

Report into the
HOME CARE NEEDS OF OLDER PEOPLE
WESTERN BAY OF PLENTY DISTRICT



August 2024

Report prepared by
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For the
Home Care Advocacy Group, Tauranga



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EXECUTIVE SUMMARY

This qualitative community-led research focused on the formal and informal care needs of older people living in the Western Bay of Plenty, Aotearoa New Zealand. Community groups were concerned about the future health, care, and welfare needs of people aged 65 years and over in this region. The research involves two distinct phases. The first phase involves semi-structured, face-to-face interviews with 26 people aged 65+ years who hope to be able to age at home (owned or rented) and avoid residential or hospital level care as they age. The second research phase involves 13 Needs Assessors and Care Professionals completing an online survey about the needs of older adults living in the community in the Western Bay of Plenty.

The participants interviewed ranged from those living happily managing their home and gardens, to those, mainly women, bravely on alert 24 hours per day caring for unwell spouses. The participants who were caring for their spouses were determined to remain well themselves in order to continue caring for their partners. These carers need to receive regular home-based care support, respite, social support and informal assistance to sustain them.

The Needs Assessors and Care Professionals survey responses highlighted the personal and professional struggles experienced trying to provide robust services to people unwell in their own homes. The survey participants' spoke about the realities of responding to overwhelming levels of complex need in the 65+ age group. The survey participants' commitment to providing effective and efficient care is evident in their ability to be creatively responsive to complex care challenges and resilient in the face of funding shortfalls that impact service provision and workforce conditions.

The findings gave voice to the realities of ageing in place in the Western Bay of Plenty of Aotearoa New Zealand. The participants wished to remain in their own homes as long as possible. Their main needs were to stay well, access key information, and to receive appropriate care support and respite care when needed, particularly for women carers. With the anticipated population growth of older adults, a coordinated approach to central and local government planning is warranted to ensure that policies are promoted that support ageing at home with attention to culturally responsive practice and adversity. Family and whānau are not always present to support for a wide variety of reasons. Aged care community-based services therefore need to be adequately funded across the country, in a manner that actively recognises and acknowledges the value and contribution that unpaid carers make to the economy. The literature identifies that expanding the availability of in-home care services to enable more people to 'age safely in place' will further reduce the risk of hospitalisation and the need for long-term residential care.

The participants reported that homecare service provision is too prescriptive, and task orientated. This meant that homebased support workers could not respond to fluctuations in need. Homecare services were particularly valued when the paid carers were more responsive, empathetic and relationship focused, as opposed to being task centred. The findings lead to the conclusion that carer burn-out can be reduced through easy access to adequate care support, networking with other carers, and a wide range of easily accessible respite options. The study concludes that there is a need to respond holistically to the overall wellbeing of the person being cared for and the needs of their spousal carers, family and whānau.

Summary of Recommendations

Policy & Funding

Increase central and local government planning for the anticipated population growth of older adults

- Promote health and welfare policies that support ageing in place with attention to culturally responsive practice and diverse needs
- Ensure adequate funding for aged care community-based services
- Improve work conditions and remuneration for Homebased Carer Support Workers
- Actively recognise and acknowledge the value and contribution unpaid carers make to the economy and health service

Reduce risks

Expand the availability of in-home care services to enable more people to age safely in their homes to further reduce the risk of hospitalisation and the need for long-term residential care.

- Increase collaboration between hospital care, primary health and home-based care services to maximise the ability of people to remain in their own homes
- Provide community support workers with expertise in specific health conditions

Responsive Services

Homecare services are too prescriptive, and task focused

- Homecare services are valued when the paid carer workers are perceived to be responsive, empathetic and relationship focused
- Homecare services need to be responsive to the deteriorating condition of the person receiving long-term care at home, and the multiple needs of their spousal carers, family and whānau
- Expand access to incontinence support and offer help to family members coping with sleep deprivation due to caring duties

Prevent Burn-out

Prevent carer burn-out through easy access to adequate care support

- Provide more access to carer respite in the form of day programmes and kaumatua programmes
- Provide regular home-based carer respite for people who are housebound
- Expand the availability of overnight residential care respite beds to increase emergency access for spousal, family and whānau care relief

Reduce Social Isolation

Develop social programmes and support networks for older adults to reduce social isolation and exclusion

- Increase the emphasis on local government to provide provision for community centres and hauora to offer these types of social programmes so that they are accessible and affordable
- These types of centres can also provide a focal point for contact with health and welfare services especially for those having issues with accessing GP and social services
- Develop a nationwide network of Carer Support Groups as a key pillar of social support for spousal, family and whānau carers.
- Specific carer support groups needed so that carers can engage with, get support from peers whose family members are suffering from similar illnesses/disorders (such as Dementia, Parkinsons, Motor Neuron & Stroke). These groups need to be located near carer respite day programmes/kaumatua programmes as well as online, to assist with time-poor informal carers accessing support.

Social Work Services

Strengthen the role of social workers in supporting older adults and their informal at-home carers to address emotional and practical needs of older adults while ageing in their own homes

- Provide social work services from Primary Health Care clinics, Hauora, Community Centres and Marae to enable older adults to navigate the application processes and outreach work needed to ensure basic needs are met.

DEDICATION

This collaborative work is dedicated to Josephine Helen (Jo) Gravit, Te Puna, beloved wife of Peter Gravit. Jo was the initial instigator of the suggestion for four local groups to work together to examine the questions asked in this study. The Western Bay of Plenty Home Care Advocacy Group was formed in 2023 by Age Concern with Jo Gravit as a member up until her untimely death on 4 December 2023. May she rest in peace.

ACKNOWLEDGEMENTS

There were many people that came together to support this community-led grassroots research. We would like to acknowledge the organisations underpinning the Home Care Advocacy Group (HCAG) for instigating and supporting this research - Age Concern, Tauranga. Rural Women Western Bay of Plenty, Grey Power Western Bay of Plenty and the Tauranga National Council of Women. Thanks also goes to the individual members of the HCAG for their advice and support throughout the course of the research - Angela Scott, Jo Gravit, Jenny Turner, Jennifer Custins, Dorothy Stewart, Adrienne von Tunzelmann, Anna Bones, Eliza Benfell, Dr Trish Hanlen, and Dr. Janet Jackson.

Thanks to the team of interviewers who assisted with this research project in so many ways - Dr. Bev Edlin, Barbara Whyte, and Dr. Lesley Lyons-McAdam. We acknowledge the University of Waikato (UoW) for providing a UoW Summer Research Scholarship to assist with this research, and to Molly Crawford for the work she did as the UoW Summer Research Scholar.

We would also like to thank the social services that assisted us with locating participants and for hosting us for some of the participant interviews. Thanks also goes to Rural Women Western Bay of Plenty who assisted financially to contribute to some of the expenses such as those incurred with costs due to travel and printing.

Lastly, we would like to acknowledge the study participants who generously shared their time and insights about the realities of living at home aged 65+ in the Western Bay of Plenty, and to the Needs Assessors and Care Professionals who completed the online survey.

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CHAPTER ONE: INTRODUCTION

Community-Led Research

This research is a community-led project that came about in direct response to the pressing concerns of community groups in the Western Bay of Plenty regarding the future health and welfare of older residents living independently. This subsection of the chapter introduces the four community groups that initiated the research, as well as the key members of the research team and their differing responsibilities that were essential for achieving the study's objectives.

The Home Care Advocacy Group (HCAG)

In 2023, the Home Care Advocacy Group (HCAG) was formed to address significant concerns held by four Western Bay of Plenty community groups about the future health and welfare of older people living in their own homes. Out of these concerns a community research project was devised to gain clarity into the support needs of people over the age of 65 years in the Western Bay of Plenty.

The HCAG is facilitated by Age Concern, Tauranga. The group is supported by Western Bay of Plenty Rural Women (RWNZ), Grey Power Western Bay of Plenty (GPW BoP) and the Tauranga National Council of Women (NCW). The Home Care Advocacy group members are Angela Scott, Jo Gravit, Jenny Turner, Jennifer Custins, Dorothy Stewart, Adrienne von Tunzelmann, Anna Bones, Eliza Benfell, Dr. Trish Hanlen, and Dr. Janet Jackson.

Research Team

This report is the primary outcome of this research and has been prepared through the collaborative efforts of Western Bay of Plenty women who make up the membership of HCAG, alongside a team of retired academics who conducted the majority of the qualitative research interviews, a University of Waikato (UoW) Social Work Lecturer and a UoW Summer Research Scholar. The term 'retired academics' is a significant label, as the women conducting the research interviews were of a similar age to the research participants and held an insider's perspective into the support needs of people 65 years and over living at home in the Western Bay of Plenty. This insider's perspective was also a position held by all members of the HCAG.

Dr. Kelly Glubb-Smith, Social Work Programme Convenor, Division of Arts, Law, Psychology and Social Sciences, University of Waikato, was approached by the HCAG with a request to consider this collaborative research to which she agreed. She was assisted by Dr Trish Hanlen, MNZM, a retired Social Work University lecturer and the National Council of Women HCAG representative.

The undergraduate student on a UoW Summer Research Scholarship was Molly Crawford and the research was conducted out of the University of Waikato Tauranga Campus. The

interviewers were Dr. Kelly Glubb-Smith, Dr. Trish Hanlen, Dr. Bev Edlin, Barbara Whyte, and Dr. Lesley Lyons-McAdam. Barbara Whyte also assisted with the literature search.

Purpose and Focus

The report describes the purpose of the research, rationale and objectives underpinning this two-part study. A short review of mainly Aotearoa New Zealand literature provides further context to the research findings and recommendations for innovation and improvement to the conditions in which home care is provided to people aged over the age of 65 years in the Western Bay of Plenty.

The first phase of this study involved qualitative semi-structured interviews with 26 people who live in the Western Bay of Plenty region and are aged 65 years and older. The interviews sought to understand ways in which people in the over 65 years age group could be or were supported to continue living well in their own home (owned or rented) in this geographical region.

In the second phase of this research, an online survey was conducted to gather insights from care professionals experienced in either assessing home support needs or providing home care services. Thirteen care professionals completed the survey. The survey was conducted to increase understanding of existing support services for the over 65 age group in relationship to the narratives contained within the qualitative interviews. The survey data was designed to expand considerations of home support service innovation, policy development and the practice of service provision that reduces the need for hospital level care.

The primary research question was:

What are the informal and formal support needs of people over the age of 65 years to continue living in their own home to avoid hospital level care?

The secondary research question was:

What can be done to increase understanding of home support services to improve innovation, policy development and the practice of service provision for older people living in their own home, to reduce the need for hospital level care?

Geographical Context

The geographical context was the Western Bay of Plenty region, as illustrated in Figure 1. The Western Bay of Plenty Region is situated on the east coast of the North Island of Aotearoa New Zealand. Within the Western Bay of Plenty region the major population areas included in this study are Tauranga, Mt Maunganui, Pāpāmoa, and smaller urban/semi-rural areas such as Waihi Beach, Katikati, Omokoroa, Te Puke, Maketu, Paengaroa and Pukehina.

This geographical area is serviced by both the Tauranga City Council and the Western Bay of Plenty Council. In June 2023, the total estimated resident population of the wider Western Bay of Plenty region was 222600, with 46350 people aged 65 years and over, therefore making up 20.8% of the demographic (<https://rep.infometrics.co.nz/western-bay-of-plenty-district>).

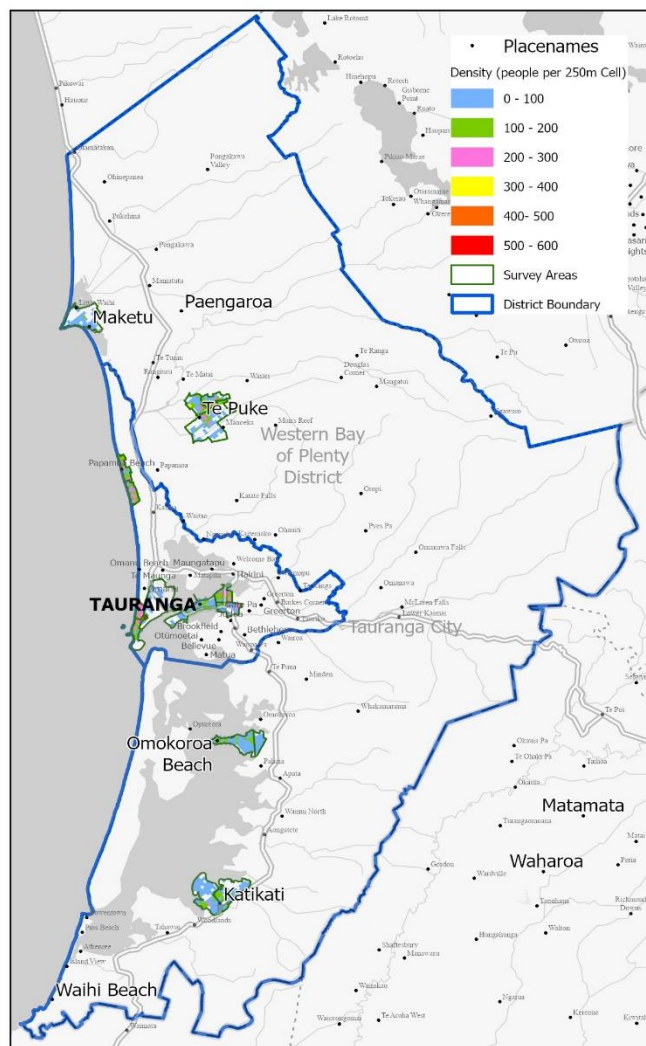


Figure 1 Map of Western Bay of Plenty

Rationale

The primary research objective was to explore the perspectives of individuals currently receiving in-home assistance, focusing on what works well for them and what enables them to better support themselves to remain at home, rather than transitioning to formal or secondary care. Additionally, the research aimed to evaluate the effectiveness of current service delivery modes and enhance understanding of stakeholder perceptions regarding potential improvements to meet service objectives. With the study's emphasis on the support needs of older adults living at home, a major objective was to extract common themes from the two data collection phases to pinpoint service gaps and explore potential innovations. Analysing service outcomes is crucial to see how they could prompt changes or sustain existing practices. The study also sought to apply theoretical constructs and practice knowledge from social work relevant to the needs of individuals over 65 who wish to age in place, avoiding rest home or hospital care. Ultimately, the research aimed to provide valuable data to inform service provision, foster innovation, guide improvement, and influence policy development and practice among NASC providers and community stakeholders, such as Community Centres, Iwi Social Services, and Hauora.

This collaborative community-driven research was conducted with a critical feminist lens, to give attention to the voices of the over 65 age group in the Western Bay of Plenty, while acknowledging the motivations and positionality of the researchers (Brannelly & Barnes, 2022). The twenty-six qualitative interviews cast a reasonably wide net to endeavour to ensure diversity of voices that would be representative of the over 65 age group living at home in the Western Bay of Plenty. The voices of the thirteen care service professionals were also prioritised to ensure robust knowledge development about what it means to provide needs assessments and in-home care services in the Western Bay of Plenty.

CHAPTER TWO: LITERATURE REVIEW

Introduction

The Western Bay of Plenty region has a relatively high proportion of population of people aged 65 years and older. The Western Bay of Plenty population aged 65 years and older is projected to increase, and is currently sitting at 23.2%, compared to the national average of 16.5% (Infometrics, 2023). Clarity is needed about the way the region can respond to the unique experiences, potential and diverse needs of this growing population. In January 2021, the United Nations (UN) General Assembly formally launched The Decade of Healthy Ageing, (2021-2030) to address global aging, modern longevity, and the demographic transition. Population forecasts for the Western Bay of Plenty are in keeping with national and worldwide trends. This research is linked to the UN Decade for Healthy Ageing project that the Tauranga National Council of Women initiated in the Tauranga Region.

The United Nations (2020) Report on World Populations Ageing signals that the world's population is ageing at an unprecedented rate. It was estimated, in 2020, that people aged 65 years and older represented 9.3 per cent of the global population and this age group is projected to increase to 16.0 per cent by 2050. This indicates an expected population growth from 727 million people aged 65 years and older in 2020 to 1.5 billion people in 2050 (United Nations, 2020). These projections highlight the need to recognise effective strategies that will enable communities globally to support the needs of an ageing population (Kam, 2023).

The United Nations Declaration on the Decade of Healthy Ageing recognises, celebrates, and offers the pathways for further extending longevity across the planet, as a cornerstone of the UN Sustainable Development Goals (SDGs) (Global Coalition of Aging, 2021). The World Health Organisation (2020) supports the implementation of the UN SDGs through strategies aimed at reducing health inequities; challenging and addressing ageism; advocating for the provision of appropriate care and support; and working to ensure services are centred on older people. A background paper for the New Zealand Treasury commodifies the projected older populations consumptions patterns, noting that an ageing population 'will put an immense strain on public funds' due to a reduction in productivity, which will increase the risk of lower savings and higher interest rates (van Rensburg, et al., 2021, p.59).

A review of an ageing population can be constructed through many different lenses. In the New Zealand Treasury economic review of the impacts of an ageing population, Rensburg, et al., (2021, p.59) conclude 'people are living longer, healthier lives, and this must surely be a positive, provided that it does not unduly influence the ability of future generations to enjoy the same benefits.' This contrasts with a more holistic collectivist indigenous worldview of ageing that emphasises the leadership that older people provide (Durie, 2004), with a focus on productive activity through interpersonal relationships (Quigley, et al., 2022).

Two iterations of the Office for Seniors (2016, 2022) Attitudes Towards Ageing survey consistently report that New Zealanders' respect for older people is high, despite only 53% of respondents considering older people as a societal asset in the 2022 survey.

Contemporary western societal perspectives are more youth oriented, while older Māori are traditionally treated with a great deal of respect, especially as community responsibilities and recognition increase with age (Naughtin & Scholfield, 2013). Older people traditionally had a major and sometimes final say over matters of importance to the community, particularly in Māori communities where kaumātua (elders) are predominantly perceived as the guardians of knowledge and protocols (Mead, 2003). Giddens (1999) asserts the authority of both men and women often increases with age. Activist groups have bolstered this authority and influence by advocating for a more positive image of elderly people, highlighting their value and societal roles, and opposing ageism (Thompson, 2016; Williams, 2019). Despite current attention to discourses on positive ageing, ageism is prevalent and persistent. There is work to be done in Aotearoa New Zealand to push back against the dichotomous stereotyping of older adults as ‘vulnerable, declining or societal burden’ versus depictions of ‘affluent leisure-oriented older adults, the kind perfect grandparent, or the wise mentor’ (Amundsen, 2020, 2022).

The World Health Organisation (2020) celebrates longer lifespans as a considerable collective societal achievement as it demonstrates advances in health, social and economic development. The implications of an ageing population will be felt through ‘all aspects of society, including labour and financial markets, the demand for goods and services, such as education, housing, health, long-term care, social protection, transport, information, and communication, as well as family structures and intergenerational ties’ (World Health Organization, 2020, p.1). In Aotearoa New Zealand the UN Decade of Healthy Ageing provides an impetus for action focused on enhancing the wellbeing of older people in our communities. To consider attitudes towards age and ageing; to consider how the abilities and knowledge of older people can be utilised to strengthen communities; and to work towards care and health services that are more responsive to the needs of older people (Gordon, 2023).

Aotearoa New Zealand Population Trends

Congruent with the United Nations (2020) global population projections, people aged 65 years and over in Aotearoa New Zealand are an increasing proportion of the population due to people living longer and lower birth rates (Statistics New Zealand, 2022). In Aotearoa New Zealand the population of people aged 65 and over doubled between 1994 and 2020, reaching 842, 000. By 2063, this number is projected to double again, with the largest growth expected to occur before 2038 when the baby boomers enter the 65 years plus age group (Statistic New Zealand, 2022). In 2048, the proportion of the population 65 years and over is expected to be between 21-25 percent, by 2073 the projected proportion will increase to between 24-32 per cent (Statistics New Zealand, 2022). Some of the key challenges related to the expanding population of older adult noted by the Ministry of Health (2023a, p.1) in the briefing to the incoming Minister of Health were that:

- ‘our population is growing, ageing, and diversifying, and our life expectancy has increased faster than our health expectancy (the time we spend in good health), so more people are spending longer dealing with chronic health challenges

- some New Zealanders experience avoidable health outcomes, particularly for Māori, Pacific peoples, disabled people, women, and those in lower income households
- our ability to rapidly grow our workforce is limited in the short-term, so we need to balance our short- and medium-term investments to make improvements
- maintaining the quality of healthcare services in the face of rising costs and increasing need is a challenge, particularly following the global COVID-19 pandemic's impact on health and economic conditions' (p.1).

The Ministry of Health (2023a) acknowledged that due to impending fiscal constraint these stated challenges will result in a need to change in how agencies, providers and communities work collectively to address the key determinants of health in an environment of growing economic uncertainty. By 2030, an additional 16, 000 aged care residential beds will be needed to support the anticipated growth in the aging population; the demand for residential dementia care beds will double by 2040; and the demand for aged care residential beds for Māori will quadruple between 2019 and 2030 (Ministry of Health, 2023a).

