- Provide information on the understanding that your name will not be used;
- Be given access to a summary of the project findings when it is concluded.

Project Contacts

Rachel Harris (researcher): rachel.harris.nz@gmail.com

Professor Christine Stephens (supervisor): c.v.stephens@massey.ac.nz

Thank you for having time to read this information. Should you have any questions about this project, please do not hesitate to contact us.

This project has been evaluated by peer review and judged to be low risk. Consequently, it has not been reviewed by one of the University's Human Ethics Committees. The researcher(s) named above are responsible for the ethical conduct of this research.

If you have any concerns about the conduct of this research that you wish to raise with someone other than the researcher(s), please contact Prof Craig Johnson, Director, Research Ethics, telephone 06 356 9099 x 85271, email humanethics@massey.ac.nz.

Appendix E: Research Project Participant Consent Form



Support for Working Informal Carers Before and During the COVID-19 Pandemic

PARTICIPANT CONSENT PROTOCOL

To be read to participants for verbal (recorded) consent to each item

Dated.....

- You (participant's name) have read the research information (or had it read to you).
- You understand the information sheet and the project details and purpose. Any questions you had were answered adequately and you understand you can ask questions at any point throughout the research process.
- You have been given sufficient time to consider whether to take part in this research. You understand your participation in this study is voluntary and you can withdraw at any point up until you release your transcript to be used in the study.
- You agree to the interview being digitally audio-recorded
- You understand that you can ask for the audio-recorder to be turned off at any point in the interview
- You understand that the audio-recording will be destroyed once my interview has been transcribed
- You understand that all information you give will be treated confidentially
- You understand that you can read, discuss, and make edits to the transcript or notes of your interview if you choose
- You agree that the edited transcript and extracts from this may be used in reports and publications arising from the research
- You understand you will have access to a summary of the research at its completion
- You understand and are happy to participate in the research under the conditions described in the Information Sheet provided

The recorded verbal consent will be transcribed and stored separately to the participants' transcribed interview (all recordings destroyed once transcribed in this way).

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Appendix F: Research Project Interview Question Schedule

Support for Working Informal Carers Before and During the COVID-19 Pandemic

Conversational Semi-structured Interview Schedule

The interview will start with an informal chat, a catch up from the first initial email, telephone, or skype/zoom meeting together.

Background Information

This part of the interview will start with a “thank you” from me for participating in the project. I will check if they have any more questions about the process in general.

Then we will move into the conversation with questions loosely based on the following starter:

“I am interested in your experiences of informal caregiving and support while working, before and during COVID-19 lockdown and pandemic”.

“What is your situation regarding care and work?” “What has your experience been?”

Example Prompt Questions

“What was it like to both work and provide informal care?”

“What support do you have?” “Currently?” “Previously?”

“What was your experience of working and caregiving before the pandemic and lockdown?”

“How has working impacted your caregiving? Or vice versa, how has caregiving impacted your work situation?”

“How has the COVID-19 lockdown impacted you as a working informal caregiver?”

“How is it different for you?”

“What beneficial changes or challenges or has there not been much change?”

“What helps you the most regarding caregiving and working?”

“Is your workplace supportive?” How?

“Is your family supportive of you both working and caregiving?”

“What do you want as support while working and providing care? Social, emotional, practical

“Can you tell me about your experience when first involved in informal care while also working?”

“How has providing informal care been rewarding or enjoyable for you?”

“What else was occurring in your life then?”

“Can you describe a time in which you didn’t really enjoy providing informal care?”

“How have you found balancing both work and informal care?”

“Do you have any specific moments that are brought to mind?”

“Can you describe an experience where other people have influenced how you felt about working and informal caring?”

“Can you describe a time when you have felt conflicting emotions about informal caring at the same time? This might be like really wanting to have some time out away from the caring situation but also feeling sad, worried or guilty that you are not there caring” This could be because you have work commitments and could

“Reflecting now, on your experience of informal caring and working, how different do you think it is compared to how you imagined it could be?”

Closing

As we draw to the end of the interview time I will ask if there is anything else you would like to share.

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