# Does remaining at home with a homecare package promote maintenance of life skills and enhance quality of life?

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# **Abstract**

This mixed methodology study investigated whether provision of a homecare package promotes maintenance of life skills and quality of life in older adults, from their perspective. Twelve participants, 49 to 80+ years of age, were recruited through a care coordination service. All participants received care coordination services, and lived in small to medium sized towns within one District Health Board in the North Island of New Zealand.

Qualitative data were gathered through semi-structured individual interviews conducted within the first week of care package implementation, and 6 weeks later. A "Yesterday Diary" was also completed at weeks 1 and 6, to gather quantifiable information on changes in participation in everyday activities after care package implementation. The rationale for gathering these quantitative data was that an increase or decrease in activity level might indicate changes in physical functioning or decline in life skills, which could impact participants' quality of life. Qualitative data were analysed using conventional thematic content analysis which identified and grouped emerging themes into initial codes then reduced themes further into broad categories. Quantitative data were summed and displayed in tables for a qualitative interpretation.

Findings revealed that participants perceived care as reciprocal; in that both the care recipient and care provider were actively involved, enabling participants to maintain skill levels and giving them a sense of being in control of the care provided, thus supporting quality of life. Care recipients reported that they formed close relationships with their carers which enhanced their quality of life.

Integrating the qualitative and quantitative data revealed an absence of meaningful activity in participants' lives, with participants spending most of their time indoors and not venturing into the community. An unexpected finding was an absence of protection

for homecare recipients who reported varying levels of expertise among carers, carers not knowing what was required, and being asked to sign off work that had not been completed. It was unclear whether these issues were due to organisational failure to provide training for carers or pass on information about homecare recipients' needs.

Further research is needed regarding how to facilitate social connections among older adults who remain at home and incorporating social connection into care packages. Although social relationships with carers were beneficial to participants, potential risks associated with blurring of roles—for both care recipients and carers—warrants future study. Further study to explore how informal caregivers benefit from homecare package provision would be beneficial.

The study had two main limitations. First, participants' perceived quality of life was not measured using a specific standardised assessment tool. Second, the Yesterday Diary was difficult to administer and provided insufficient data to calculate whether there was an increase or decrease in participant activity levels subsequent to care package implementation. An alternate strategy to get a true sense of how older homecare package recipients spend their time, and implications for maintenance of life skills and quality of life, might involve observing participant activity over a 24-hour period. A strength to observing participants over a 24 hour period could be that this methodology may provide greater insight into how participants spent their time, as the level of detailed data gathered in the Yesterday Diary was determined by participants motivation and ability to recall events fully.

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**Attestation of Authorship** 

"I hereby declare that this submission is my own work and that, to the best of my

knowledge and belief, it contains no material previously published or written by another

person (except where explicitly defined in the acknowledgements), nor material which

to a substantial extent has been submitted for the award of any other degree or diploma

of a university or other institution of higher learning."

Dele Poles.

Signed:

Date: 15th February 2020

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# **Chapter 1: Introduction**

# **Introduction and Rationale to Study**

This mixed methodology study investigated whether remaining at home with a homecare package effected maintenance of life skills and quality of life (QoL) from the perspective of 12 older adults who received such services in an urban setting within one regional District Health Board (DHB) in the North Island of New Zealand. Home support services aim to meet client identified care needs. To gather service user perceptions on how their lives had benefitted from the provision of a homecare package, semi-structured individual interviews, guided by qualitative descriptive research methodology, were to be conducted within the first week of care package implementation, and six weeks later (reference). However, this was not possible as eight of the participants had already had their home packages in place for a number of weeks prior to the initial interviews. Thus, where possible, interviews were completed with all participants during weeks one and six. In addition, "Yesterday Diaries" were completed at weeks one (where possible), and six, to gather quantifiable information on any change in the participation of occupations post care package implementation (Gershuny, 2004).

Time spent on Instrumental Activities of Daily Living (IADL) and Personal Activities of Daily living (PADL) was gathered via the Yesterday Diary to examine how participants spent their day. PADL encompass the following functional skills; mobility, feeding, eating/swallowing, personal hygiene, toileting, sexual activity, and sleep. IADL involve interactions and activities which extend beyond self-care; caring for others, communication, accessing the community, managing finances, managing health, religious observance, managing personal safety, shopping, managing the home, home maintenance, and meal preparation (Foti & Koketsu, 2013). The rationale

for gathering this data was that an increase or decrease in participant activity post homecare package implementation might indicate changes in physical functioning which could impact on the participants' QoL, life skills, and life roles.