Inequities in Life Expectancy

In a Health NZ (2024) Health Status Report it was noted that older adults utilise primary care services more often than younger individuals and face few barriers to access. As of March 2023, 98% of people aged 65 and over were enrolled with a Primary Health Organisation, and additionally 94% of older adults had consulted a GP in the past year, compared to 78% of younger individuals, and 38% visited a practice nurse, compared to 22%. The report also noted that older adults have a higher average number of visits (4.3 vs. 2.9). They are less likely to cite cost as a barrier to care (6.5% vs. 13.1%). However, significant disparities exist, with Māori and Pacific older adults more likely to report cost as a barrier compared to their non-Māori/non-Pacific counterparts. The Social Wellbeing Agency (2023) collaborated with the Ministry of Social Development and the Ministry of Health to calculate the needs of older people in relation to their health, housing, finance, social connection, and accessibility needs. They concluded that 54% of older people are doing well, but at least 33% of older people experience vulnerability and 13% have complex needs and therefore experience multiple disadvantages (Social Wellbeing Agency, 2023).

Life expectancy has continued to rise in Aotearoa New Zealand despite the impact of the Covid pandemic (Health New Zealand, 2024). Socio-economic and health factors have resulted in a rise in the age of the population, and medical science is advancing so people are healthier and as a result are living longer (Aldrich, 2010). The population of people aged 65 years and older are often viewed as a group that experiences better outcomes than other sectors of the population, however they are not a homogenous group (Social Wellbeing Agency, 2023). Life expectancy in Aotearoa New Zealand is currently 80.0 years for men and 84.5 years for women (Ministry of Health, 2023b). Inequity is evident for Māori, Pacific peoples and disabled people when considering life expectancy. Promises made in Te Tiriti o Waitangi for equity in ageing have not been realised given the persistent gap in longevity for Māori (Kerse, 2023).

Māori life expectancy is currently seven years less than non-Māori, Pacific people's life expectancy is five years less, while the life expectancy of people with disabilities as a cohort is currently unknown (Ministry of Health, 2023b). Positive ageing for Māori is impacted by health inequities that are grounded in discrimination through the on-going processes of colonisation (Glubb-Smith, 2020; Hikaka & Kerse, 2021; Hokowhitu et al., 2020; Parr-Brownlie, et al., 2020). Māori and Pacific people experience high levels of chronic health conditions and are less likely than other populations to seek health care support (Abey-Nesbit, et al., 2021).

Pae Ora (Healthy Futures Act) 2022

Currently, population-based strategies are being developed as a requirement by the Pae Ora (Healthy Futures) Act 2022. The stated purpose of this legislation is to protect, promote and improve the health of all. The legislation has a particular focus on equitable health outcomes for all population groups, in particular Māori through the establishment of a Māori Health Authority. The Māori Health Authority was designed to address the ongoing breaches of Te Tiriti of Waitangi that have resulted in inequitable health outcomes (Came, et al., 2024; Waitangi Tribunal, 2023).

On 30 June 2024, the Pae Ora (Disestablishment of Māori Health Authority) Amendment Act 2024 came into force to remove the Māori Health Authority established under the Pae Ora (Healthy Futures) Act 2022. The Pae Ora (Disestablishment of Māori Health Authority) Amendment Act 2024 was passed by the new National-led coalition Government under urgency without consultation with Māori (Baker, 2024). Te Tiriti o Waitangi establishes the right of Māori to partner with the Crown to design and implement health services (Hikaka & Kerse, 2021). The Māori Health Authority was an innovative world-leading initiative to eliminate institutional racism and rectify health inequities through the establishment of an independent indigenous authority to lead Māori health policymaking and commissioning (Came, et al., 2024).

The decision to disestablish the Māori Health Authority was agreed to in the 100-day plan that was finalised in the establishment of the coalition agreement after the 2023 elections (Reti, 2024). Due to the current Government's rejection of co-governance, the locality planning provisions in the Pae Ora (Healthy Futures) Act 2022 for joint decision-making has been repealed, however there is vague acknowledgement that 'there will continue to be a role for iwi-Māori partnership boards in determining local priorities for the health system (Cabinet Office, 2024, p.2). The impact of this legislative change is yet to be fully realised, but equity in health is through the process of honouring and upholding Te Tiriti o Waitangi (Keenan & Carryer, 2024; Lilley & Reid, 2023; Minister of Health, 2023).

Home and Community Support Services

The 'Ageing in place' policy was developed in the 1990's as part of a wider OECD strategy to reduce the amount of people living in residential institutions and support people to age in their communities (Davey, 2006). The ageing in place discourse reflects the personal

preferences of older people who value their independence and express a preference for home-based community support services to reduce the likelihood of them needing residential care (Rose et al., 2022). People being supported and assisted to remain at home also has the desired economic outcome of decreasing the numbers of people entering the more expensive option of long-term residential care (Tinetti, Naker, Gallo, Nands, Charpentier & O’Leary, 2002). The Health, Work & Retirement study Policy Report (2016) states that the trend in New Zealand towards ageing in place philosophy means “that many more frail, ill or disabled older people with high levels of dependency will be cared for within the community by family members” (p.5). The report noted that the negative impact of providing care was highest among women carrying a higher burden than men.

Moore et al., (2024) conducted a strategic assessment of aged care services in New Zealand and reported that approximately 80 000 people aged 65 years and older receive government funded Home and Community Support Services (HCSS). This home-based support is typically focused on assisting with personal care routines and household management tasks (Ministry of Health, 2020). In 2022/2023, the Ministry of Health funded \$732 million for this care, inclusive of respite care for informal carers (Moore et al., 2024). The latest OECD (2024) economic survey of New Zealand reports that by 2040 government expenditure on age-related health and pension spending will rise by nearly 3% of GDP. The OECD report recommends policy reform to control age-related expenditure, as pensions are becoming a significant factor in the increased level of new expenditure. This OECD recommendation is linked to the need to gradually increase the retirement age.

Home-based and community support services are usually accessed through a health and wellbeing (interRAI assessment) via Support Net in the Western Bay of Plenty. Support Net is the Needs Assessment and Service Coordination Service (NASC) for Hauora a Toi Bay of Plenty, Te Whatu Ora/Health New Zealand. Support Net provides NASC services for people aged 65 years and over who have long-term chronic health needs or a long-term disability or age-related health need. Support Net conducts needs assessments and service planning to assist older people to remain living as independently as possible. Support Net conducts the eligibility assessments of all people going into Aged Residential Care.

Collaborative partnerships and multi-disciplinary teams

The primary healthcare workforce has expanded to include social workers into the primary care environment by attaching them to general practices, family health centres and Māori or Pacific health providers (Döbl et al., 2017). Health social workers possess specialised knowledge, addressing biopsychosocial issues holistically to take into account the complex interplay between environmental, cultural, psychological, spiritual, and emotional factors, while still focusing on social justice along the micro to macro continuum (Foster & Beddoe, 2012; Glubb-Smith, 2020). Cultural values and social norms provide important insights into care-giving traditions. Utilising an ecological systems perspective health social workers are well placed to gauge expectations and work collaboratively to ensure care support provided is relevant to the person needing care (Glubb-Smith, 2020). Social workers based in the community, at iwi or hapu social services or community centres, are not constrained by

boundaries of secondary services, they are able to make home visits or visit residential care and therefore are able to provide a more responsive and integrated service (Foster and Beddoe, 2012).

Aotearoa New Zealand is witnessing a rising effort to incorporate health social workers into district nursing teams, large medical clinics, and private accident and emergency centres (Glubb-Smith, 2020). Health social workers are well placed to help people navigate their way through complex health and social issues, and therefore can assist with accessing practical information about relevant support groups, community resources, welfare rights and respite care (Glubb-Smith, 2022). This type of information can help maintain older people in their own homes and communities (Foster, 2002).

This literature review serves to introduce some of the key concepts relating to the home support needs and home support services for older adults in the Western Bay of Plenty. The next chapter of the report will explain the research design that was used to undertake this research. The following chapter describes the method and methodology used in this research, its reliability, and limitations, as well as ethical considerations.

CHAPTER THREE: METHOD & METHODOLOGY

This research sought to advance knowledge and understanding of the complex and varied needs of older people over the age of 65 years who wish to remain in their own homes, rented or owned in the Western Bay of Plenty. The study aimed to find out what the home care needs were and how they might be met, to allow older people to remain in their own homes as long as possible. This chapter of the report outlines the research design, methodology and research methods used to gather this information.

Research Design

The research design for this study follows a constructivist qualitative grounded theory research framework to explore the experiences and perceptions of people 65+ years living at home in the Western Bay of Plenty and the perspectives of needs assessors and care professionals. This research involved two phases of data collection with these two distinct groups. Multiple forms of data assists with situating the lives of the participants within wider social and political structures (Charmaz, 2020). The data collected from the two phases were compared and contrasted with each other and then with existing research to triangulate the findings. The study aims to generate insights into the needs and experiences of people aged 65 years and older in the Western Bay of Plenty derived from the data obtained from the following research phases.

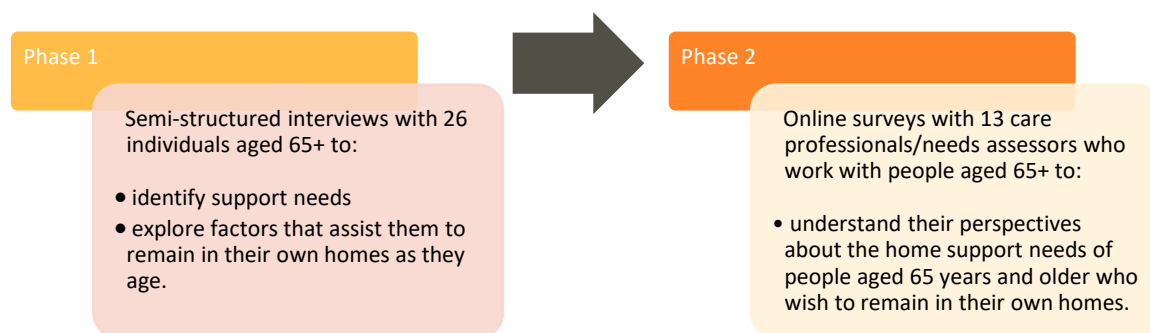


Figure 2 Phase One and Two Category Configurations

Methodology

This research drew on constructivist grounded theory and feminist theory to develop an understanding of the home care needs of older people who had an association with community centres, and social or health services in the Western Bay of Plenty. This research was initiated by the HCAG and represents a community-led initiative to improve the provision of homecare services to the over 65 age group in the Western Bay of Plenty. The research is representative of a wider movement towards increased service user involvement by older people who want to meaningfully contribute to the funding decisions that affect their communities (Bindels, et al., 2014).

As a community driven initiative led by an all women cast, the project enabled a rich collaboration between the research team and the experiential knowledge of the four community agencies that make up the HCAG. Feminist research acknowledges the way that life experiences shape research practice, and is mindful of difference, voice, and power (DeVault & Gross, 2012). Regular meetings were therefore held between the researchers and HCAG members to share updates and perhaps most importantly have reflexive discussions about the meanings being derived from the participant feedback (Brannelly & Barnes, 2022).

A constructivist qualitative research design enabled insight into the everyday subjective realities of people receiving care services and providing care, within the Western Bay of Plenty (Charmaz, 2020). Data interpretation within constructivist research acknowledges the influence of the research team's experiences and fosters reflexivity about the way in which both the researchers and the participants construct their social reality (Creswell, 2014).

Procedures of Inquiry

This section of the chapter outlines the specific procedures of inquiry used to consider the experiences and support needs of people in the Western Bay of Plenty who want to remain in their homes as they age. Information provided in this section describes the sampling and recruitment processes, data collection procedures, and the techniques used for constructivist grounded theory data analysis.

Research Participants

This research explores the specific experiences and unique views of two distinct populations: older adults aged 65 and above in the Western Bay of Plenty who prefer to remain in their homes as they age; and the needs assessors or care professionals who support them. A non-probability purposive and snowball sampling method was employed to locate participants (Patton, 2002). This sampling method enabled the identification and targeting of individuals who best represented the specific populations needed for each of the research phases (Davies & Hughes, 2014). This sub-section of the report will present the recruitment and demographic information for each of the two research phases.

Phase One Recruitment

The criteria for participants selection for the first phase of the research included being aged 65 years and older and currently residing in own homes (rented, owned or otherwise) in the Western Bay of Plenty Region. Additionally, the participants needed to express a clear preference for 'aging in place' at home rather than transitioning to residential or hospital care.

The research team engaged managers from community centres and Iwi social services to assist in participant recruitment. These managers functioned as independent third parties,

distributing information about the research to individuals within their networks who fulfilled the criteria for participation. This method was chosen to ensure that random selection of participants across the reasonably diverse older population in the Western Bay of Plenty region.

Two Iwi Social Services were successful in locating participants for this research. Efforts to recruit participants through community centres was not quite as successful primarily due to the lack of specific programmes for people over the age of 65 years within the community centres. With ethical approval, the researchers broadened their participant recruitment efforts to other types of community groups, striving to include individuals with diverse ethnic backgrounds, age ranges, socio-economic, geographical and gender characteristics. Over 30 community, health and social service providers were contacted in the Western Bay of Plenty region to seek interest of potential participants.

Phase One Demographics:

There were 26 participants interviewed in the first phase of data collection and the key demographic information about their gender, age group, ethnicity, and wider living circumstances is as follows:

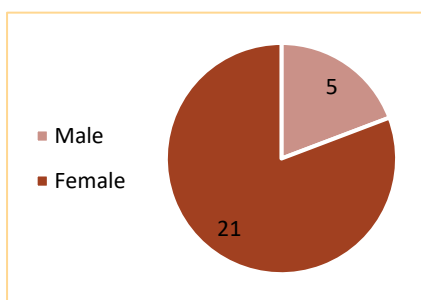


Figure 3 Phase One Participant Gender

Twenty-one of the participants identified as female and the other five participants identified as male.

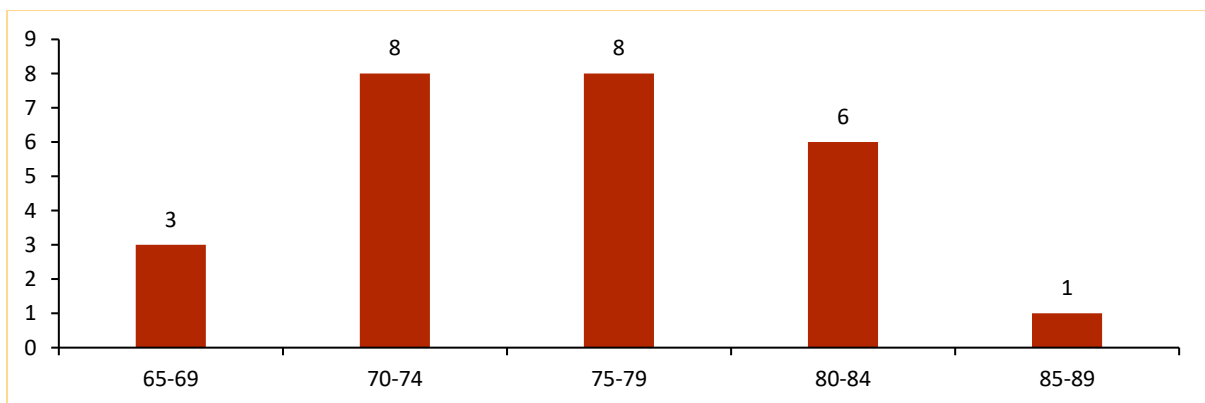


Figure 4 Phase One Participant Age Group

Over half of the participants were aged between 70-79, with no participants over the age of 90 years and only one participant aged between 85-89 years.

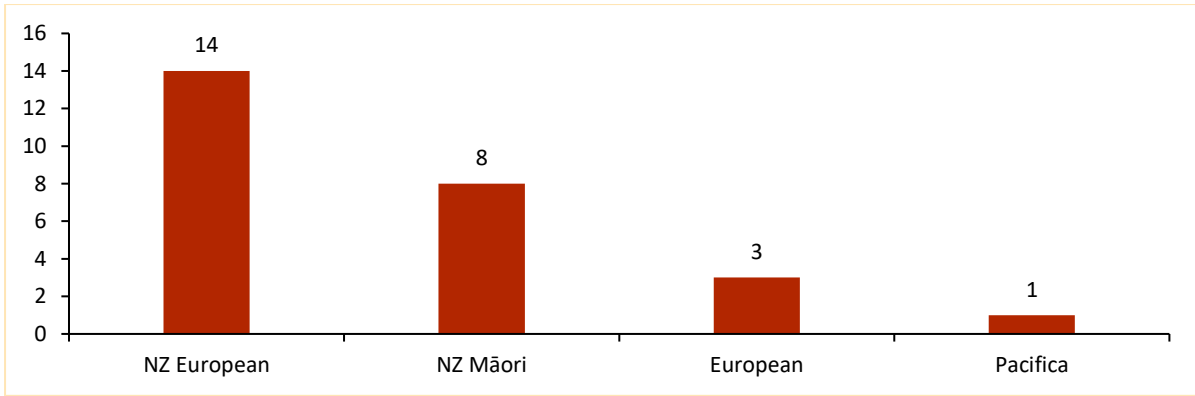


Figure 5 Phase One Participant Ethnicity

The majority of the participants identified as New Zealand European (New Zealand Pākehā), and all of the participants named a single ethnicity when questioned about their ethnicity.

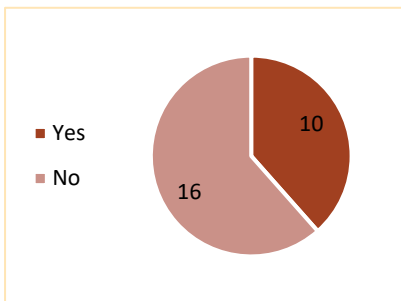


Figure 6 Phase One Participant Living Alone

Sixteen of the participants lived with either their spouse, children or whānau, while ten participants lived on their own.

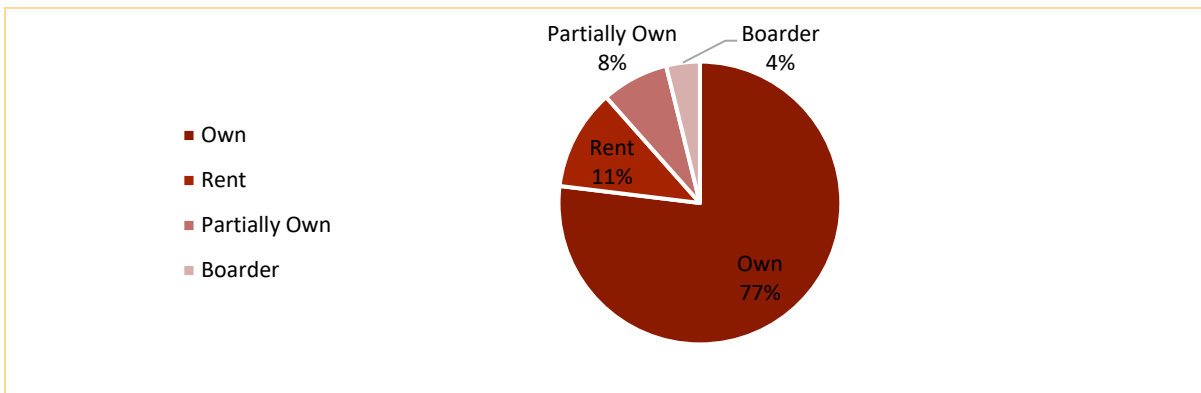


Figure 7 Phase One Participant Living Situation

Twenty of the participants owned their own home, with another two participants being partial owners of the property that they lived in, sharing the ownership with family/whānau members. Three of the participants lived in rental accommodation, and one participant boarded with people due to housing insecurity.

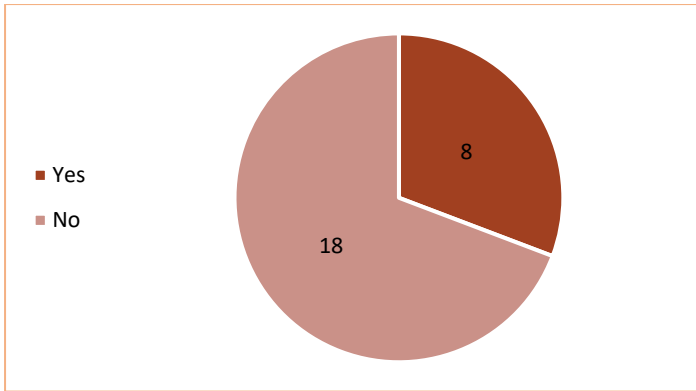


Figure 8 Phase One Participant's Providing Informal Care

In this report 'Informal Care' and 'Formal Care' are defined in the following manner:

- Informal Care: care in which a person in the home provides care, or the carer has arranged the care themselves. These care arrangements may be with either friends, family, whānau, community, or support people with no financial payment involved (but other exchanges may be made).
- Formal Care: care that is paid for, in the home. Primarily home-based care support that is accessed via a NASC needs assessment.

As portrayed in the figure above, eight of the twenty-six participants had a significant component of their interview reflecting on the informal care that they personally provided at home to an unwell family member. Seven of these eight participants provided care at home to an unwell spouse, while the other participant provided care at home to an elderly parent. Further to this, one of these participants also spent time in the interview reflecting on the impact of end-of-life care that they provided at home to both a spouse and an adult child. The other eighteen participants stated that they did not provide informal care to other family or household members. The interviews of the eight participants who are or were informal carers provided rich insights into the realities of being the primary care person for a family member.

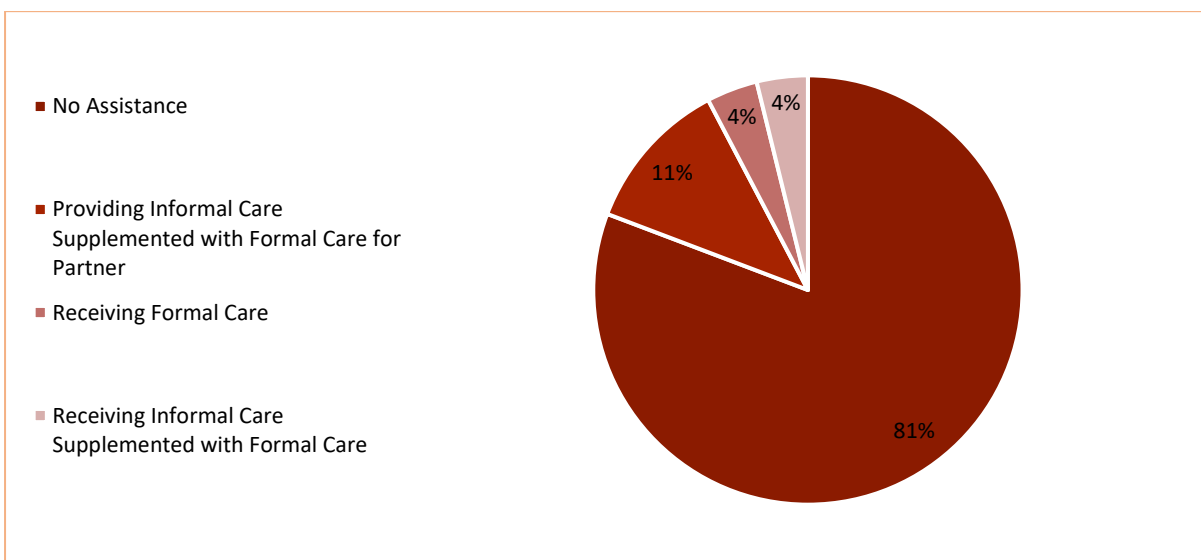


Figure 9 Phase One Care Assistance

This figure illustrates the types of care assistance provided to the participants. Twenty-one of the participants received no regular care assistance at all. Three of the participants had funded home-based care support in their own homes for their spouses, with them providing

the rest of the care. One of the participants had formal home-based care for themselves, and the other participant had formal care that supplemented the informal care that they received from their family.

Phase Two Recruitment

The criteria for participant selection in the second phase of this research was that participants were Needs Assessors or Care Service Professionals for people aged 65 years and above in the Western Bay of Plenty. The recruitment process for this phase of the research involved members of the Home Care Advocacy group (HCAG) contacting Care Service Providers for older people and Support Net Services Co-ordinators to introduce the study to the providers and to help locate participants for the survey. The principal researchers then received contact information from the HCAG, and reached out directly to the care professions, emailing them the link to the online Qualtrics Survey.

Phase Two Demographics:



Figure 10 Phase Two Participant Gender

There were thirteen participants that completed the survey and all of them identified as female. This gendered demographic was not unexpected given the gendered nature of care work in Aotearoa New Zealand (Charlesworth & Heap, 2020).

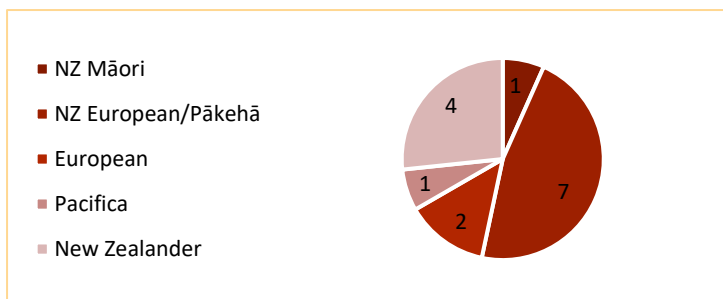


Figure 11 Phase Two Participant Ethnicity

Two of the thirteen participants recorded dual ethnicities in their online survey responses. Seven of the participants identified as New Zealand European/Pākehā. Four of the participants identified as a New Zealander without specifying their ethnicity beyond that category. There was one participant who identified as Māori, and another single participant that identified as Pacifica.

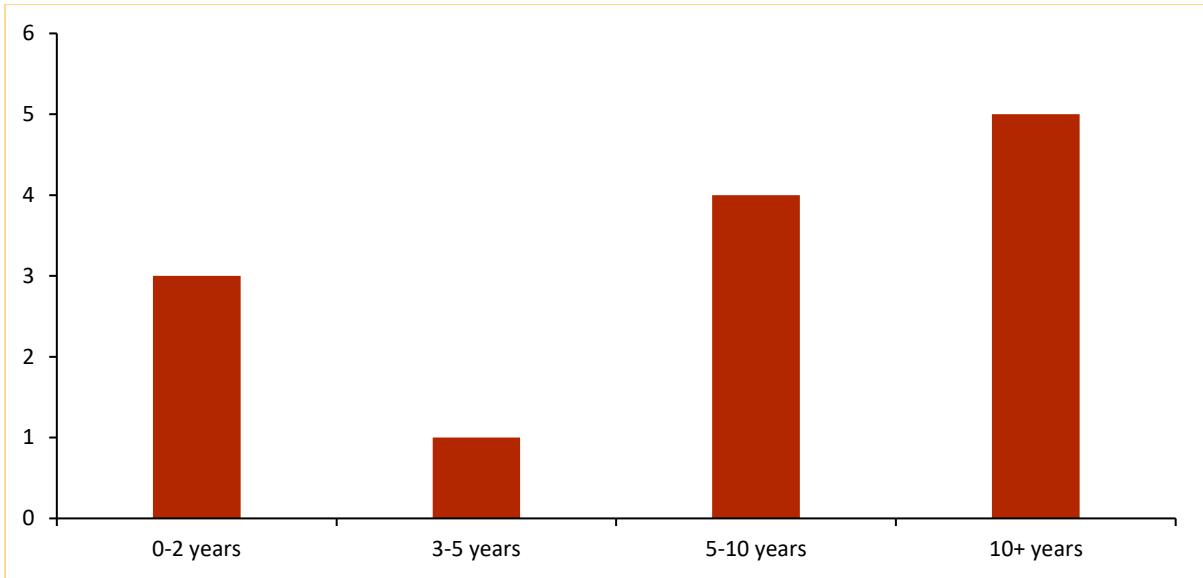


Figure 12 Phase Two Participant Years of Experience Within Their Profession

There were five participants that had over 10 years working as either a Care Professional or a Needs Assessor. The next biggest category was four participants who had between 5-10 years' experience. There was only one participant with 3-5 years of experience, and three participants with under 2 years' experience.

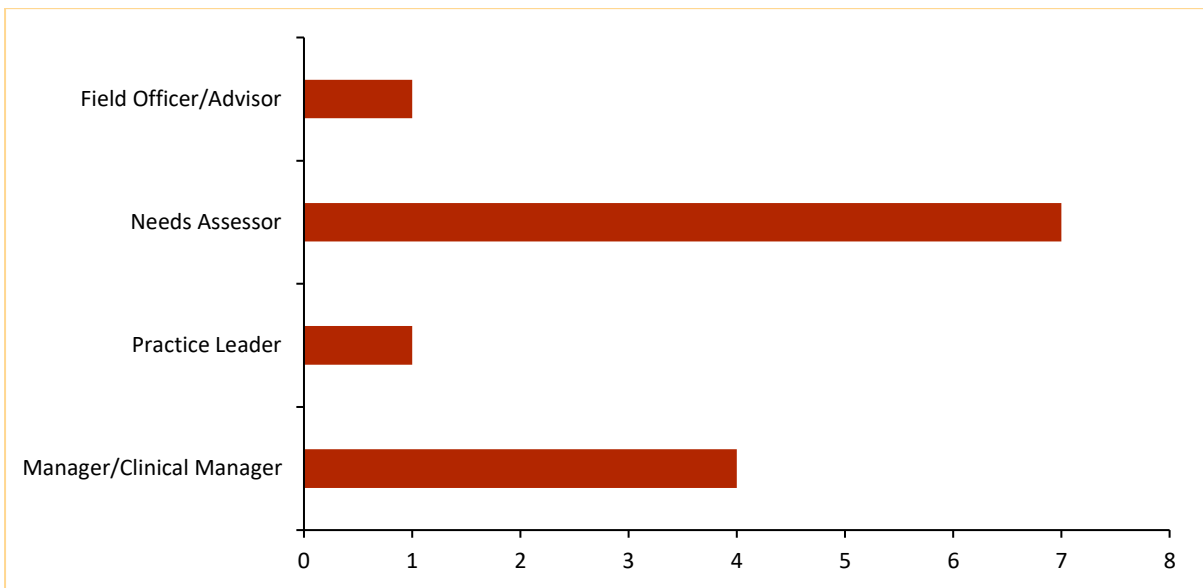


Figure 13 Phase Two Participant Work Context

Of the participants who completed the phase two online survey, seven of them stated that they were Needs Assessors. Four of the survey participants identified their role as being a Manager or Clinical Manager. One participant stated that they were a Field Officer/Advisor and another participant identified their work role as that of a Practice Leader.

Data Collection

The procedures that underpin this research project across both phases of data collection are explained in this section.

Phase One Data Collection

Phase one of this research involved conducting a series of intensive semi-structured, conversational, face-to-face interviews to gather rich descriptions of the personal, social support, cultural and practical needs which contributed to the participants living in their own homes, as opposed to hospital or rest home care. The interviews took place between September 2023 and February 2024. These interviews sought to advance knowledge and understanding of how the formal and informal home care needs of people 65 years plus, living in their own homes are met. In keeping with the research being a community-led initiative, the research questions were initially designed by the HCAG to target information that they wanted to know about the realities of aging in place in the Western Bay of Plenty.

The interviews were predominantly individual interviews, but family/whānau and wider support people were able to attend. As a result of the openness to have family/whānau in attendance to support the participant, three couples were interviewed together. The semi-structured interviews were between 60-90 minutes duration for the data gathered in a conversational tone. As there were 26 people interviewed, each member of the interview team conducted at least two or three interviews. All the interviews, but one, were audio-recorded. For the participant who chose not to be recorded, the UoW Summer Research Scholar was present and able to take handwritten notes.

The participants had chosen the venue for the interviews, which was principally their own homes, in an environment they felt comfortable in. One interview took place on a Marae and a group of 7 participants were interviewed in an iwi social service setting. Feminist research suggests that the interviewer makes time to build trust and begin to establish a more open relationship between themselves and the participant (Miller, 2017). Some participants were nervous about the interviews, some having never participated in an interview in their lives. Most offered a drink, which was accepted, as this action appeared to settle participants nerves and provide relationship building time before the audio recorder was turned on. This approach to relationship building aligns with the concept of whanaungatanga, emphasizing the development of connections and a shared understanding of the research objectives (Rewi, 2014).

Phase Two Data Collection

During the second phase of the research, data collection occurred from December 2023 to April 2024. Phase two of the research used a Qualtrics online survey to gather qualitative data of care service professionals and support needs assessors about their perspectives of the home support needs of people aged 65 years and older who wish to remain in their own homes in the Western Bay of Plenty.

Data Analysis

This section of the chapter details the processes employed for data collection across the two phases of data analysis. The research involved collecting data in two stages and then using a method of triangulation to validate and compare the findings with existing research to add depth to the knowledge gained. The figure below represents the main category headings developed from the two phases of data analysis.

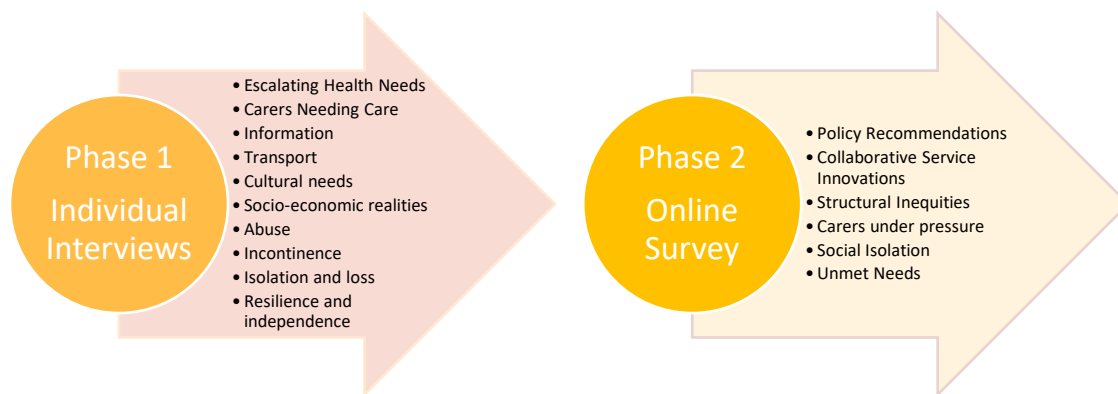


Figure 14 Phase One and Two Category Configurations

Phase 1 Data Analysis

The recorded interviews were transcribed using Otter.ai to establish a preliminary transcript. Each text version of the interview was carefully reviewed, with researchers listening to the audio recordings to correct any transcription errors. The corrected transcripts were then imported into NVivo software, where the data was categorised and analysed. Through iterative refinement, emerging concepts and focused codes were developed to capture key themes and insights.

In keeping with the constructivist orientation, it is important to declare the insider knowledge of the research team, as personal experiences, assumptions, and disciplinary perspective have influenced the research (Charmaz, 2014). The interviewers were all women, predominantly older women (four retired University lecturers) and one University lecturer. Three of the five interviewers were widows, some with the experience of nursing partners until they died, or having the experience of nursing elderly relatives, or friends with ill husbands. The other researchers had all supported older family members through the transition of needing home care support or into residential hospital level care.

This insider knowledge means that the interviewers had reflexive team discussions about the research interviews and subsequent analysis as a protection against bias and assumptions (Kanuha, 2000). Interviewers met more than once to debrief as some interviews were upsetting, and to identify and refine the many categories that were emerging. The data analysis and integration of the relevant literature, and findings was completed by the two principal researchers although the wide experience of the group were invaluable contributions and the Summer Research Scholar provided significant assistance establishing the data analysis within NVivo.



Figure 15 Phase One Category Configurations

Phase 2 Data Analysis

The Qualtrics online survey elicited 13 qualitative participant responses which were analysed to identify key codes. These codes were then compared to those formulated during the initial phase of research with a different set of participants. This comparative approach sought to elucidate consistent and divergent themes across participant narratives. Coding was further validated through the process of comparing the codes across the different participant groups. Consistency in coding categories across the two phases of research and then comparing the refined coding to findings in literature served to contextualise the findings, lead to more nuanced insights and strengthened the sense of research reliability. Insights gained from comparing the codes across the research phases and relevant literature have practical implications for interventions, policies, and further research about tailoring service initiatives to older people in the Western Bay of Plenty who want to age in their own homes.

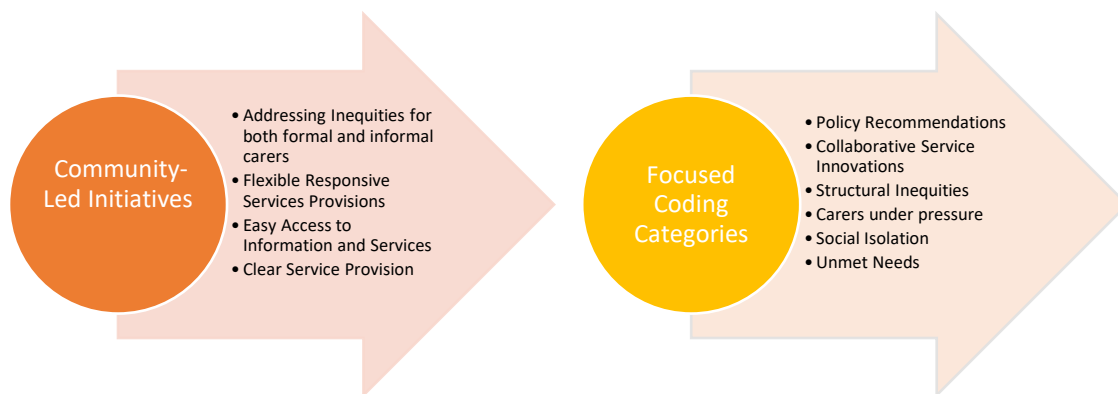


Figure 16 Phase Two Category Configurations

Reliability and Limitations

The constructivist paradigm required the researchers to gather data that is trustworthy, credible, transferable that can be confirmed, for the research to be valid. This research involved an analysis of the narratives of 26 people aged 65 years and over who want to age in their own homes in the Western Bay of Plenty, alongside the voices of 13 Western Bay of Plenty care professionals and needs assessors. The phase one data that was gained was rich

and full of detail about the realities of living in their own home as they aged, however, it was gathered from a relatively small cohort of people at a specific point of time.

The study limitations proved to be around the selection of participants to interview. As the Western Bay of Plenty region has well above the national average of people over the age of 65 years, there were limitless number of people who would have loved to be interviewed about their home situation and needs. The number required for a cross section of the population for a qualitative study needed to be managed. Over 30 invitations to participate were sent to community centres, social services and support groups that provided care services or needs assessments to the 65+ age group across the wider Western Bay of Plenty; and the responses received were from Eurocentric and Māori organisations. Further we did not want a homogeneous group of affluent older people who had chosen to retire in Tauranga.

We had assumed that community centres in most suburbs would have an extensive range of people using their services either as volunteers or as social service clients in the age group chosen for this study. It was a disappointing limitation to find that the chosen community centres, (mainly administered by Tauranga City Council) with managers, approached to recruit a cross-section of participants, in a city with such a high older person's population, did not cater extensively for older people. The choice of community centres proved to be a limitation, hence we had to expand the participant search into the health sector and gain further ethical approval.

The phase 2 data provided important commentary on the realities of assessing need and providing care services to this section of the population. Despite sending out the link to numerous care professionals, service providers and agencies, we only received 13 responses. It was hoped that we would receive participant responses from more care professionals who do the hands-on paid home-based support care, and the voices of this particular cohort could be the specific focus of further study so that the realities of formal care services can be further explored.

This study was conducted during the summer months, with the Christmas period in between. It is recommended further research be conducted outside of the summer holiday period, perhaps the winter months when managers of organisations may not be so stretched with deadlines, as this may have adversely impacted upon participation rates. Another limitation was that this research was not funded, apart from a donation from Rural Women to cover the cost of biscuits, petrol, and some stationery.

Ethical considerations

Ethical procedures and privacy considerations were followed. As identified the ethical issue of access to participants, was carefully considered as was informed consent, confidentiality, potential harm to participants and minimization of harm, their rights to withdraw at any time and ownership of the research materials. To safeguard the identities of the participants, pseudonyms were allocated to the interview participants, while the online survey participants are referred to by a number to differentiate the information between the two distinct participant groups.

Ethical Consent was gained from the University of Waikato Research Project FS 2023-37 dated 31 July 2023. Information sheets and Consent forms were prepared for Ethical approval. Some social issues and personal or family struggles did arise in some interviews, so it was important to not allow too much straying from the questions while simultaneously focusing on the voices of the participant. It was often necessary and important for the interviewers to debrief after their interviews with the principal researchers, while maintaining confidentiality and attention to privacy. The interview tapes were primarily transcribed by the UoW student on summer scholarship who had signed a confidentiality agreement and a principal researcher.

The research design has been described in this chapter to clearly explain the research methodology and procedures of inquiry. This chapter also sets the scene for the findings and discussion that follows in the next chapters, which will subsequently underpin the recommendations drawn from this research.

CHAPTER FOUR: FINDINGS

The primary research question focused on determining the support needs, both informal and formal, of those over 65 years old to enable them to stay in their own homes to prevent the need for residential or hospital level care. Initially, the research focused on the lived experiences of twenty-six participants aged 65 and over, residing at home in the Western Bay of Plenty. In the second phase, the study expanded to incorporate the viewpoints of participants who were either Needs Assessors or Care Professionals who provide services to this demographic. To differentiate between the participants in the two different phases of the research, the phase 1 interviewees' voices are recorded with pseudonyms, while the phase 2 online survey responses are numbered.

In this chapter, the findings from both research phases are examined in detail, correlating the findings with existing research on the health needs, personal costs, mental health, informational and social needs, community and transportation issues, housing, family support needs, personal mobility and time requirements of older adults.

The illustration below visually depicts the way that the category development occurred across the different stages of the research process. These conceptual categories were developed through the analysis of the individual participant interviews, and then iteratively refined through the analysis of the online survey findings to develop the principal analytic categories that represent the key findings of this research.