QoL, according to the World Health Organization (WHO, 2018), encompasses a person's physical and psychological health, their belief systems, social relationships, and relationship with the environment. Life skills are defined as, "abilities for adaptive and positive behaviour that enable individuals to deal effectively with the demands and challenges of everyday life" (WHO, 1999; p. 1). The WHO (1999) proposed that there are five main life skills: 1. Decision-making and problem-solving 2. Creative thinking and critical thinking 3. Communication and interpersonal skills 4. Self-awareness and empathy 5. Coping with emotion and stress. Studies show that life skills enable individuals to adapt and cope with changing life situations and environments; and help individuals to achieve self-efficacy, increase in self-confidence, and self-worth (Chakra, 2016; Miller, 2012). Life skills are learned; they vary over a life course and need to be maintained for older adults to participate in meaningful and necessary occupations as well as manage their environment. In the field of occupational therapy, a skill is defined as a performance component acquired through training and practice (Abaogulu, Cesim, Kars, & Celik, 2017).

Occupational therapy promotes functional independence of individuals with their daily life skills (Abaogulu et al., 2017). For the purpose of this study, I took an occupational therapy perspective; thus, the words "life skills" in the research question refer to PADL and IADL. Using the term life skills in a broader context encompasses the concepts of physical, emotional, social functioning, and participation which align with the broad intentions of the *Positive Ageing Strategy* (Ministry of Social Development, 2001). This definition aligns well with the overall purpose of the

present study and was the working definition that I used. The legislative context of the study will be discussed later in this chapter.

The focus of the study is in line with the overall aim of homecare service provision which aims to "promote and maintain independence in people who have difficulty caring for themselves" (Ministry of Health, 2003, p. 2) to maximise the independence, QoL and self-reliance of the individual. Home care services employ and train care staff to provide homecare packages to eligible individuals (see page 12). Homecare packages provide people with disabilities assistance with washing and dressing, toileting, getting in and out of bed, on and off the toilet, in and out of the shower, feeding, assistance with drinks, shopping, meal preparation, and domestic chores (Ministry of Health, 2003). Care is provided by low paid carers. The demographic for a typical homecare worker is that of a middle-aged woman with low educational status. According to International and New Zealand data the role of carer involves minimal training, high workload pressures, and limited opportunities for career advancement (King, Parsons, & Robinson, 2012; Yamada, 2002).

My interest in this topic arises from having been an occupational therapist for 18 years. In that role, I have assessed children and older adults with chronic health difficulties and disabilities living in the community, in both the United Kingdom (UK) and New Zealand. I have recommended equipment and minor and major adaptations to enable people of all ages to live independently in their homes. I have also conducted needs assessments and implemented homecare packages. As an occupational therapist, my role involves the use of clinical reasoning skills to evaluate my practice. I evaluate treatment plans, whether patient goals have been met, and whether equipment ordered has met the client's needs. Although I have conducted numerous needs assessments and implemented hundreds of homecare packages, I

have never evaluated the effectiveness of those services in generating the intended health and social benefits (once they have been put in place) other than to occasionally advise carers on manual handling techniques.

As an occupational therapist, I had assumed that the desired outcome of maintenance and promotion of life skills, with regard to PADL and IADL, were met. I had also assumed that assisting individuals with PADL and IADL would enable them to maintain their life skills and promote independence and QoL. More specifically, occupational therapists, in general, have not assessed how homecare package provision has effected the lives of their clients. Little research has been undertaken on this topic in New Zealand. Research that informed this project is primarily from overseas.

From an occupational perspective, ageing in the community, rather than in an institution, can be assumed to have health benefits. Deinstitutionalising care and remaining at home has been found to enhance the QoL among the older adults (Ilinca, Rodrigues, & Leichsenring, 2015). People are likely to remain more active in community contexts, and participate in occupations that have known health benefits such as leisure activities and social interaction (Iwarsson et al., 2007; James, Wilson, Barnes, & Bennett, 2011b; Kjersti Vik & Eide, 2014). However, whilst employed at a residential care home in New Zealand, I was alerted to the possibility that homecare packages may not achieve intended outcomes. I noticed a decline in residents' functioning, as well as reduced participation in PADL and IADL, and observed learned dependency in residents within weeks of admission. This observation prompted me to question whether the same decline in functioning was evident in older adults living in their own homes when homecare packages were put in place. The intended treatment outcome, for homecare provision, is that the person living at home with assistance will

be in control of their daily routines, fulfil their life roles, and stay connected to community and family (Ministry of Social Development, 2001).