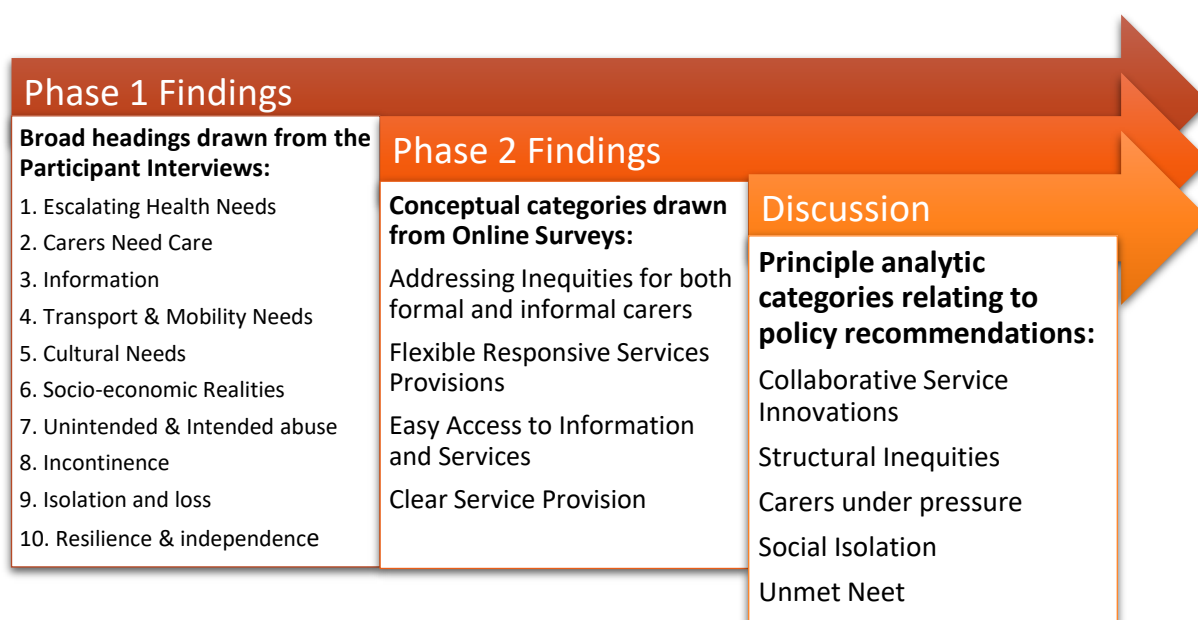


Figure 17 Development of the Principal Analytic Categories

Escalating health needs

The twenty-six participants who were interviewed were not a homogenous group. There was a wide range of living circumstances that impacted upon their health needs and age was not

an easy indicator of the amount of social or medical support needed to maintain wellbeing. For instance, one of the youngest participants' health needs were significant due to issues with his memory and eyesight, while the oldest participant was being well supported by a spousal carer. With the anticipated population growth in the Western Bay of Plenty there will be an increasing number of people in the 65+ age group experiencing vulnerability and multiple disadvantages (Social Wellbeing Agency, 2023).

Some of the participants interviewed experienced multiple indicators of disadvantage, relating to issues with poverty, literacy and complex health needs. A care professional's survey response reflected on the challenging work that she did dealing with social issues impacting upon older adults that can result in a loss of hope:

Some of my older people are suffering severe depression and other mental health issues (hoarding, PTSD, anxiety). It is very hard and sad when they have lost hope. Hope is what I try to restore and that is not an easy task sometimes. I have found that making progress towards regaining hope is often harder for older people. I have also noticed they tend to need more referrals to and support from multiple places; other agencies/doctors/specialist services, particularly around health care needs (Participant 13).

This quote speaks to the concerns held by the survey participants about the complex needs of people over the age of 65. The survey responses from needs assessors and care professionals often reflected worries about the escalating need and complexity of care, with many noting that one of their primary challenges is their "inability to provide services when it is clearly needed" (Participant 8).

A key goal of the interview participants was to maintain their independence through good health. Many of the participants were motivated to stay healthy through good nutrition and exercise, as depicted through this participant's reply when questioned about her goals "... doing the best to look after yourself, by the way we eat and to do a bit of exercise" (Sarah). The participants were not passive in their approach to their wellbeing and took conscious steps to safeguard it. For instance, Lucy, used an ACC app called 'Nymbi' to assist her with maintaining her fitness and wellbeing. Beatrice acknowledged she and her husband had managed to set aside some money to use for any future medical expenses. Beatrice emphasised the importance of planning ahead for changes in health while also living in the moment and doing what you can to be as mobile and active as possible.

Margaret reflected on action taken to proactively manage her wellbeing through regular screening, stating "I've been having blood tests every couple of years since I was 60, to keep an eye on if diabetes were coming. So being proactive." Margaret is aged 80-84, lives alone with very limited family or social support, she was also living with significant pain prior to recent knee and hip replacement operations. Despite this, Margaret had a bit of fun when answering the question about goals, amongst sharing some of the harsher realities of living in pain on your own as an older adult, as captured below:

Researcher: How do you think your personal goals influence your wellbeing and ability to stay in your own home?

Margaret: What goals? Waking up in the morning? [laughter]

Researcher: Is that a win?

Margaret: Yes, it is a win [laughter].

Researcher: How long has it felt like a win? Since all those operations or...?

Margaret: Well yeah, sometimes before them [the operations] you wish you didn't wake up

Researcher: You were in pain?

Margaret: Yeah. I don't know... I always said I was gonna live to 100. So um, yeah.

Researcher: So that's your goal - to live....?

Margaret: Yeah. I'm gonna have a card from King William [chuckle].

Being healthy to enjoy time with family, especially grandchildren was another common theme that related to wellbeing goals. Elisabeth stated, "We've got three wonderful grandchildren here, who are more than enough incentive to make sure you live as long as possible". Enjoying time with grandchildren was also seen as being a help with managing grief and loss. Alice stated that "my personal goals have changed considerably, in that my husband died not 12 months ago. And so, my personal goals are to maintain my independence and to enjoy life..., you know, just celebrate life and spend more time with my grandchildren."

Some of the participants who were most affected by a change in wellbeing were those with a partner who had long-term deteriorating health conditions such as Alzheimer's or Parkinsons. For some, the change in role came on quite quickly leaving them feeling anxious as to what was to come and in time realizing that their home situation could only get more challenging. Many of the participants portrayed this sense of pragmatic acceptance of the reality that their health needs were on a deteriorating trajectory. This sense of pragmatic realism is plainly demonstrated in this participant's statement "... there's no roundabout at the bottom of the hill" (Holly).

The keeping of good health was the most common response to being questioned about their goals. It was especially important if the participant was caring for others in their own home. Participants realised they would not be able to stay there, if they became sick or unwell or needed medical care themselves. The keeping of good health was also relevant to those couples caring for each other when well or for those living alone.

Carers needing care

Carers needing care was a significant finding of the research, and this was drawn from the commentary of the eight participants who spent a significant component of their interview reflecting on the informal care that they provided at home to an unwell spouse. The participants who cared for a spouse with significant health needs were more likely to delay attending to their own health needs due to the responsibilities that came with caring. The

findings identified there is a group of women who were caring for others, who were mainly husbands, without enough support to sustain them in their role as carer. As Alice, an interviewee said of her husband, who had recently passed, “He needed an awful lot to be able to stay at home that society didn’t provide.” For this group of participants, the carers were primarily women and wives caring 24 hours per day, with little respite during the 7-day week. This excerpt from Beatrice speaks to the unpaid labour that she did in her role as a wife “Again, really everything. If he's poorly, I get him food. I cook, I clean. I drive if he's been in for a colonoscopy that sort of thing? Then I drive him there, bring him back. Everything a wife does. Really. Too numerous to list”. Sarah spoke about the conscious decision that her spouse made to assist with housework when they had young children “he said ‘I see how much work you have to do. So, I've decided I will pick up my clothes off the floor. And I will bring them down to the wash basket.” As identified in earlier research, many women in this age group cared for their partners with whom they lived (Budge, et. al., 2016).

In response to the question as to what the participant’s needed the most to assist with staying in their own home, Alice responded that it was “good health and probably to a certain extent, some support for things that I can’t do any longer, such as cleaning the guttering and mowing the lawns”. Alice was a carer for her husband who had Parkinsons, she said that to please her husband she now has somebody coming in to do the lawns. Alice reported that even with this help she still struggled to look after her home. Alice’s response depicts a common theme of ‘struggling’ expressed by the participants who were yet to require daily home help to assist them with their personal care needs. These participants tended to place high value on their physical wellbeing and stressed the importance of maintaining it.

Personal costs of informal caregiving

The findings suggest that good physical, emotional and cognitive health may be reduced for those participants caring continuously for another, and that this care work was often gendered. This finding is consistent with the Alpass et al., (2013) research that demonstrated that while older caregivers perform a vital service for both society and the individuals they care for, they often jeopardize their own health and well-being in the process. Health systems all over the world rely heavily on women in unpaid caregiving roles, and this contribution needs to be acknowledged, quantified, and compensated (Davies et al., 2019).

The World Health Organisation (2020) UN Decade of Healthy Ageing Action Plan pays clear attention to power relations and norms in terms of gender and intersectional identity, acknowledging specifically that older women are more vulnerable to poverty, alongside being the providers of most of the unpaid caregiving. As older adults, women and Māori are more likely to assume caregiving roles compared to men and non-Māori, and the health of these older caregivers is impacted by their age, ethnicity and work status (Abey-Nesbit, et al., 2021; Alpass et al., 2013). The participants’ narratives reflected the findings of these studies, especially given that it was the women who were most often the primary carers, and most of the Māori participants whānau appeared to be committed to providing at home care for their elderly relatives.

Dementia is an umbrella term for a collection of symptoms resulting from failure of the brain involving a progressive decline in the ability to remember, think and reason (World Health Organisation, 2017). The World Health Organisation (2017) recommends a whole of government public health approach to engage people with dementia, their carers, and other stakeholders. Participants observed that caring for someone, particularly in the early or mid-stages of dementia, became challenging if the individual did not acknowledge or understand the strain their condition placed on those around them during their lucid moments. A participant with dementia stated that “I feel like I feel I am quite capable of looking after myself and doing things whether it's shopping. I pay the accounts; I'm paying electricity and water and I feel I can look after myself quite independently”. His wife's reality though was that she had two carers in place to support her and was having regular counselling to assist her with managing the stress of caring. A particular challenge for her was her husband's inability to understand the level of support he required, and this was a source of antagonism between them.

Society's understanding of the impacts of providing home care to a spouse with Alzheimer's, was said by one woman participant to be “very limited” and generally people did not know the “reality of what it is like to care for someone” and this is especially more difficult if the person being cared for, denies the diagnoses, or forgot it. This carer could see that the illness was only going to get worse. This lack of understanding about the realities of caring later in life often served to increase the participants' sense of marginalisation and alienation from others in their communities.

The burden of being a full-time carer, reluctant or not, also meant that there was no time for themselves, family, whānau, friends or voluntary work which one of the participants said, she enjoyed in the past but unable to leave her husband to participate. The longevity of the role was expressed as ‘unknown’, one carer said she needed a holiday at the time of the interview with one organised the following year with anticipatory care. Alice expressed frustration about the following experience of a needs assessment “one of the things I did ask for was, could I have someone to do the vacuuming? And I was declined because I'm an able-bodied woman”. At the time of the assessment Alice was providing care for her partner who required significant support due to having Parkinsons disease. Parkinsons is known for its tremors and motor skill impairments, however the disease is much more intricate than these symptoms alone. Constipation is a notable and often disregarded symptom, emerging years before the more recognisable motor symptoms (Neurological Foundation, 2024). Alice said that she was suffering from disrupted sleep and chronic exhaustion, however when she requested support in the form of house-cleaning so that she could focus on the needs of her husband she was declined. This sense of frustration was echoed by the survey participants, as evident in this statement about the biggest personal challenge experienced in practice being bridging the difference between “what clients wish for and what we are able to provide” (Participant 4).

Emotional health needs of carers

The personal cost of being a full-time informal carer, for some, it meant feelings of frustration with the person needing care. The constant repetition of instructions, or repetitive questions, and how the person being cared for, could be mentally oblivious to the impact their exasperating behaviour would have on the carer spouse.

For those who were too time poor to find someone to talk to about their situation, experienced loneliness, and felt an inability to cope. This person found that people pulled away from her because of what they might talk about. The question was asked “Who do I talk to?” (about her husband’s dementia). Another woman felt lonely because of the partner’s incapacity to communicate. One participant had been mulling over the hard decision of residential care for her partner in saying: “The other option is he goes into care, and I’m on my own, and I don’t want that”. This data was unclear as to whether she was referring to companionship for herself or for her partner.

Three of the survey participants specifically mentioned the needs of spouses caring for their partners who have dementia. Participant 1 acknowledged that for the person with dementia remaining in their own home assists, as it is a familiar place. It was noted that more day programmes providing respite for the at-home carer is needed and that there is a need for specialised “support workers trained in dementia care” (Participant 6). While this survey participant stated concerns about the unique difficulties that come with dementia, stating that “sometimes someone with dementia is independent with their personal cares but can't be left on their own” (Participant 4). These concerns mirrored the concerns expressed by the spousal carers in the participant interviews, as these carers expressed heightened feelings of having to be vigilant to manage risks due to memory loss, while also feeling trapped and isolated while providing care.

The personal cost also included the feeling of being imprisoned, of being isolated from social contact, along with the feeling of one wife saying she was “not able to cope” being on the edge of depression and sadness and needing to seek medical help. One participant had received a complaint about her care of her husband, so feared her own vulnerability of someone complaining about the care of her spouse, even though this participant felt she was doing the best she could, whilst needing to work. Social support is correlated as an important buffer in supporting caregivers of people with dementia as it decreases feelings of loneliness and averts the emergence of further stressors (Fekete, et al., 2019).

There was also the fear of losing the love in their relationship or questioning if, and when the love for the other person will be lost. On the other hand, another participant said they loved their relationship and would do anything required until death parted them, despite her husband’s dementia. Millar (2001) identified that many people caring for another 24 hours a day may pine for recognition from their loved ones or to hear some words of acknowledgement, with some in rare moments, receiving a response.

Physical health needs of the carers

The physical health of the carer is impacted and considered it could be severely impacted if the spouse got up to the toilet (and missed it) or wandered around the house during the night, resulting in broken sleep and tiredness for both in the morning. Such drains and strains, and lack of sleep led to exhaustion and heightened feelings, for the carer. When Alice reflected on what she needed the most to assist her to remain at home when caring for her sick husband, she stated that “I needed time to do all the things I needed to do.” With caring around the clock, another participant said she had no time for herself or for her interests, although they occasionally did go to some concerts that her unwell husband appeared to enjoy.

Recognising Carer Stress

Physical indicators can include:

Chronic exhaustion
Lethargy
Weight loss/gain
Frequent colds/infections
Backache/headache
High blood pressure

Emotional indicators can include:

Loss of interest and motivation
Anxiety
Sudden mood changes
Anger at self &/or dependent person
Feelings of isolation
Low self esteem

Adapted from Age Concern NZ (1995)

Although this is not recent literature the findings signal that in-home caring can create carer stress such as chronic exhaustion, anxiety, anger, feelings of isolation and the necessity of doctor’s visits for the care of the woman carer. Carers experiencing chronic exhaustion due to moderate to severe sleep deprivation is correlated with having to transition into residential care within a twelve-month period (Gibson & Gander, 2020).

Carer respite in the form of day programmes or overnight care can help support carers. Five of the thirteen participants surveyed indicated that the services that they provide target some form of carer respite. In response to the question ‘what would enable people over the age of 65 years to be better supported to remain at home?’. A lot of the participants’ responses related to reducing social isolation and the need to provide respite for carers. For instance, Participant 9 stated that the sector needs “to provide better in home respite options for full time carers to reduce carer stress”, while Participant 6 stated that there needs to be “greater availability of day programme/care, and respite care to support spouses/other full-time carers”. Participant 4 wanted carer support to be available during the day, acknowledging that:

Sometimes day programmes aren't suitable, and it is difficult for carers to attend to their own needs safely. Carer support needs to be more appropriately funded as it is only a contribution to the cost. Residential respite should be offered within the home. Carers to be available up until say about 9 PM - not everyone wants to go to bed at 5 pm (Participant 4).

Informational needs of carers

Understanding processes and systems when dealing with health needs can be complex. The interview participants often relied on family for information as well as more general support. Eligibility criteria for services often needs to be considered carefully and at least one participant missed out on follow-up care services due to difficulties understanding application forms and processes. The participants who were carers felt particularly time poor and stressed by the amount of knowledge that they needed to effectively manage their partners health condition. One participant felt she was bereft of information about the progressive nature of her husband's condition, questioning what support was available and what would be the impact on her own paid work role, which she needed and wanted to retain. She felt there was a need for a 'Bible' to follow which she would have valued at the onset of the medical diagnosis so as to dip into it, over the course of the ageing complication in their home. Another participant said she was "too tired to read brochures" even if there was a reaching out for information. She felt there was a need for someone to tell them about the medical condition, rather than just handing out the printed word.

There was also sadness expressed for those who are full-time caring who are not skilled enough to reach out for information or resources, able to advocate for themselves or others, or competent with technology, as it was assumed that getting help would be so much more difficult. It was certainly felt to be an advantage and seen as a positive aspect of caring, if the carer could use the internet, had time to read the newspaper or look for information. Fekete et al., (2019) highlight that older adults respond to the challenge of caregiving in many different ways and that a significant finding of their research was the importance of caregivers receiving relevant information about the challenges of caring early on so that they have realistic expectations and can adapt their lives accordingly.

Dudley et al., (2019) research into Māori kaumātua who have dementia concluded that whānau need urgent information to enhance their knowledge of dementia care needs and be involved in care planning. They call for integrated healthcare practices that draw on mātauranga Māori (Māori knowledge) to offer culturally relevant and thorough care for whānau.

Transport, driver's licence and mobility needs

The study found from the interviewed participants that the availability of their own transport was an important consideration to assist these older people to remain in their own home. With the population increasing in the Western Bay of Plenty some of the participants commented on the difficulties driving in fast busy traffic. "I can drive. I can do my own shopping" was expressed with pride by one participant, but this sense of achievement and relief was commonplace amongst participants who were still driving. Margaret noted the importance of a Tauranga initiative that aimed to assist people over the age of 65 with accessing public transport, she stated

There was a woman doing a project at Age Concern and she was getting house bound people onto the buses. That that type of thing because a lot of people, and it seemed

to be mainly women, maybe hubby had always driven, and he died, and she didn't drive or she was scared to, and looking at Tauranga drivers I do not blame her (Margaret)

Margaret was also a regular public transport user noted with bemusement that Tauranga is one of the few cities that you can't catch a bus to or from the airport.

The possession of a driver's licence along with the ability to get to medical appointments was vital for all participants. A couple interviewed together, mentioned that having a stroke or any other type of deterioration in their health and they lost their licences and not be able to drive "this would mean they had to make changes in their living situation". Finding a close enough park to the entrance of the Medical Centre was another concern for a woman caring for an ill husband. Many of those interviewed said there were always frequent medical appointments at the hospital, laboratory or Doctor's room, to drive their spouse to. It was said by Margaret, a participant that "Tauranga is not built for the non-driver". Perhaps for older drivers there may be that fear of losing their own licence, particularly if they themselves had started to lose their way home or to find the destination that was familiar to them a few months or years earlier, had given them moments of uncertainty.

For rural people it was suggested, that without a licence, it precluded them from medical access. It was said sadly, that in some instances, it could mean selling the family home to buy accommodation adjacent or close to public transport and facilities, as suggested by a rural dweller. The findings indicate that the loss of driver's licence may also constrict social activities and contribute to social isolation, disconnection, and loneliness, especially for those living in rural communities. Although writing about the reduction of health inequalities, social interventions across the life course in social work education in the United Kingdom, Coren et al., (2011) recommended that the care of older individuals should not be influenced by their location; having access to social and leisure facilities is particularly crucial in rural regions.

Personal physical mobility was another aspect of the need to assist people to continue living in their own home in the Western Bay of Plenty, in this study. Participant 1 noted that one of the ways they support people to remain in their homes is to make sure that the person providing the paid personal care service is keeping an eye on the person's mobility. "For example, a walk to the letter box to collect the mail, our kaiāwhina [workers] may notice they are not walking as easily as normal" (Participant 1). Personal mobility and agility to be able to do their own housework, climb stairs and just be mobile around home and neighbourhood, was seen as an important need of these older people, whether living alone or with another person. The findings suggest that a loss of licence or restricted mobility may also equate to a loss of independence and control of their own lives, a situation that was felt keenly by these participants over the age of 65 years.

Cultural needs

Out of the 26 participants in the first phase of data collection, eight of the participants were Māori. This section of the report will focus primarily on the cultural needs of the eight participants who are Māori. Some of the online survey response participants were acutely aware that there cannot be a one size fits all approach to older care service provision. For instance, Participant 1 expressed concern about culturally responsive practice, in relation to the ability of carers to understand tikanga (customary values and protocols). Participant 1 also stated:

We would love it if Te Whatu Ora looked at alternative solutions for rural and Māori whānau. Don't expect Māori to seek respite when they are ensuring their whānau get to 'age in place' at a rest home in the Western Bay of Plenty when none of the people in those places look like them. It's uncomfortable and upsetting. It means that they give up on the system and end up struggling alone, meaning those whānau members then require care themselves, for mental health, for burn out.....

For Polynesian cultures providing for the older person at home is a strong cultural value, tradition, and ethical responsibility. From the participant interviews, values that give emphasis to the whānau (family) unit, respect for elders, love for those in need, ongoing whānau traditions of care, protection, or strong views of self-sufficiency or filial obligations are concerns for caregiving and caregivers were evident. Due to traditional values, informal caregiving for Māori (and Pacific) communities is considered a cultural responsibility, supported by extended family. This shared caregiving aligns with their values of interdependence and community, reducing stress for caregivers but possibly leading to under-reporting of caregiver distress. (Schluter, et al., 2022).

Waldergrave et al., (2023) research into issues of loneliness that older Māori face emphasises the impact of disconnection from culture and whānau support, changes in roles of elders due to disconnection, and the grinding problems of poverty related to the trauma of colonisation. Land was a focus of some of the Māori participants' interviews, home ownership often related to whānau belonging and connection rather than individual ownership of the land that the homes were located on (Pihama, Beverland & Cameron-Raumati, 2023). Living on whānau land means that your community is present, as illustrated by Henry's comment about what he does when he starts to feel at a loss for something to do, "If I get bored, I just go to the next-door neighbour." For many of the Māori participants homes were not seen as being theirs to sell as they were located on whānau land, as one participant stated, "My husband built for the family.". This sense of collective ownership had an impact for the participant as her house was becoming unsafe to live in, she had no savings and reverse mortgages to pay for bills for much needed home maintenance was not an option due to not recognising Western notions of land ownership.

Many of the interviews for the Māori participants took place alongside a kaumatua programme, and they spoke about their needs being met holistically within this space. Millar (2001) noted that the status and respect given by Māori to their older men and women can be evidently seen, and this was true of the Māori participants who appeared to be very much involved and embedded in their communities. In Pākehā society, ageist views are widespread (Kerse, 2021). Old age is perceived to be unattractive as it is equated with reliance, and the societal status of older people diminishes gradually but is clearly observable in multiple ways (Maidment, 1996). This type western thinking still exists today and impacts Māori kaumātua (elders), however 'Māori culture has remained steadfast in upholding elders as cultural/community anchors (Hokowhitu et al., 2020, para.1). By and large the participants in this study were surrounded by whānau who were there to support and the whānau appeared to have back up plans for care if health needs deteriorated. One participant whose whānau support her holistically has taken a pragmatic approach to being open to go into residential care should her health deteriorate further, and this approach is being met with mixed reception by her whānau, as illustrated below:

I've said to my granddaughter and my daughter - 'We are only people, we are all people, and we get tired'. You know, we will all get tired. It is all very well to say 'Nan, I will look after you'. I said 'there will come a time' I said 'you're not going to sit beside me. 24 hours.' So I said 'You will have no choice but to put me in a home and that is fine with me (Em-Jay)

The participant interview with the person who has Pacific heritage highlighted the importance that she too put on caring for a family member. It was evident in the interview that she was exhausted from constant caring for a sick spouse, to the point where her own mental health was at-risk, but in her interview, she did not immediately consider residential care as an option for her spouse.

The eight Māori participants in this study upheld their valued place in society, conducting many years of work for their communities and still doing what they can when they are physically able. This sense of belonging and community activity is exemplified in the following participant's dialogue:

"I've only been retired two years, but I've been busy. I always like a mission, always like something to do" (Isla)

"I'm always busy at the Marae. I have a marae meeting this weekend. When you are brought up your mother did what she did, and now it is all on me [meaning marae-based work]" (Ruby)

Researcher: So, isolation can be a serious health risk for people who decide to age at home. So, do you feel isolated or lonely?

Lily: Never!

Researcher: And so, what sort of social activities do you enjoy?

Lily: Oh, I come here [Hauora] two days a week and a [kaumatua] Group on a Friday. I [also] go to meetings.

These interview excerpts are typical of the Māori participants in that they were engaged with both their whānau and the kaumatua supports within their communities, alongside keeping busy at the marae. The narratives demonstrated that the values underpinning Māori society are enduring for the participants in this research, as they tended to be an active part of their traditional communities (hapū and iwi) and not disconnected due to wider trends of urbanisation and migration.

Work, financial and economic needs

The HART (2023) study identified that whilst caring may be invisible carers feared being perceived unfavourably at work due to their caregiving responsibilities. Alice spoke about having to give up a “dream job” because her husband had “got to a stage where he was so unwell that he I couldn't leave him. The financial cost to another participant was suggested as losing or having to resign paid work, which was part of the reason she could pay some formal and some informal substitute care for her husband while she was absent. To continue her job this participant said that extensive planning was required. Plans were needed for changes in her work schedule to provide travel to medical appointments, plans for organising informal carers or friends, or respite care and weekly paperwork that accompany it. She also had to make plans for simple jobs for her spouse to do in her absence, such as collect the newspaper and mail from the gate or walking to the dairy to buy needed items.

The aging population labour force has recently increased, demonstrating a trend for later retirement, it is noted that these workers can be valued for their experience, depth of knowledge and industry networks (van Rensburg, et al., 2021). As the HART (2023) study suggests, many caregivers make a “vital and economically valuable contribution to society” by caregiving and being able to work, although this means that carers struggle with the challenges this ‘juggling act’ entails (p. 171).

The participant named Hazel suggested that her home needed to be altered to improve her wellbeing, but she could not afford it. Health insurance was also felt to be unaffordable. Hazel said she needed to know where she could “get financial assistance if she needed it with things like trees being cut down and that sort of thing, it is really the maintenance side and I know people say ‘oh, just give aged care a ring’, but it doesn’t always work like that I don’t think”. She further indicated that “I’ve probably got sufficient funds that if I need to, I

can get somebody to help with vacuuming or anything that I find difficult,” which suggests Hazel is finding this task too strenuous.

To pay for care needs, a male participant needed to downsize and gain a reverse mortgage as he had to travel to fulfil his wife’s will. This person had received an inheritance but there was none of this left, so he had to pay for care out of his own pocket. Another participant had indicated that they could not afford a medic alert device. Evidence from the HART (2023) study suggests that older caregivers experienced a decrease in psychological well-being, which was associated with poorer living conditions, unemployment, living with the person needing care, and inadequate support from friends and family for daily activities, leading to heightened psychological stress.

On the other hand, rental accommodation participants Elizabeth and Barb stated “they had health to look after themselves with, we’ve got the money to pay the rent and the power and all the rest of it” in their home. While Alice worried that if she had to pay someone to help with her husband’s care, she would have had to cut back somewhere else on her pension.

Housing, socio-economic status and hardship

The findings of this study suggest that to continue living in their own home the “managing and keeping good health helps them continue to live in their own home” and this couple said they “put a lot of effort into this”. The husband thought mobility, being busy and active was very important, although they knew this could change at any time, but hoped this (eventuality) was still far away. The couple said they owned another house in Mount Maunganui, for downsizing later, but would not consider living there currently, although it would be very central to a lot of things. Having a “purpose in their lives and setting goals” was deemed important to them, this helped facilitate their wellbeing and their wanting to stay in their own home and develop their large section and their love of gardening.

The study only asked quantitative questions about housing such as whether their home was owned or rented. The study findings suggest that most participants were content with their housing, not mentioning it as a need in response to the study questions. However, a few participants were concerned about home maintenance unaffordability and Māori participants were more likely to mention risks incurred through substandard housing, as characterised in the exchange below:

Lily: See if they can help me with my outside walls. They're old and all, my son put a new one up and could just put your hand right through the....

Researcher: So, you need some more boards?

Lily: Oh, just the whole place needs redoing, I think..... It is just myself I'm thinking do you fix it? But no, finances are pretty hard at times.....

The Health and Aging Research (2023) also found that housing tenure was an important determinant of health and wellbeing for older people, as it provided a sense of psychological security for older people and possibly feelings of safety in the neighbourhood. Coran, et al, (2011) suggested that one way to promote independence and protection from danger or harm of older people is the provision of extra care housing. They also recommended providing in-house social, recreational, and medical services to enhance safety and protection, maintain independence, and strengthen the sense of community and security.

Although Retirement Villages are said to improve both independence and security for older adults, not all of the older adults wish to live in them or can afford most of what is offered. Further, as people age there can be the impact of the worry of the financial consequences of dying without means to pay for a funeral, cremation, marked grave or plaque, particularly if there is no or limited family involvement. A question about socio-economic circumstances was not asked in this study, but financial worries were indicated by a few participants.

The next chapter provides examples of the impact on unpaid carers, usually wives, who bravely but silently disclose the impact of a serious disorder, on their lives.

CHAPTER FIVE: FINDINGS

The findings below illustrate some further examples of the unfolding of the symptoms of dementia in some of the home care situations and a situation of reported abuse. An example from a participant interview related to observations made about a person being cared for in his home by his spouse and him over-estimating his own abilities. He thought that he was quite capable of many of the normal activities of daily living, however, his behaviour proved otherwise, and this was obvious to others around him. The unwell person, especially if they have some form of dementia, such as Alzheimer's, are often unaware of the impact of their behaviour and can become upset by restrictions imposed on them to keep themselves safe as the condition progresses.

One participant whose husband was no longer allowed to attend a local care programme designed to provide carer relief, due to his verbal outbursts spoke about his dementia stating, "with his condition he can't remember what I've said, so it's not his fault, it's his condition. But it's all very well and sometimes I can't take it. I find it a struggle". This quote doesn't quite demonstrate the depth of the challenges that the participant felt, as the participant was quite emotional during parts of the interview. The day programme struggled to contain his behaviour to keep others safe, while she herself was dealing with the behaviour one-on-one entirely on her own for most of the time.

Another view from a participant who was caring for her husband was:

I still think Alzheimer's is a grieving journey. Yes, it is from the moment of diagnosis, you know, where it is going to end up, it is not about if it is when that happens. But it is both a blessing and a curse. It is a blessing in that you have got time with each other even though this person who has been such an active, involved, cheery person has all disappeared. But can I say the shell is still there and therefore for a person who has memories that's important (Shannon).

These findings are consistent with the literature that states that the onset of Alzheimer's symptoms is gradual and hard to pinpoint, with only the closest person noticing the changes. Early on, individuals can often maintain convincing social interactions for short periods. The changes are often mistaken for normal aging, including language difficulties, significant memory loss, disorientation, impaired judgment, personality changes, reduced ability to perform routine tasks, and mood or behaviour changes. These early symptoms can be difficult to distinguish from grief, depression, stress, or anxiety. As the disease progresses, daily living becomes increasingly challenging, and some individuals may eventually become completely dependent and inactive (Millar, 2001).

Unintended and intentional abuse

One participant reported experiencing unintended abuse in the form of potentially lethal aggression by her husband who was unwell. The most frequent behavioural and psychological symptoms seen in people with dementia include apathy, delirium, depression, hallucinations, irritability, anxiety, disinhibition, sleep disturbances, abnormal motor activities, agitation or aggression, changes in eating and appetite, and episodes of elation or euphoria. (Bozgeyik, et al., 2019). Aggression is a type of behavioural disturbance commonly seen in neurodegenerative diseases, with recent studies indicating a high prevalence in Parkinson's disease and similar conditions (Macchi et al., 2022).

The participant said that her husband lacked awareness that he could be violent and had threatened and even strangled her. She stated:

They think he had it (his condition) about 20 years or more. Because it is when I first woke up with his hands around my neck and I never thought I would get them off. And from time to time, he has had a violent dream and I have just managed to wake him up.

Behavioural changes that lead to aggression, physical attacks, and verbal abuse can be very distressing and may cause family and others to feel alienated (Millar, 2001). Caregiver burden is further exacerbated by aggression from those they care for, as these hostile behaviours are strongly associated with increased depression and care resistance among caregivers (Macchi et al., 2022). In the context of the need for in-home services, the situations occurring behind closed doors can be lonely, isolating, abusive, and violent, contrasting sharply with the idealized vision of ageing in place (Mathews, 2012).

On the other hand, Foster and Beddoes (2012) state that the reverse can happen when those 'aging at home' can be supported by stressed caregivers, sometimes with multiple responsibilities, which may or can lead to situations where abuse, neglect and exploitation of older people can occur. Either way, the data interpretation indicates that support is needed by either the carer or those being cared for. In either case it is unlikely that support will be sought from the Police or by legal intervention to restrain a close relative.

The participant findings suggest that some people needing 24/7 care are unaware of it, that they are cared for day and night, and they need constant supervision during the day and for some at night-time, if they do not take sleeping tablets. For those enduring this type of health issue there is a requirement for someone else to co-ordinate their care, while the person being cared for, can be unaware of strain placed on loved ones or carer.

Fear of violence, embarrassment or abuse may restrict the activities of those that are caring or those cared for in this age cohort, who may be particularly embarrassed to speak of it. Although only one instance of physical abuse was identified in this study, abuse can be physical, psychological, financial, sexual abuse, abandonment, neglect or self-neglect. There

is limited research into what contribution or factors may arise from the person being cared for, to provoke what may be considered abusive behaviour. However, there can be a continuum of progressive behaviours in the older age group such as a need to control, misuse of power, jealousy, marital discord or alcohol or drug abuse. Factors can also be a partner's acceptance of obedience as a means of control, past modelling of physical aggression, a person abused as a child or aggressive personality styles.

Two of the participants talked about being scammed "I got scammed. \$600", while the other participant lost significant assets due to an investment fund that was later under significant scrutiny from the Serious Fraud Office, however charges were not laid. Financial abuse was also a concern expressed by one of the participants in relationship to what he observed with a good friend during the final months of his life as described below:

Richard: Lots of leech type people hanging around this friend of mine. They were scalping him of stuff. And it was a bit cruel. But anyway, I was gonna get all heavily involved at one stage, but then I thought, nah, not my business. Yes, yeah. He was. He was financially abused. Yeah. Because of the situation. I feel. Yeah. Because he was....

Researcher: Vulnerable? Were they family members or...?

Richard: Nah that one in particular wasn't. But you know, [friend] was a very generous person in his own right anyway, if the people had asked, [friend's name] would have given them the stuff. You know. But none of that was agreements, made and then never met. And then [friend's name] passed away, and the debt was just never paid. horrible situation. But yeah, never mind. They took advantage of a good man. And I think he died knowing it.

Incontinence in unwell person

The toileting assistance required of an unwell person day and night was a finding in this study, which was hard for participants to talk about. An unwell person's unawareness also spills over to the fact that incontinence can cause considerable washing and cleaning work, frustration, and concern for the carer. Spills, inability to find toilet or misjudgements of receptacle, and misses of the toilet, or incontinence during the night can mean considerable extra laundry for the carer and at times the need to change the bed linen during the night. One of the most pressing needs for support for the care of a person living in their own home, is for relief to help with toileting during the night or at least assistance or respite care so the carer, usually the wife, can be re-invigorated by a good night's sleep.

Alice indicated how trying it was when she had consistently a disturbed night's sleep, "...so it would be six times a night to give him assistance because he was never able to lie in bed and use a bottle." She reflected on how "he would stand a while, but sit before finishing peeing", so "that meant the sheets were wet, which meant having to change the sheets, even though

a draw sheet was used, this went on the line”, meaning the draw sheet was already wet. She continued relaying her difficult journey by saying,

and then we did get [name of service] home care in I had to pay for them to come and stay, but at \$200 a night I could only afford that two or three times, but it would just give me a night where I could have a sleep all the night through, but it also meant changing rooms. The hospital bed there was helpful, although he did not like the cot sides up. And he used to have nightmares so sometimes he would leap up against the cot sides...To have someone there at night would have been magic...and I mean really taking care of him. About 8 o'clock at night we started to go to bed, but it would take him a couple of hours to get organised to go to bed. And yeah, it was bloody tough I have to say. It was tough.

The findings suggest that respite care at another venue from the home is not always practical, agreed to by the person cared for, or available, when needed. Further, two carers did not wish for their husbands to go into respite care.

Distress was also felt when the wife would take her husband for an outing and found it was difficult to access parking outside public toilet facilities and having to assist him in the male toilets, as he did not know what he was in there for.

This chapter has disclosed some participants' views on difficult home care situations, such as unintended abuse, concerns about intentional abuse and hygiene issues. The following chapter discusses the findings into the informal support needs, such as self-care, family, whānau, friends and the need for wider community support.

CHAPTER SIX FINDINGS

This chapter presents findings from interviews and literature regarding the homecare environment, support needs and experiences of solitude and loss in older adults.

Although the study findings indicate that some of the carers need care themselves, most of those in this study recognised that they had to act themselves to preserve their sanity and care for themselves, by taking steps to reach out for help. On the other hand, John, whose wife had just passed, lamented that “I am just a husband who loved his wife and didn’t want anybody else to be doing for her that I could do”.

The research data suggests that generally the full-time carers felt invisible to families, their families did not recognize what was going on, be short of understanding, or lacked awareness of what it was like for the carer, particularly if the person cared for had been diagnosed with Dementia or Parkinsons. It was felt by some that this was because in some cases, the family members lived far away. Some of the carers reported that they did not like to ask for help or tell family that they needed help. This finding supports the New Zealand literature which indicates that some older adults will require assistance when their families are unable to offer support and care due to family fragmentation (Aldrich, 2010). This author asserts that due to work commitments, families frequently cannot provide care for their older family members, and this adds to pressure in families. Many suburban communities are often empty during the day due to work commitments, and this can lead to older individuals having restricted social networks. With the prevailing trend in ‘ageing in place’ focuses on informal family support there are clashes with policies that encourage all able members of households to work or be in study (Aldrich, 2010).

Two participants did not want to ask family members for help and in one situation where the family members lived close and another an hour away, the husband with Dementia refused to let his wife tell the family of the extent of his condition, how it was for her and that she needed their support. As Millar (2001) states, “many families have deep wounds from past events and relationships. While a person is still alive, healing, reconciliation and forgiveness is possible even when they have dementia. For many families the opportunity to give and receive love is precious and helps to create some meaning out of the suffering” suggests Millar, (2001, p. 79).

For most participants in this study community contacts were very important. Friends, church friends, community groups, neighbours and care from other people who understood the illness or had their own partners with the illness were highly valued. As one participant said: “your whole social life really involved people who were affected by Parkinson’s because they could understand” which may be a comfort when there is “the frightening world that you navigate”.

A woman participant had an over the phone prayer partner, while another participant read her Bible every day. Yet another participant illustrated how she drew on her spiritual beliefs when times were tough, "I found an inner strength through believing in a higher God, and he saw me through many occasions." According to Millar (2001) "the religious traditions that have been part of life for many people should not be overlooked. People with dementia often find the familiar rituals of worship in a service very helpful and calming.... It is another loss of a person's life when they can't attend their place of worship. For the carer it is very painful when their church community forgets and doesn't offer support to them or their loved one. Family members can find it very meaningful to share in a service when their loved one is in residential care. Some homes encourage this" (p. 78).

Given the gradual decline of physical and or cognitive abilities older adults can become increasingly dependent on family members to make and sustain relationships. Millar (2001) states that for a person with dementia the essence of the person is unchanged, and the memory loss can result in patterns of communication and interaction occurring at a deeper and more basic level, 'where the language of love given and received is the language of the spirit and not dependent on words alone' (Millar, 2001, p. 79).

An older person's sense of self-worth and personal well-being is significantly influenced by how 'help' is provided. Research unsurprisingly shows that incorporating reciprocity into the helping relationship is linked to higher life satisfaction (Maidment, 1996). The findings of this study indicate that there was a degree of concern about the well partner becoming ill or disabled and unable to continue care. The literature assumed that an ageing person or couple will have children to step in and care for the older person or persons. This quote from the literature below by Roland (2018) also suggested that the older person can afford assisted living or skilled nursing care.

"An older couple who knows all too well about living with a chronic illness may be acutely aware of what their relationship could withstand if the well partner were to become ill or disabled. These couples may benefit from help in addressing realistic concerns about the need for enlisting greater support from adult children or extended kin or hiring a part- or full-time caregiver. In cases of more severe disability, they may need to consider a move to an assisted living or a skilled nursing facility and possibly being separated in the process. Fostering open patterns of communication and joint decisions about future eventualities are the best preparation for these critical life-cycle junctures" says Roland (2018, p. 271).

The study found that those participants who were looking after a partner for 24-hours found this task hard to bear. Many of the caregivers found it difficult to find help. As Millar (2001) asserted, women often find it more challenging to accept help compared to men, who research shows, are better at seeking practical assistance. Respite care is crucial for wellbeing, along with having someone to share emotions and issues with. Friends, family, and health professionals play a vital role for many informal caregivers. Discussing a person or

partner and admitting their difficult behaviours can make caregivers feel disloyal; however, bottling up the frustrations can also be detrimental to the relationship.

A lonely journey

True friends are like diamonds precious. There'll be people that have been very dear to me and near to me that I connect very well with... But sadly, of recent times, so many of them have just passed away (Sarah).

“I'm scared to open the paper some days. Who is gone now” (Olivia)

The quotes from the participants about the realities of feeling alone in later years of life were rich and varied. Below is an excerpt of Em-Jay's interviews when she is with her adult grandson who is concerned about her being alone too often, despite the fact that Em-Jay lived surrounded by whānau:

Well, everybody is dead now. A couple weeks ago, I had my grandson at my place, cutting hedges and what have you.

And he says: 'Nan, can I ask you something?'

I say: 'Ask me anything you like'.

And he goes: 'Why don't you have friends? Do you have friends?'

I said: 'Yeah, I got some friends here'

And he says: 'But you've been here a long, long time, and I haven't seen anybody come to see you'. You know. And he goes, 'Why?'

And I said: 'Do you really want to know why?'

And he goes: 'Yeah'.

I said, 'They are all dead'.

Erina's situation was quite different, and she is adjusting to a life stage that has left her feeling isolated

“The only true time in your life you're isolated is when you're old and alone. When you think about it, from birth, you've got someone right through there's people but when you start to live alone when you're old you can become shut in” (Erina).

For other participants this isolation could have serious consequences, as illustrated in Lucy's statement “But if I fell over in my house. How long would it be before somebody noticed that I'm missing? The neighbours might notice that I haven't pulled the blinds, but they might think ‘oh, she's just gone away and hasn't told me’ or something like this” (Lucy). Family and whānau were central to overcoming feelings of isolation in the participants who

were fortunate enough to have loved ones living close, as illustrated in Elisabeth's comment "We've got three wonderful grandchildren here, who are more than enough incentive to make sure you live as long as possible" (Elisabeth). Conversely, some participants enjoyed the quiet life, living on their own surrounded by whānau support, as illustrated in this participants statement "I'm on my own and I like it that way. I have 18 Mokos [Grandchildren] and I always had the Mokos staying with me going to school in Tauranga [laughs], so it is nice to be on my own love."

In this study a participant who was living alone but vulnerable to losing mobility with frequent operations, reflected on her relationship with her children and a few partners. With two children living overseas who text on her birthday, and one in Auckland, she has not seen in many years, the family contact is very limited. Apart from the occasional visit from a grandchild, in-home care and a weekly game of cards her social contact appeared minimal, with many hours each day alone. She indicated that "being an introvert helps" as she felt she "did not need a lot of people" for social contact. This finding may relate to what the NZHWR study (2023) refers to as emotional loneliness caused by an 'absence of an engaging and desirable social network" (p. 204).

To offset this some of the care services specifically targeted issues of loneliness, recognising that the care professional visiting might be a significant point of contact, while other care services were able to specifically cater to issues of older people being isolated in the community through a combination of Ministry of Health Funding and funding through Age Concern – 'Our visiting service provides companionship to people over 65 who are lonely / socially isolated and would like a regular weekly visit from a friendly volunteer' (Participant 12). Other providers acknowledged the need to have similar visiting services but were not able to fund such a service. Participant three stated that 'more socialization / day program opportunities for those unable to access outside activities' was central to providing better support for people to remain at home.

A concerned participant lamented the situations that some of her peers were in, stating: "I have grave concern for a lot of older people. They seem to be isolated." Findings from the HART study (2023) suggests that loneliness for older adults has become a significant public health concern with research evidence demonstrating the negative effects of loneliness on both mental and physical health. The HART study differentiated between different types of loneliness noting that 'social loneliness' is caused by disconnection from communities and social networks, while 'emotional loneliness' relates to feelings of abandonment and anxiety. The predominant feeling among the participants who were providing intensive spousal care was that of disconnection and a sense of 'emotional loneliness'. These feelings in part relate to how they became socially excluded by time restraints and emotional pressures linked to their day-to-day care activities.

Social exclusion occurs due to a complex and dynamic range of individual risk factors tied to a person's intersectional identity, their social relationships, psychosocial attributes and social opportunities that are all embedded within a social policy context shaped by societal norms, workforce demands, environmental influences (Burholt et al., 2020). Further, the New Zealand Health Workforce Research (NZHWR) (2023) findings show that lower levels of loneliness in later life were associated with being a woman, being married or in a de facto relationship and higher adult life socioeconomic status (for men but not for women). These findings suggest that lifelong exclusion from material resources, which is related to belonging to particular social groups, is a risk factor for later-life loneliness. "To tackle late-life loneliness, it is therefore important to consider how life course socioeconomic circumstances, in particular, inequalities in accessing and accumulating financial resources, contribute to outcomes in later life." (p. 59). The HART (2023) study concludes that "it is clear that loneliness and social isolation, and poorer economic circumstances, are potent drivers of inequalities in health at older ages". In addition, the NZHWR study findings show that housing satisfaction, social cohesion, and access to facilities contributed to the development of the broader social network types, such as those including friends and neighbours (and) reduce the risk of social loneliness among older people (HART, 2023, p. 207).

There has been a shift towards recognising the influence of a social and physical environment as supports for ageing well. The NZ Government 2019-2034 Better Later Life – He Oranga Kaumatua strategy names some guiding principles with limited reference to the impact of social and physical environment on older people, such as housing, neighbourhoods, economic resources which contribute to an older population's ability to participate in the wider community. Given the ongoing processes of colonisation, social policy that is informed by Te Tiriti of Waitangi is needed to provide equity in outcomes. An emphasis on 'equal' access to health services encourages a default to the norms of the dominant group that does not serve women, Māori or other minority groups well (Ahuriri-Driscoll, 2016). It is evident from these limited findings combined with the recent Aotearoa New Zealand literature, that social factors such as isolation, social and physical stress, insufficient income, relationship difficulties and the physical environment can all impact on mental health and feelings of being invisible, not valued sufficiently, not being needed and feeling of loneliness.

Chapter seven analyses the findings in terms of the aspects of older adult's lives that gives them pleasure, builds resilience and positivity.

Chapter SEVEN: FINDINGS

Despite growing old, this meant loneliness and sadness about multiple losses for some. The findings indicated that many participants worked hard at staying cheerful and finding pleasure in their lives and in the environment around them. This chapter also considers the findings on the theme of what keeps people active in their home such as the love of gardening or having a garden to wander into.

Resilience and positive thoughts

I've lost a lot of friends in the last 20 years. You know, just sick. I felt disappointed in a way that they've never had any motivation for them to move around, during the time they were sick. I reckon some of them would have survived if they just got up. 'Come on, you know, get out of bed.... you know' (Em-Jay)

Resilience or the ability to bounce back from adversity was linked to the participants capacity to have a positive mindset or to rectify situations that they were unhappy with. There was plenty of evidence in the participants' interview narratives of them fighting against a 'not coping' attitude, focusing on what needs to be done in the immediate moment and striving to concentrate on what was most important to them. This ability to not be passive and take control of the situation is evident in Shannon's comments about her plan of action when her husband was first diagnosed,

"When he was first diagnosed, he was absolutely shattered. And he said to me, 'What are we going to do?' I said, 'I'm glad you use the word 'we'. Because whatever we do, we're going to do it together....."

Shannon talked about having to move beyond a subservient relationship with her doctor when dealing with her husband's health issues, to ensure that she could discuss their health needs and advocate for him, "When it comes to my health and my husband's health. I'm an advocate for him. So, I need to be able to stand up right for it". Another participant spoke of her ability to advocate for herself with regard to a local council decision, pushing boundaries to get systems corrected while also noting the gendered nature of the response that she got. The participant stated "I went to the city council, and they just kept passing the buck, and for a woman, you know, you're waiting, because we trust them. And you're waiting for an answer. They haven't done anything about it....." (Maia).

With respect to being positive, Elisabeth spoke about her husband's ability to maintain a positive outlook and adjust to a reduced level of wellbeing, "he actually enjoys a good standard of life. He's good in his spirits. You know, he's a happy chap. He just accepts that his energy levels are not what they could be." For another participant the focus with her partner was the importance of making each other "laugh and to find joy", despite their ill health. Whilst another person living alone said with humour "I need a sidekick." She said she loved

to help people, it is what helps me stay here (in her flat) as well because I bring home left-over food (from her voluntary work) and give it to other people. Any of the free bread left, I give it to my sister who has pigs”, so not only does her voluntary work and the ability to give away free food lift her spirits up, it also helps others who are less fortunate.

The participant named Sarah provides her husband with more assistance than he can provide her. The main things she says her husband helps her with is managing their finances and keeping her company. Sarah says her husband can do his own personal cares but that she does all the shopping as her husband’s shakiness and anxiety make shopping hard. Sarah said that her husband used to do so many chores and outside jobs but because of the arthritis in his neck he is unable to help as much anymore. Sarah says that she is an optimist and thinks that this helps her ability to stay in her own home. She says that she does the best to look after herself as well. Focusing on things like nutrition and a little bit of exercise. Sarah uses a walking stick but still takes great care of her husband, as evident in these types of statements “I iron, he likes everything ironed. I still manage to do that. And I iron his hankies and things for him and really keep him looking perky.”

Participation in community events was another factor that seemed to be linked to resilience. Another couple said they had always been busy, well known in the community “liked to be fully involved” and join in their rural community, so participation was very important to them as well as enjoyment of the environment. Others received an uplift of spirit by being able to pray or read the Bible every day. Further, to remain positive a woman participant thought it was important to join clubs, go the local shops, library and to the supermarket with her husband. Another thought it was important to keep being strong and able to manage everything. Olivia said, “that’s what the doctor keeps saying to me – we are going to look after the game”. Whereas a couple said “so as we both say to each other, we have got to look after ourselves. So, we are here for each other to look after you know, keep the ship running.” Love and loyalty also shone through with other women who spoke “I certainly would not go overseas or anything like that. Not while he is on this earth. I am staying here!” (in own home). As a wise woman concluded “It is the quality of life that makes life worth living”.

A seldom mentioned activity in the social work or health literature is the pleasure and uplifting of spirit is the joy, pride and exercise afforded by their own garden and the pleasure of gardening, of people living in their own homes and the independence and uplifting of the spirit it brings.

Independence and gardening

The literature suggests that independence is a difficult concept to clarify (Matthews (2012) but Mathews quotes Plath’s meaning of independence as:

- Doing things alone

- Making one's own decisions
- Having physical and mental capacity
- Having resources
- Having social standing and self-esteem (Plath, 2008, p. 1357).

The study findings identify a strong need for independence by many of the participants. Independence and the need to stay in their own home was illustrated by a couple's need for internet coverage in a rural area- "you know, you get anything through the mail, it says go on to our website for further information", which suggests how important a reliable computer and internet is for those living in rural situations. This participant promoted "gardening for both physical and mental health as gardening gets you out in the fresh air. It is physically challenging. Even if your knees refuse to cooperate. Grow vegetables, so you're eating good vegetables" One determinant that affected the well-being many of the participants was their love of gardening. For some there was an awareness of the future and possibility of physical decline, but with the resolve to maintain their independence, keep and maintain a fruit and/or vegetable/flower garden and keep well. As authors Hale, Barrett and Gauld (2010) concluded, that the underpinning policy assumption of ageing in place and in-home care is to provide independence and maintain it in the community.

Many study participants expressed the importance of their garden, even if they employed a gardener, as a place of pleasure, of solace, of changing interest with this providing them with an opportunity to enjoy the environment around their home. As the interviews were conducted at participant's homes, different interviewees discussed the importance of their garden and the pleasure it gave them. They indicated that it gave them the ability to leave their homes, gain some exercise outdoors and be revived by the refreshing environment. Elizabeth and Barbara said: "we basically live at the bottom of our garden, it is absolutely lovely, so we don't know what else we need". Another participant said proudly, "I can do everything (in my garden). Just. I am lucky to have a garden area"

On the other hand, one female participant said her daughter worried about the extensive garden her husband had, but if he lost his ability to do his garden, then they had other decisions to make. The effects of not being able to care for their own gardens or home can lead to difficult decisions, which some older people may make and plan for. Others may be in a financial position to pay for garden and home maintenance, downsize or stay living in their own home. Another participant, although renting a small flat without a garden, gained pleasure by making up posies of pre-loved artificial flowers to give as gifts to her neighbours and friends. Due to the importance of maintaining gardening when 'ageing in place' Participant 13 stated that her agency provides help for people who don't have family to help and can't afford to pay for assistance, stating "we can help people maintain their properties (a one-off service mostly), give their backyard a blitz so it is manageable for them/their whānau again. This service offers small house moves, rubbish removal and backyard maintenance - lawns, water blasting, gardening etc".

The participants who were carers often had to restrict their daily activities to be present to minimise risk for their spouse. In this participant quote, the woman speaks to the moment when she realised that she could no longer garden in her backyard due to the risk of her husband having a fall while she was outside “She and I were working out in the garden and I came in to see if he was okay. And he wasn't okay at all. And he was trying to go down the hallway to go to the toilet. And very indignant because he was going to do that by himself. And so, you even got to a stage where you couldn't go outside and do the gardening.” This quote illustrates how the independence of a carer can be so restricted that they have little small pleasures left for themselves, unless quality respite can be sourced through the family or service providers.

There are multi-faceted needs of carers living in their own home. One of the themes appears to be a need to free up some time, with home help, not only to do the home maintenance jobs, but time for the carer to do the things they used to enjoy, before their partner became too unwell to do tasks that they previously managed. We now move on to chapter eight to offer an understanding of what the participants identified as needs for home care and respite care to assist their journey.

CHAPTER EIGHT: FINDINGS

The objective of this study was to understand what the home care needs of those over the age of 65 years were and how these needs are met or resourced. This chapter discusses formal care provided by government in the form of home help, respite care, paid care service and finances. Potential for collaborative partnerships with social workers is considered, as well as the need to declutter and multiple losses as people aged is also considered in light of the findings.

Home and community support services

A Ministry of Health (2020) report into Home and Community Support Services (HCSS) stated that in New Zealand, more than 75,000 elderly individuals receive government-funded HCSS in their homes. In the 2017/18 fiscal year, District Health Boards (DHBs) allocated over \$478 million to HCSS. These services typically include assistance with personal care, household management, clinical coordination, and support to help older people stay active and independent. HCSS are crucial for maintaining the health and wellbeing of older individuals, allowing them to live in their homes and stay connected with their community.

Accessing home-based support

The participants had various levels of success accessing home-based support services. The participant named Sarah who provided care for her spouse talked about how she has osteoporosis and had unexpected fractures which were very painful and debilitating. When this happened, their son saw how much pain she was in and came and stayed with them to help. Sarah said that this help was amazing and also received help from a physio after the fractures which she found very useful. The physio focused on prevention to help stop Sarah from ending back up in hospital. While Sarah was injured, they were receiving home-based support from ACC for vacuuming and carer support with showering. Sarah said that the care services wanted to continue the care after the ACC funding stopped and told her she was eligible if she had a community services card. Sarah said that she was eligible for a community services card but because she had to “go through hoops and hoops and hoops to go to WINZ and get the community card” and because the community card didn’t get processed easily she lost the offer of continuing care. In the interview, Sarah said she felt that she was capable and wanted to do things herself, but she was advised to make use of the help while she could receive it. She talks about the good care she received and says that some of the carers were travelling from places as far as Whakatane.

An online survey participant who worked at Support Net stated that for their service “home help is only given if they have a Community Services card”, while “Carer support is a contribution to funding and client needs to top this up”, but that “usually funding is sourced through the DHB.” It was noted in some of the participant interviews that the participants were ‘asset rich’ but ‘money poor’. This made it difficult for some of the participants to fund

homecare services privately without disposing of assets, and of course the main asset is most often the house.

One of the Māori participants supported both her husband with the help of hospice nurses and then her adult son due to cancer diagnosis. Before her husband's diagnosis she had supported his dialysis for the previous 10 years and she credits this caregiving experience as being of assistance in managing the more complicated end of life care in a small semi-rural community well away from hospital level services.

I said, 'No, I will take him home'. And they said, 'It's a lot of work.' I said, 'Yes, I do know that'. The [hospice] nurse was coming in twice a day. That was okay, she was administering [morphine/medicine]. And I said, 'Show me how to do it and I will do it'. She said, 'Will you?' I said, 'Well he has been on dialysis for 10 years and him and I we know the machine in and out'. So, they put a little box here.

The success of this woman to access support and manage the health needs of her husband and son was not only due to previous caregiving experiences but also because of the strength of her relationship with health professionals, whether it be her General Practitioner, District Nurses, Hospice Nurses, or the Local Hospital. A Māori participant spoke of the independence and determination that she noticed amongst her peers, stating "Māori would never ask for help, they are too bloody stubborn. But I know there's quite a few even in this Hauora here who need it." It is unclear if this observation was made due to kaumatua not trusting outsiders to provide care, or a desire to be independent, or if it was because they did not know what is available to them. Hikaka et al., (2020) research into Māori older adults' experiences of medicine and health related services underscores their need and wish for autonomy in health treatment and the significance they attribute to forming authentic relationships with their healthcare providers. The participant who provided palliative care to her husband and son expressed confidence in her ability to communicate her needs to medical professionals and to participate in the treatment decision-making process. This confidence also translated into her expectations that support would arrive when required and allowed her independence and the ability to care for her loved ones in a manner that appeared to feel appropriate to the needs of her whānau and culture.

The findings indicate that the participants who had experienced formal homecare found that not only was there a shortage of government paid caregivers, but the carers also tended to rush the visit and care provided. Margaret said she has "not had an assessment (from Support Net) for two years. I have three quarters of an hour cleaning a week, which is the bathroom, the vacuuming, and the hard floors, that's all." But she said it "does depend on who does it. Like I've just got a new one. So, it is so hit and miss, she manages about half an hour. But I'm a bit concerned when I notice that the shower stool never gets moved. It is supposed to be ¾ an hour. She's away in half an hour". Margaret said although she is

efficient “she has not come in and talked to you about the weather or asked you about the book that you read. No, there’s no small talk. No, no talking.” She then referred to another caregiver that did not stop talking. She wished for “somewhere in between”, that has cleaner tasks completed well and social engagement such as noticing her bunch of flowers, but certainly more friendly. The theme of limited relationship building is a thread that has been repeated in this study data.

Respite Care

Locating appropriate respite care, especially at short notice was acknowledged as being problematic by both the interview participants and the care professionals who completed the survey. In one instance, there seemed to be upward adjustments to the initial allocated hours for respite care in recognition of the severity of need for carer support, as explained by the participant:

I have been allocated 50 days if I want to take it for respite care, and also a week of respite if I need it...I got 26 to begin with. And when he was reviewed, they said ‘he’s, you know, high needs.’ So, I’ve taken two half days, since we have been allocated it. You have to find your own [respite care], ...And that is the issue for a lot of people. They find out it is really difficult to get. And you have got to realize that what they get as pay is very limited. So having had contact with a lot of people, they always top up what they get from Support Net, you know, I mean, they are getting \$70 something or something for half a day. Right? That is very little money.

It appeared that having respite days funded did not necessarily easily equate to utilising respite days due to difficulties in locating appropriate respite care.

Furthermore, a participant felt strongly that there was a lack of relationship building and trust could easily arise during the sometimes-brief visit of the paid carer. The participant stated, “What would have kept my husband at home would have been the engagement and not the focus on the task.” This was another key finding of the research. The findings suggest that because there was little time allowed for a relationship between parties it was difficult to trust the formal carer. Alice said she could never say to herself, “okay I have got an hour for me, I can go away” because although her husband needed an hour’s assistance with showering and dressing in the mornings, some of the caregivers would come and say “no, no, I don’t need that long, I can do this in 15 minutes”. Her husband was in and out of the shower, the caregiver rushing around and off out again, so it there was no time. Alice indicated that there was a need for a person coming in with ‘nous’ as “it was the mental elements of the non- motor that were the biggest problem” with Parkinsons. Alice reflected on the couple of times “when I couldn’t get him out of bed at all. Like because there is a whole lot of apathy that goes (with Parkinsons). I just thought ‘I am at the end of my tether’ and rang an ambulance and was asked ‘what did she want them to do?’. In the end her husband was taken to hospital where the sympathetic hospital nurse recognized that she really tried to look after her husband, but his whole body was exhausted.

Quality of home help

In reference to the quality of the home help provided, this participant statement speaks to a lack of empathy demonstrated by the home-based support carers, “Well, I actually need someone with understanding, I need a little bit of time for myself. I need someone to hear.” According to Matthews (2012) the literature suggests that standard in-home care is primarily focused on tasks, provided through uncoordinated and uniform services by poorly trained and compensated workers. These workers often must manage their responsibilities based on the time requirements of their employers and funders, alongside their own caregiving obligations. Often these home-based carers have little or no contact with the client’s medical team (Hale, Barrett & Gauld, 2010, Ryburn, Wells & Foreman, 2008). Matthews (2012) indicated that many care workers are ‘sandwich generation’ women caring for their children and/or their parents or other older relatives. This author said that they compensate for the low pay by their ability to work flexible schedules, even where this does not suit the needs of the older person, who prefers stability and predictability in care. They do not have a seat at the disciplinary table, and their knowledge of the homecare needs of the person that they care for is often missed in wider interdisciplinary discussions.

Matthews (2012) notes that often the home-based support service worker acts as ‘fictive kin’ and may be the most trusted person in the lives of some older adults. A survey participant however demonstrated that the observations of the HCSS carers can be utilised and acted upon quickly to prevent a breakdown in care, “A phone call to our RHP ensures quick, early intervention and a possible referral to additional services to ensure that tangata [older person] remains in place rather than in residential or hospital care where we know they deteriorate more rapidly” (Participant 1).

Another view expressed in the findings was that the matching of a person’s needs may end up as a mismatch and possibly distressing for both parties. Margaret questioned why the Care Service “would send a man in his 20s to shower a 70-year-old something spinster.” She went on to suggest that “we still have a lot of elderly people who do not want to rock the boat”, which suggests that older people are reluctant to complain and afraid to lose the service. Some of the difficulties with mismatched or perceptions of ill-equipped carers could be as Moore et al., (2024) acknowledge, HCSS providers are finding it challenging to attract and retain staff, as travel data indicates an 8 percent decrease in HCSS employees over the past two years. Recent pay raises for Te Whatu Ora nurses have widened the pay gap with aged care nurses, intensifying the difficulties faced by providers.

Home-based service collaboration

The online survey data demonstrated that the HCSS are very collaborative in their approach to meeting the needs of older people in the Western Bay of Plenty. Here, some of the responses to the survey when they were asked ‘how do they collaborate with other home care providers or others in the sector?’

We regularly meet on a local and national level to share frustrations and learnings. Additionally, we have key relationships where we share care if we are unable to provide care for the full package (Participant 1)

There is a MDT, I think, 3 monthly. But apart from that we are kept up to date with fortnightly staff meetings and our team leaders keep us in the loop We also have our CCC team that can negotiate with home providers, or we can email them. We also get a weekly provider capacity report so we can see availability of regions per carers and referrals (Participant 5)

At times I contact Community Care Coordination if a client in the community who is post stroke by some months /years is referred back in and don't meet the post stroke hospital care requirements (Participant 7)

Management attend regular meetings. We have fortnightly meetings and are informed of what is happening in the sector (Participant 8)

Liaise with the wider community allied health team, hospice, Alzheimer's Society etc. Refer on to additional services, e.g. physiotherapy, OT (Participant 9)

Super Support is a fantastic example of organisations collaborating together. Collaboration is how we transform the community, not just for older people but in general. It is one of our core values here at GN. If we can make the Super Support service easy to access and effective for older people, why not for other vulnerable populations too (Participant 13).

These quotes serve to illustrate that the HCSS providers (who are predominantly women) in the region are joined up, collaborative and informed so that they can be innovative and flexible in planning and resourcing the needs of their communities. However, as one participant noted that despite this collaborative approach when it comes to logistical supports needed it is

More difficult to overcome these challenges. Increased level of support from funders would be helpful - often their approach is to change providers if there is an issue, rather than support to resolve issues. increased funding in order to pay higher rate to employees (Participant 2)

The HCSS also had a lot to say about their need for more staff, for more attention to recruitment and staff retention, as illustrated in this comment about what was needed to look after people over the age of 65 years in the Western Bay of Plenty

More staff!!! Better conditions for those carers on the ground doing the hard work, i.e. better pay. Make it so people want to apply for a support worker role with our companies (Participant 5)

Higher pay rates and support with moving around the region to provide care in homes was seen as something that needs to be improved. Survey participants also recommended a move to “Open Day’ type expos for” (Participant 2), and a “national campaign on the benefits of being a carer” (Participant 1). Another systemic issue that was noted was the need for more funding for Support Net as it “has a weight list of 700 odd and at times it is difficult to provide services in a timely manner. Consider shortening assessments particularly if only looking for home help” (Participant 4). The expected doubling of the older adult population in Aotearoa New Zealand provides an opportunity to consider how home and community support services can be more effectively delivered to ensure cultural safety and health equity (Parr-Brownlie, et al., 2020).

Not everyone in the study chose to take up the home care services offered by the government. A woman taking care of her ill husband said as she knew him very well as him being a private person. “I would find it very hard to get someone to come in to wash him, I do everything in that way...but to actually get someone to come in every day when I’m standing there, you know, probably waiting for him to finish and I would just find that difficult, so in many ways, it has to do with me not having taken respite.”

Age care workers

A Ministry of Health (2020) report into HCSS found that many individuals aged 65 to 74 live at home independently, without formal support. However, as people age, the need for assistance rises. Those receiving HCSS are typically over 75. About half of those aged 85 and older live at home with HCSS, while 28 percent reside in residential care. Other older adults who need homecare assistance may receive informal support from family, whānau, and friends, or they pay for private support services. A Ministry of Health (2023, p.24) Briefing to the Incoming Minister acknowledged the following:

Aged residential care and home and community support services are facing challenges. These include staff shortages, pay disparities across the health workforce, inequitable access to care and managing increased demand pressures. Aged care providers are reporting that financial sustainability is impacting on their ability to provide quality care.

Ferriera (2024) review of literature on aged care services in Aotearoa New Zealand concluded that homecare support services have been under considerable strain due to funding and workforce shortages which have been exacerbated by the Covid Pandemic. This strain is reported to be linked to the delay in the development of funding and service delivery improvements. It is noted however, that despite the issues with regional variations, ethnic access disparities and issues with staff retention, HCSS services are effective in assisting older people to age in place and delaying the necessity for rest home or hospital level care (Moore et al., 2024). These findings are consistent with the voices of the survey participants who made statements such as this

Care staff need to be funded appropriately so their roles are sustainable as the more experienced the staff, the more value they can add to onboarding and recruiting

successors/new energetic and passionate care staff. Need to create a peer training system as well as using external evidence-based training resources (Participant 13)

The desire to remain home and avoid residential care was a strong one, as evidenced by participants' statements like Ruby's, "I am going to be there [at home] until I go upstairs love. But I would really appreciate it if there was home help." Participants like Ruby talked about how they have been turned down for care assistance when they have reached out for it, then reflecting on being no longer able to manage the vacuuming and the house not being vacuumed for over six months. The Ministry of Health (2020) acknowledges the clear financial savings that people ageing in place have for the health system, recognising that HCSS is effective in delaying admission to residential care and in some instances avoiding it altogether. Despite the acknowledged effectiveness of HCSS many of the participants struggled to access relevant support in a timely manner, for instance, Margaret observed "But I think for a lot of people, the help needs to be easier to access. Yeah. You shouldn't have to jump through hoops".

The survey participants also expressed frustration about how time poor the contracts are for service, not allowing time to move across town.

All carers are rushing from 1 place to the next usually 20 mins across town to another house. Allow 15 mins travel between all houses i.e. client 1 9am-10. Next one is 10.15 NOT 10! This allows for traffic etc and if they finish the 1st house early most clients are not fussed if you turn up to their home a little early. Better incentive for wear and tear of their own car use. Don't over book them as then they are always trying to rush and evident to clients to the next house (Participant 5)

These types of work conditions were reflected in the comments of the interview participants. For instance, Alice, suggested there was a lack of reliability when the caregivers came. Another participant said she was made to feel secure and believed they were wonderful. However, she felt that not know what time of day somebody was going to be coming in and "I could not hang around and get dressed. I like to get up and get on with life, you know". She said she could manage changing the sheets of the bed "if I'm very careful". Even though she thought them wonderful "they have to travel after they'd been here, they had some jobs Whakatāne or Te Puke or whatever". She said they did not want to complain about the girls, but it appears a friend did not know the system. They are all from different countries "so that was good for my brain power to try to remember their names, and no I could not fault them."

Survey Participant 10 highlighted the need for "more support - that is consistent and time/need focused" as being essential to people being able to age in place. This lack of consistency was an issue, for instance, Margaret indicated when her regular carer went on leave, she was never sure whether "I was going to get anybody. So, you don't strip the bed until you know if somebody's gonna come because otherwise you are going to have to battle to make it [on her own]. But sometimes they refused to help me to make the bed, so I stopped it (home help) if my cleaner was on leave, then they would say 'you don't need anyone.'" Margaret went on to say it was difficult to get anyone on the phone at [care

services agency] to sort out issues when they arose. In contrast, it was felt by one participant that a lot of support was received from the Parkinson society and their nurse was described as 'brilliant'.

A participant who was some years younger than her husband who was diagnosed with Alzheimer's. She needed to work as she paid one of her two carer support workers, and the government paid a second support worker. Claims had to be made monthly on an hourly basis. She had to make sure the carer got enough money for petrol for pick up and drop off at music and half a day once a month at a local Community Centre. Their tasks involved driving her husband to medical and hospital appointments. As a paid worker she indicated how much planning was needed to be made in advance where she guessed her "energy is keeping up to date with his needs, asking Support Net for increased hours which gets gobbled up week by week with the hours going into his enjoyment of music."

There were varying reports on the quality of home help workers in these findings. One participant said she would be happy to have home help come in, but quickly said "I would not know if I could trust them and that made me sort of think I am a sort of trusting person. I'm not naïve and stupid. But I like to take people at face value, but (need) to feel a little bit cautious", as suggested by her friend. Oliva said she had a lady coming in to help her now, but she keeps saying she's going to come back but she has not. Then Oliva said she is "currently getting home help as far as washing, showering and dressing him every morning." That day she had just been told by the Support Net worker, who was re-evaluating the needs and was told that she was entitled to carer support "and they will pay \$80 a day for that person to come and sit with him and stay with him." To which this participant said she did not know that. She was sent a lot of information brochures on the support offered but "I never had time to sit and read it...because I am so busy looking after him all the time. And when I am not doing that, but to me, I found it difficult to sit and read and understand these things." Furthermore, she expressed annoyance when asked 'you don't have a Community Card do you? And I said: 'well no, but I knew she had to know whether I had one'. But it was the way it came across. I suppose some of the Community Card holders feel that they are down there." She was also told "the carer could be anybody, it could be a family member or anything, and they will pay for them too, which I thought was quite good." It appears ACC had stopped some care, but they wanted to continue with help with vacuuming and shower but could continue with a community card or through the doctor. It appears that as they did not want to be seen as 'bludgers', they managed their finances to pay somebody to get the help they needed.

One participant, Margaret, said "my first carer was a bully. The carer kept saying "I'm going to ring the office and tell them you only need half an hour, or you don't need any work." Margaret said she responded by saying "And if I said you have not done something I'll just tell your office". Margaret later complained to [some authority] about this caregiver.

According to the 5th wave of the New Zealand Health, Work and Retirement study (HART) Policy Report (2016), the frequency of care provision ranged from daily to less than once every few months. In a recent newspaper article HCSS provider, Vision West cites a shortage of aged care workers in a "tight labour market", with the "continual challenge to attract

support workers,” said Murray Penman. The organisation indicates there are staff shortages across the health workforce with barriers to recruiting support workers. The head of their health and community services Penman said “the home and community support services sector is ‘heavily reliant’ on people who were ‘willing and able’ to work throughout the week, including evenings and weekends” (New Zealand Herald, 2023).

Professional Involvement

Foster and Beddoe (2012) see the potential of the primary care context for social work with older adults. Against a background of “professional, policy and practice challenge the authors argue for a service model better designed to meet the needs of older adults and their caregivers.” (Foster & Beddoe, 2012, p. 40). To create a healthy community, it would seem logical to move resources to primary health care from secondary care. As Foster and Beddoe (2012) state:

Positioning social work in primary healthcare may increase awareness of the range of skills required in care of the elderly and reduce misunderstandings about the potential role and function of social work in health care. This requires action from social workers as there is danger that we reproduce the problems of the hospital-based multidisciplinary teams with primary care settings.... Social work also requires courage to advocate for relationships-based work with elders, where policies may focus more on targets, costs, efficiencies and reduction of risk. (Foster & Beddoe, 2012, p 40).

On the other hand, it could be argued that time consumption of a social worker placed in primary care to be effective, it would require a full-time role to provide the support needed, although much less than that carried out by 24 hr per day that at-home carers currently provide unpaid.

It is argued by Foster and Beddoe (2012) that “the greater presence of social workers in the community would help support caregivers in their role, advocating for support by formal health systems, as well as respite systems for caregivers themselves, and ultimately to begin the discussions for the transition of those few older people who need residential care” (p.42). These writers also argue that social workers can make a specialized contribution of facilitation, problem-solving, decision-making skills, networking, and care-coordination with “the decision to move into residential care, for instance, is best made with the older person in consultation with significant others, and in a measured way. This allows the older person to explore options at a pace that is acceptable to them. Too often this decision is made following, or during, an acute admission to hospital, where decision making is compromised not only by the urgency of the need to discharge the patient from acute care, but also by the sudden frailty and change of health status of the older person coupled with caregiver anxiety” (Foster & Beddoe, 2012, p. 42).

In addition, Foster and Beddoe (2012) suggested that working with caregivers through conflicting emotions, grief, and loss, following the placement of partners or parents into residential, or hospital care is a role for social workers. They say that the loss of a role which has filled a large part of the older person’s life, along with possible feelings of guilt,

loneliness, depression. Working with grief and loss is an integral part of social work practice and this skill base could be effectively used to support and assist older adults who are isolated and struggling both physically and emotionally while 'ageing in place' (Foster and Beddoe, 2012). Knowledge around the role of social work within primary health is still developing (Feryn, et al., 2024), however these authors also called for increased collaboration with social workers in the primary care environment.

Nurse training

The participant who was a retired nurse educator reflected that, in hindsight, nursing training was "too narrow" and with a focus only on hospitals and what they were producing was too task oriented, the care was lost, and it was because the 'bean counters can see a task, but they can't see the nurse'. This thinking was echoed by Participant 1 in the online survey where she asserted:

Absolutely, but we need to be less prescriptive with the services provided (totally task based as in shower, dressed, make bed, make breakfast) and should be co-designed with whānau to ensure our tāngata [people receiving the services] feel more in control of what is happening in their home as it is still a disruption to their everyday living. Sometimes we are the only faces they see all week, so we are their only connection to additional services and are perfectly placed to identify any deterioration that requires intervention. We are a connector and a voice, in particular for those who do not seek services for themselves as they don't want to be any trouble to anyone. This is another way to enhance their mana [sense of self/authority/control/influence...] in a space that is familiar to them (Participant 1).

The next chapter builds upon this information, addressing how planning is crucial when living alone at home for this older age group, or after the death of a spouse; emphasizing the tough choices, financial planning, and existing government policies that can impact the well-being of older adults.

CHAPTER NINE: FINDINGS

The study found that a few of the participants mentioned the need to plan for care of their loved one. This chapter considers how planning is important to either being on one's own at home, or after the death of a spouse and the hard decision making, financial planning and current government policy, that may impact on the well-being of the older person.

Planning for change: decluttering and multiple loss

The study found that many participants were either on their own or were caregiving a spouse in their own home. Only one man was caring for his wife. As Millar (2001) acknowledges most men are outlived by their partners and are often not well prepared for life after a loss of a spouse, especially if that spouse cooked, cleaned and cared for them. On the other hand, Millar (2001) said many men manage household tasks well, especially when they have been in a caregiving role.

Some of those interviewed were confident in their ability to manage their own affairs whilst planning for a time when owning and living independently in their own home would come to an end and wanted to be prepared for it. Decluttering and thinking about the disposal of non-essential items was indicated by some participants. For example, a woman who was working and also caring for her husband with dementia said that if anything happens to him, they will have to downsize. She said he could fall on the stairs and need to go to hospital. She may not be able to care for him. So, they are decluttering before that happens. Some carer participants wished to have a more accessible smaller home, perhaps in a retirement complex or alternatively plan for the need for residential care for the husband being cared for at home who had become too difficult, demanding 24-hour care. The downside to such a move was expressed in the findings as "having to find a new social group", besides having to adjust to a new social group and the living in a whole house or "suddenly one's possessions must fit into a small room or even half a room." Downsizing demands parting with material things, immediate social contacts, but possibly the most difficult task of all is to "leave the security of a familiar home and neighbourhood. The emotional cost of such a move is high. The losses for both the older person and the principal caregiver are great." (Maidment, 1996, p.11).

Changes for older people usually involve losses of some kind, most of which become more pronounced and frequent for the carers and participants as they age. "Frequently cited losses focus on growing physical frailty, the deaths of spouses or friends and the accompanying loss of friendships and companionship. It is clear however, when working alongside older people the losses experienced in later life are far more pervasive and all encompassing..." (Foster, 2002, p. 229). Further, change may involve:

loss of status, work identity, independence, friends and possibly a home, all contribute to substantial lifestyle changes in old age. The experience of incurring multiple losses is not uncommon. How an older person and their family respond to

these losses and view the future is dependent on several factors. Research shows that thoughts about death occur more frequently as a person grows older. Other determinants that affect an older person's view on life and death include physical and mental health, religious orientation, socio-economic and occupational status, community attitudes, family attitudes to death and the individual's own psychological integrity and maturity." (Maidment, 1996, p.11).

Millar (2001) explains "everyone's journey into their older years brings an awareness of mortality and one of the developmental tasks of life is to confront and live with the awareness of life's transitory nature. People respond in many different ways, some deny or ignore it, others may develop an anxiety that can take away quality of life. There is a process of preparation which may involve grieving for life as it has been. For most people the awareness of death adds value and perspective to life and its quality." (p.81). Part of the planning for the older age group, may involve Retirement Home living for some, with availability, quality of care, and affordability major considerations, whether for a person alone or a couple. As Alice said "God forbid (if) anything happened to him I would go into a Retirement Village. I'm fortunate enough to be able to do that", which indicates that she knew of people less fortunate financially.

A study participant named Hazel had thought about the cost of Retirement village living.

There are people here in Tauranga now, that went into villages near enough to 20 years ago, that are locked in now because they only get 70% of what they paid when they moved in. They can't go anywhere because they are in and yet, if the property was resold, it would come up to current market value. "The government has got to do some changes.

Hazel, living in her own home was aware of some of the pitfalls of going into retirement villages in what she considered 'too soon'. She felt the government needed to make changes to the legislation in relation to Retirement Villages and cost. She also reflected on the cost of dying by suggesting the satisfaction and cost effectiveness of making your own coffin. In relation to the study question about family or anyone else ever suggesting you might need to live somewhere else, Maia said that for Māori there is a general acceptance that it is about the land – "if we are living on our land, no worries".

The hard decision of residential care

The New Zealand retirement village and aged care sector says Aotearoa New Zealand needs 61,121 more retirement units in villages, in the next ten years, based on 1.3 residents per unit. It is estimated that in New Zealand between 2023-2050 the age group above 80 years will increase by more than 60 percent. Auckland, Hamilton and Tauranga will continue to be the main areas for village growth, with 46 percent of the aged population in the country according to (Melville, 2023, p.15).

In a response to care for a husband with Alzheimer's, one woman said she was very cautious about who she would have staying in the house overnight, to help her and would have liked someone to assist her to find a facility for him to go into care as "it was very difficult to find a facility", when living in your own home in the community. The decision to place a loved one in residential care is usually made after a period of increasing stress, suggests Millar (2001). Placing a family member in residential care is often made for pragmatic reasons, linked to the care needs of the person, but their decisions are often wrestled with and agonised over by the caregivers. In writing about these types of changes and challenges, Miller (2001) pays attention to issues of loss and grief, acknowledging the impact that these changes have as they transition through illness, struggling to 'age in place' before considering residential care.

Chronic disabling illnesses and disease processes bring ongoing losses. Losing independence, restricted mobility and activity all bring grief, the effects of which may be put down to normal old age rather than a specific condition. The major physical illnesses of the older years are heart disease, cancer, stroke, respiratory disorders, diabetes, and arthritis conditions, all of which have the potential to radically alter a person's lifestyle. Major surgical procedures such as mastectomy and colostomy which affect body image and sexuality can cause grief. Hearing loss and visual impairment are common in advanced years – sometimes both have to be coped with. Many people have multiple health conditions which increase losses and intensify the grief that they experience." (Millar, 2001, p.60).

The journey into residential care is described by some as a lonely journey and a time of major decision making for some to move from their own home, which may have a lifetime of memories. For some, a time to make hard decisions, for others, to worry about home maintenance and for others the joys of having their own garden.

Current policy and caregiver activity

Current policy is influenced by the population ageing and the predicted population increase of older adults has increased governmental attention to the importance of supporting the wellbeing of this demographic effectively (HART, 2023). The HART longitudinal study (2023) identified that "changing family structures, employment trends, and retirement policies have altered the availability of informal carers while the need for informal care of older people and children with disabilities has grown" (p.171). This longitudinal research found that "broader workplace conversations are needed that include organisational recognition of care and the provision of support networks for care to enable carers to consider a range of employment types and to maintain their connection with supportive organisations while caregiving" (HART, 2023 p. 173) and in paid employment.

Population projections are that Aotearoa New Zealand will become more ethnically diverse, with the New Zealand European ethnic group projected to have the slowest growth (Stats NZ, 2021). With increasing diversity, the provision of more culturally appropriate community engaged care services needs to be funded, this will involve a shift away from service

provision models that are primarily targeted at New Zealand Europeans (Kerse & Cook, 2021).

Pihama et al., (2023, p.142) state that 'whānau is the foundation of Māori society.... What we now know is that whānau was also considered by colonising forces as a barrier to the embedding of individualist capitalist systems and as such became a target for colonial intervention. For many people, whānau remains a site of collective wellbeing, obligations and responsibility, despite the attacks upon our social systems.' The impact of ongoing colonisation processes was evident in the interviews, for instance one participant interviewed repeatedly returned to the impact of land confiscations that happened during her grandfather's lifetime, with humble but proud acknowledgement of her whānau slowly gaining back parcels of confiscated land.

The personal is political (Hanisch, 2006). Old age can be "best described as a political construct, and aged care policy is best considered as a product of a homogenised view of norms, expectations and beliefs about what it means to be old" (Brook, 2016, p. 128) As Oetzel et al., (2023) assert:

Today's kaumātua grew up prior to the Treaty of Waitangi Act and lived in a society that was more racist than in present and were affected by an education system that banned and punished people for embracing tikanga Māori (cultural protocols) and speaking Te Reo Māori (language). This colonial historical trauma contributed to health inequities through cultural dissonance or feeling of separation from their own culture. Further, kaumātua have not been recognized for their contributions to a dominant society even while Māori culture upholds elders as, "carriers of culture, anchors for families, models for lifestyle, bridges to the future, guardians of heritage, and role models for younger generations" (para. 3).

It is the respect, aroha (love) received and sense of being central in the life of the whānau which enabled the Māori participants to thrive in the face of adversity, as illustrated in an everyday interaction with a kaumatua and her great-grandchild who lived right next door "I had the little one this morning, three [age 3] she came in she gave me a cuddle. They all call me 'big nan'. She said, 'give you a cuddle big nan, give you a kiss and you have a gooooooooood day'. They all do that aye, they always cuddle me" (Em-Jay). Kaumatua like Em-Jay are acknowledged for their wisdom and leadership within their communities, they also need to be given the opportunity to actively contribute to developing solutions to support Māori to age well in place (Ozetal et al., 2023).

At a local level in Aotearoa New Zealand "the current 'ageing in place' policy has created a greater need for continuity between the home-based system of care and acute hospital care. The longer people stay at home the higher the risk of their being admitted to hospital" suggests Richmond (1997), therefore services between primary and secondary care need to be much more aligned than they are at present. As Foster and Beddoes (2012) said some years ago, "social work can take a lead role in advocating for better integration of services in the community and is in a unique position to facilitate integration of care between primary and secondary services." (p. 42-43).

Further, “the current policy in New Zealand and elsewhere to encourage older people to age at home, rather than in institutional care, has had unintentional negative consequences for family members who care for them. Caregiver burden has been identified as an increasing issue (Lilly, Robinson, 2012; Almborg, Grafstrom, and Winblad, 1997; Brodaty, Green & Koschera, 2003) with fewer long-term services being available (Armstrong & Kitts, 2001) and a body of caregivers who are themselves often growing old.” (Foster & Beddoe, 2012 p. 42.)

The quote below, written over two decades ago, is still relevant to this study in these rapidly changing times and into the home care needs of older people in the Western Bay of Plenty region.

“The individualism of our times has contributed to a loss of the sense of community. This impacts particularly on people who are becoming frailer and more dependent on others for support” (Millar, 2001, p.12).

There is a necessity for investments in primary care, community involvement, and collaboration across sectors such as health, social services, transport, housing, and local government to deliver culturally relevant information and primary care services that improve the well-being of older adults (Kerse & Cook, 2021). Policy makers have an important role to play in the transmission of cultural values, the social and cultural situations of such a large diverse group of people over the age of 65, who are generally termed the ‘elderly’. This term of ‘elderly’ can be offensive to many. Such a term is applied to people aged between the 40-year life span of 65-105 years and does not differentiate between the newly retired, physically active older person, the carrier/sharer of wisdom, or people who are frail or infirm.

One of the survey participants who is social work trained acknowledged that there is no significant governmental funding for the non-governmental services that her agency provides to older people in the Western Bay of Plenty. This means that a lot of time is spent sourcing funding and donations which can divert from the holistic work that the agency is set up to do. For most of the survey participants however, the services that they provided were through Ministry of Health Funding, and it was acknowledged that single source funding only provides ‘some flexibility’ to shape services to specific needs. Other sources of funding identified were “ACC, Whaikaha (because disabled persons grow old too), LTS-CHC [Chronic Health Contract]. Additionally, there are services provided by iwi, including home visits” (Participant 1).

The advocacy and support provided by field officers through organisations such as the Stroke Foundation, Age Concern, Parkinsons New Zealand was seen to be of great assistance to some of the interview participants. When considering the survey data, it is apparent that these types of agencies could provide visiting services, provide information on eligibility criteria and available support, alongside a listening empathetic ear and advocacy when needed. Some of these types of agencies also helped to facilitate peer support programmes and counselling which was also valued. One interview participant spoke to how the respite drop off has become an important point of peer support for her and other carers, that

organically the carers have begun to drop their spouse off at the respite day programme and then meet at a nearby café for coffee. This informal coffee group was said by one participant to be a key activity that sustains her through the trials and tribulations of caring and is an example of how funding isn't always needed, that communities can organically come together to support each other.

Back in 2012 Mathews, (2012) drawing on knowledge acquired from social work practice identified that in-home care work needed 'fundamental reform' that required re-organisation to give emphasis to capacity building, coordination, with an interdisciplinary approach to improve quality of life and participation of older people in their communities. In writing about the need for participation of older people in social services, their community and politics, as well as global ageing issues, Karn (2023) suggests that there is a need for greater advocacy in the areas of policy at local and national level. This author proposed that older people can be empowered by consultation, giving feedback, and provided with increased opportunities to make choices. Karn (2023) argues for involvement of older people in service management and implementation, assisting in running programs and activities, taking on active roles in groups and projects, working in partnership and sharing power, along with involvement in decisions and the control of services for older people.

Again, there was a recent plea for Government to cover the cost of providing quality and affordable care more fully for those who can't pay for their own care. In commenting on the 2023 budget, the Executive Director of Radius Care Brian Cree said there needs to be significant changes to funding aged care from chronic underfunding. He said that the—

quality of care available remains mostly determined by what a person can afford. New Zealanders partly finance aged residential care by selling their home, but with fewer people owning their own houses than in previous years, elderly access to quality and affordable care is becoming more and more limited... loved ones, who can't pay for their own aged care are at risk of becoming effectively homeless as their care needs change with age. The rate now paid by the Government no longer covers the cost of providing the care they need" (Cree, cited in Bay of Plenty Times, 3 April 2023).

The Ministry of Health (2023) Briefing to the Incoming Minister acknowledged that the pathway to promoting healthy ageing while responding to increased pressures on the health system is through supporting 'ageing in place', improving access to primary and community health services, continue to improve acute care and end of life care through service design that will future proof the aged care services in the face of increasing demand. As identified in the literature, Lilley and Reid (2023) explored the intersections between policy, social work practice and equity of access to palliative care for older adults in Aotearoa New Zealand. They considered ageism and inequity experienced by older adults, including Māori and LGBTQ+ perspectives. These writers identified that it was family and whānau filling the gaps by their provision of unpaid care, to fill the gaps of residential care deficits.

This chapter identifies the research findings into the need to plan for change, considering also the way the participants faced multiple losses and made hard decisions in light of the

current 'ageing in place' policy. A summary, recommendations and conclusion follow in the next chapter.

CHAPTER TEN: RECOMMENDATIONS & CONCLUSIONS

Research Summary

A summary of findings is examined in this chapter, along with recommendations and conclusions to this study into the home care needs of older people living in the Western Bay of Plenty, Aotearoa New Zealand

The findings indicated that all the twenty-six participants interviewed wished to stay in their own homes as long as possible before they had to find alternative accommodation. Research emphasises that for the ageing in place philosophy to be effective, in-home care services must be widely accessible. The provision of accessible home care services for older people has an economic outcome of reducing long-term residential care placements and the cost of care.

To remain safe in their homes, some of the participants had overwhelming financial needs for necessary home maintenance, while others were in a financial position to pay for someone to help with lawn-mowing, house cleaning and personal care assistance. In this study of people living in their own homes, the majority of carers of unwell husbands were women and those living alone were women, a finding supported by the literature. The needs of people caring for an unwell person were expressed as unrelenting and, in some situations, a cruel burden, they had to bear alone. As spousal carers, some of the participants felt that they were invisible and suffered in silence. These carers expressed frustration about access to relevant care assistance and respite, alongside a strong sense of social isolation and at times abandonment. For instance, one participant had been refused care for herself after an operation, because she was able-bodied. This refusal to provide care while she recovered from surgery meant that there was no active recognition of the need for someone to take over her caregiving duties to make sure that her spouse who was dependent on her stayed well. To prevent carer burn-out it is recommended that Health Authorities ensure there is no waiting list for respite care beds, so that spousal carers can receive their own medical treatment without the worry about who is going to care for their loved one, whilst they attend to their own necessary medical needs.

The participants who were spousal carers often felt that they were too busy to meet their own health and social needs, as they too struggled to manage their own aged-related issues in their unpaid caregiving roles. This lack of care of the carers could result in more people entering residential and hospital care earlier because of carer burn-out and more attention (and resources) is needed to care for the carers. It was observed by the researchers and from the data gathered and interpreted that some of the participants interviewed were reluctant to ask for help from formal services or could not afford paid help. These participants appeared to depend on available family and whānau, or from those they knew that offered help and support. Very few mentioned help or support being received from neighbours or churches. It is recommended that as the participants spend a considerable amount of time at doctor's surgeries, that social work services become available from these venues. Social work services could assist with carer stress, exhaustion, anxieties, isolation,

loneliness, self-esteem, and social networking, with an outcome of interconnectedness and multi-stakeholder partnership. This recommendation is made with the acknowledgement that many people are struggling to register with a family doctor, and that many GP surgeries are under threat of closure due to staff shortages and rising costs (Wilson, 2024). Rural Doctors are reporting to the media in Aotearoa New Zealand that rural patients are disadvantaged and have worse health outcomes (Hill, 2024). Consideration needs to be given to older adults who live in rural and semi-rural locations as they may be further disadvantaged due to difficulties locating paid carers to attend to them in their homes.

The participants were confident enough to consent to interviews, although most had never been interviewed before. Their responses suggest an awareness of the needs of people in their age group, offering a range of both positive and negative factors that influence the lives of their peers. Some were nervous at the commencement of the interview process, but age group matching of interviewers allowed for quicker rapport development. As the data interpretation shows, respondents were honest and forthright about their own needs and the needs of their spouse, which in most cases involved women as full time (unpaid) carers of their husbands. Further, it has been identified in the findings that those living in their own home have found it difficult to find a facility to care for those suffering from dementia. The survey participants were also forthright about the conditions and pressures that they work under, striving to be collaborative and client focused. Their survey responses demonstrated a keen attentiveness to the needs of older adults in the region and a willingness to be creative and flexible to maximise service delivery while also protecting the needs of care staff who are under pressure due to working conditions, as one participant said, 'Get pay equity over the line'.

In this geographical area it was noted from the data analysis that very few older people had family members immediately at hand and there was a reliance on people they knew as friends, those in social groups or their doctors. Māori participants were more likely to have whānau geographically close and able to support them. The network of Kaumatua groups across the Western Bay of Plenty was found to help ensure that kaumatua are active and included in their communities. These Kaumatua groups were also aligned with other social and health services that provided holistic support. Social support from churches, in these findings, was less visible but a few participants referred to the power of prayer, daily reading of the Bible and support from Christian friends for their spiritual support. Some participants mentioned that there was always a worry that they too would become ill or be physically unable to provide care for the person they cared for. It was evident that many participants did not have family close at hand to provide substitute care. A change in thinking that family or whānau will be on hand to adequately care for ageing older people is required in local and national social and economic policy and elder care procedures.

This study has found that carers of people with Parkinson's, Dementia or other progressive disorders were seeking more information for themselves about how the illness progressed, how it would affect them, and the person cared for. One person called for an 'information Bible' for guidance on dementia progression, detailing what supports were available to carers living in their own home with a person with a dementia diagnosis. An increase in

specialist nurses available for home visiting is recommended to funders, private enterprises, or social services.

Some carers formed their own support networks made up of people who were caring in similar situations. The findings suggest that there is a need for education and social groups whereby carers can discuss experiences, make friends, and receive social support. Instances of elder abuse may be recognised and addressed by such group interaction, particularly in situations where family or whānau members may dismiss or accept it as a normal pattern of behaviour.

The findings indicate that carers can be very isolated, with dwindling friendship support and family support. The literature suggests social workers be employed to support the caregiver through their conflicting emotions, grief, and loss, during or following the placement of their partners or parents shift into residential, or hospital care. They say that the loss of a role which has filled a large part of the older person's life, along with possible feelings of guilt, loneliness, depression, and other losses, places these carers at further risk. Professional support would be a critical aid to support the restoration of physical and emotional health during these types of transitions.

Anecdotal evidence suggests that there is limited short-term supported accommodation for the person being cared for in their own home in the Western Bay of Plenty. It is suggested a review of the availability of what is known as Respite Care beds to ascertain future needs of a growing population. This study has found that those caring for someone with a progressive illness or disorder, needs some time for themselves, to go shopping, to the Doctor or attend to other needs, which suggests the need for short duration weekly relief carers.

Organisations such as those who instigated this study, and others such as the Red Cross, may be able to provide a supported volunteer service for visiting homes of those who are full-time carers, caring for those with social needs.

The research process highlighted that many Community Centres did not accommodate social programmes for older people. It also identified that Iwi social services and marae provided well planned care for their kuia and kaumatua. Local policy improvements may involve the Local Councils, via their Community Development team, to develop policies requiring Community Halls and Community Centres to cater for the older persons, in their service delivery, beyond the provision of exercise groups.

Social groups organised on community development principles for both the unwell people and separately for their carers simultaneously would benefit the wellbeing of both groups. No population in society is homogenous; therefore attention is needed to the collaborative development of social groups for older adults with diverse needs and identities. Ideally large centres for Older Persons (such as Parkside, Rotorua) that deliver many different services would benefit older people in health, mental, social and informational matters and develop a sense of belonging. Services run by Citizens Advice Bureau, such as Free Legal, Financial planning and J.P services could support older people's information needs. City Council, social and community work services could all be provided in the larger suburbs and in rural districts if needed. A day programme for people with dementia or care and craft type

programmes could be provided for social connections for older people to increase participation. An identifiable outcome would be to contribute to meeting World Health Organization (2020-2030) aims to reduce inequity, exclusion and division.

Some participants had worries about transport particularly if the caregiver lost their licence to drive the family car or their neighbourhood did not provide adequate means of transport to hospital or medical care facilities, which was often a regular necessary occurrence. If walking was possible for older people, the neighbourhood design, regular location of public toilets, smooth footpaths, bus shelters and regulations in relation to bells on bikes and scooters could be policy decisions for local Council to consider.

Although this study was restricted to older people over 65 years living in their own homes, further study may extend into Retirement complexes and villages, particularly where full hospital or dementia care, medical or social services are not available. Elder abuse, neglect and risk to older people have been well canvassed in other literature, with the focus being upon the person being cared for as the recipient of abuse. The limited study data has uncovered an incident whereby the person cared for was the abuser, attempting to strangle his spousal carer with force and inflicting pain. Further a few participants described the anxiety and fear that the unwell person caused them emotionally, and in one instance spending money on unneeded items, thus causing relationship discord.

Finally, the importance of having a garden or tending to a garden was a significant finding that contributed to the well-being of participants, for some, it was a positive and important need, a hobby, an interest, a time filler and a source of enjoyment that kept them in their own home.

Recommendations

Policy & Funding

Increase central and local government planning for the anticipated population growth of older adults

- Promote health and welfare policies that support ageing in place with attention to culturally responsive practice and diverse needs
- Ensure adequate funding for aged care community-based services
- Improve work conditions and remuneration for Homebased Carer Support Workers
- Actively recognise and acknowledge the value and contribution unpaid carers make to the economy and health service

Reduce risks

Expand the availability of in-home care services to enable more people to age safely in their homes to further reduce the risk of hospitalisation and the need for long-term residential care.

- Increase collaboration between hospital care, primary health and home-based care services to maximise the ability of people to remain in their own homes
- Provide community support workers with expertise in specific health conditions

Responsive Services

Homecare services are too prescriptive, and task focused

- Homecare services are valued when the paid care workers are perceived to be responsive, empathetic and relationship focused
- Homecare services need to be responsive to the deteriorating condition of the person receiving long-term care at home, and the multiple needs of their spousal carers, family and whānau
- Expand access to incontinence support and offer help to family members coping with sleep deprivation due to caring duties

Prevent Burn-out

Prevent carer burn-out through easy access to adequate care support

- Provide more access to carer respite in the form of day programmes and kaumatua programmes
- Provide regular home-based carer respite for people who are housebound
- Expand the availability of overnight residential care respite beds to increase emergency access for spousal, family and whānau care relief

Reduce Social Isolation

Develop social programmes and support networks for older adults to reduce social isolation and exclusion

- Increase the emphasis on local government to provide provision for community centres and hauora to offer these types of social programmes so that they are accessible and affordable
- These types of centres can also provide a focal point for contact with health and welfare services especially for those having issues with accessing GP and social services
- Develop a nationwide network of Carer Support Groups as a key pillar of social support for spousal, family and whānau carers.
- Specific carer support groups needed so that carers can engage with, get support from peers whose family members are suffering from similar illnesses/disorders (such as Dementia, Parkinsons, Motor Neuron & Stroke). These groups need to be located near carer respite day programmes/kaumatua programmes as well as online, to assist with time-poor informal carers accessing support.

Social Work Services

Strengthen the role of social workers in supporting older adults and their informal at-home carers to address emotional and practical needs of older adults while ageing in their own homes

- Provide social work services from Primary Health Care clinics, Hauora, Community Centres and Marae to enable older adults to navigate the application processes and outreach work needed to ensure basic needs are met.

Conclusion

This study was to examine the informal and formal support needs of people over the age of 65 years, what would assist them to continue in their own homes and avoid hospital care. The study findings found that many participants believed they cared for themselves well, enjoyed their environment, but simultaneously were aware that given their age and stage of life span, their situation could change quite rapidly with the onset of ill health or a disability in themselves or in their partner or husband.

An evident theme for these older adults, was not only for them to keep as well as possible but also to prepare a plan for what may happen in the future, particularly when support was needed from either formal or informal carers or from family or whānau. In this study it was notable that some of those interviewed did not have family in the same district, which may mean intermittent care from fly-in, fly-out family members or whānau, or in a few instances no family at all to seek support from.

The possession of a current driver's licence was highly valued by someone in the household, with anxiety and worry generated about its possible loss or having it suddenly or severely restricted, as this would affect their independence and perhaps habits of a lifetime as well as adapting to a reliance on others for transport. This loss of independence could also mean that their time to care for their home (and others) was further reduced. Transport to medical appointments and personal maintenance, was almost a weekly occurrence for some. Promotion of available older driver support courses is needed.

A considerable group of participants were not living alone but caring for a husband or partner who was unwell with a progressive illness and in need of more assistance than they could provide themselves. It was quite distressing for the researchers to hear their stories, about the strains, frustration, exhaustion they were under, along with the emotional impact on the carers of conditions such as Dementia, Parkinsons and issues with incontinence.

There was a significant degree of carer concern about the reliability and consistency of care between home care support worker experiences. Care worker reliability was questioned when workers failed to show up, with worker shortage given as the reason. Inconsistent support was accepted even if they did not feel satisfied with the reliability or quality of caring shown, but questions need to be asked around – Why did they not want to speak up?

Low quality of care that some workers provided, left the cared for person feeling that the care provided was a task-oriented job to be completed in the fastest amount of time with minimal client interaction. If there was a spouse present the rushed nature of the work did not allow for a degree of carer respite, as spouses felt that their needs were dismissed. At times it was felt that there was coercion into not needing help, that they were eligible for, due to staff shortages. Some women felt they put themselves into a risk situation, because there was not enough staff to assist with home care of a sick or disabled person, who were mainly men. On the other hand, a few older people did not want the help that was needed as they believed they could do everything themselves, as they had always done; while another interviewee did not want to let someone they did not know into their home. Lack of information, having 'to find their own care' or having 'to jump hurdles' to get in touch with

people created problems that often felt unsolvable. For older people living alone, the paid care worker may be the only connection with the outside world the older person had, so how the worker interacted with their client was identified as vitally important.

Given the clearly projected demographic rise in older people in Aotearoa New Zealand (and internationally) it is imperative that aged care is funded and cohesively planned for by all relevant government sectors. The caring professionals such as social workers and other allied health professionals being visible in the community will enhance the health and well-being of older adults who have so much to contribute to society. However, many older people find it difficult to ask for help, so tact is required when assisting what is known as 'caregiver burden'.

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Appendix

UoW Summer Research Scholar Poster Presentation

Understanding home support needs of people aged 65+ years in the WBOP

In Aotearoa New Zealand the population of people aged 65+ is likely to grow from approximately 842,000 to 1.5 million by about 2050. (Stats NZ, 2022).

This research seeks to understand ways in which people aged 65+ years can be supported to continue living well in their own home.

This community based research project was developed in partnership with members from Age Concern Tauranga, Tauranga Rural Women, Grey Power Western Bay of Plenty and National Council of Women Tauranga who came together to form the Home Care Advocacy Group.

This group proposed that there were gaps in the current system that provides at-home care for those over the age of 65, and were passionate about finding ways to better support people to remain in their own homes as they age.

Summer Research Scholar: Molly Crawford
Principal Researchers: Dr. Kelly Glubb-Smith & Dr. Trish Hanlen

Conducted alongside the Home Care Advocacy Group



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Two Part Qualitative Study

1

Stage One: Interviews

Semi-structured interviews with 19 people over the age of 65 that are currently living in their own homes.

Research aim: What informal and formal supports do people over the age of 65 years need to continue living in their own home and to avoid hospital level care?



Stage Two: Survey

Survey run through Qualtrics and sent to employee's of Care Service Providers and NASC (needs assessors) coordinators

Research aim: To improve innovation, policy development and the practice of service provision for older people living in their own home, to reduce the need for hospital level care.

Stage One:

2



Thematic Analysis



3

"There's no roundabout at the bottom of the hill."
- Holly

"The support is there, but it is difficult to access."
- Shannon

Participant's Voices

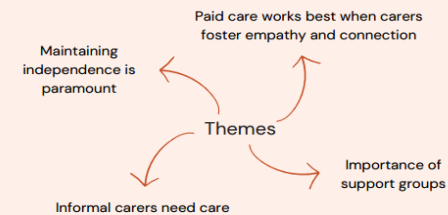


"I have a grave concern for a lot of older people, they seem to be isolated."
- Erina

"The other option is he goes into care and I'm home on my own and I don't want that"
- Olivia

Outcomes

4



Where to from here?

- First journal article from Stage One in process
- Stage Two results to be analysed
- Report from both stages to be published
- Advocating for changes to be made!