As occupational therapists, it is important that we do not to rely on assumed outcomes, but that we separate theory and knowledge from our own personal belief systems (Carpenter & Suto, 2008). This study thus aimed to explore the effect of homecare package provision on older adults living in their own homes, and whether homecare packages effect care recipients' maintenance of life skills and QoL post provision.

# **Context of Study**

# Healthcare costs associated with an ageing population

New Zealand has an increasing older population. In 2018, the total population in New Zealand stood at just over 4.5 million. The over 65 age group made up 15% of the population at 687,824 people (New Zealand Demographics Profile, 2018). The number of older adults over the age of 65 is set to rise to over one million by the late 2020s (Stats NZ Tatauranga Aotearoa, 2012). By the late 2030s almost one quarter of New Zealand's population will be over 65 years of age (Stats NZ Tatauranga Aotearoa, 2012).

Ministry of Health (2017d) data suggest that without health improvement there will be an increase in those requiring services; and, therefore, an increase in costs associated with service provision. Aged care could be regarded as a growing business which will need to expand to keep up with growing demand. Consequently, there is risk that demand for services may soon outstrip supply (Metzelthin et al., 2017; Whitehead, Worthington, Parry, Walker, & Drummond, 2015).

In 2017, District Health Boards (DHBs) spent a total of \$983 million on support services for older people. DHB spending statistics (Ministry of Health, 2017d) reveal

that people over the age of 65 used 42% of the health services. Of that, approximately 60% of the funds are spent on residential care, and only a quarter of annual expenditure is spent helping people remain in their own homes. Although greater funding is currently allocated to residential care, legislative support for services (Ministry of Social Development, 2001, 2013; WHO, 2002b) suggests that enabling people to stay at home is preferable to having them live in long term residential care (Ministry of Health, 2017d). Historically, homecare packages have been regarded as more cost effective than residential care. However, the Care Support Workers Settlement Act (Ministry of Health, 2018), and subsequent 21% increase in the minimum wage (from \$15.75 to \$19 per hour) for 55,000 New Zealand care workers, has meant that remaining at home may no longer be a cheaper alternative to residential care or supported living.

Not only has legislative change increased staffing costs, but it has also increased staff training costs. It is now a legislative requirement that continued professional development and regular training programmes are provided for care workers and are paid for by employers; that is, homecare organisations and/or individual private purchasers of care (Ministry of Health, 2017c). As the cost of remaining at home is set to rise, more tools may be needed to evaluate homecare services to ensure that DHBs spend public money effectively.

The introduction of the Results Based Accountability Framework in New Zealand was an attempt to provide a quality standard for the providers of home based support services (Ministry of Health, 2017a). It was developed in response to previous concerns that highlighted inconsistencies in the quality of homecare package provision (Controller and Auditor General, 2011). Ministry of Health performance measures, which form part of the Results Based Accountability (RBA) Framework, currently utilise client satisfaction surveys to evaluate whether client needs have been met to

ensure that the client can remain living safely in his or her own home. The RBA stipulates that client care plans are reviewed annually as part of the evaluation process. Clients are asked whether their care has been provided at the agreed time, and whether this care has been provided without any interruption to services (Ministry of Health, 2017a). There is no mention in the RBA or Home and Community Support Service Specifications (Ministry of Health, 2003) of the requirement to audit whether or not client goals have been achieved, even though client goals are detailed in the Ministry of Health online guide for service recipients—What you can expert from homecare support services. The guide states that the service user support plan, "outlines the assistance you will receive and the goals you can work towards to maintain or improve your independence so you can do the things that are important to you" (Ministry of Health, 2013, p. 2).

Restorative models of homecare involve time limited, target driven intervention using a multidisciplinary approach (Metzelthin et al., 2017; Whitehead et al., 2015). Pilkington (2011), who set up reablement/restorative homecare programmes in the UK as part of the Department of Health's Care Services Efficiency Delivery (CSED) team, argued that people wish to retain their independence and that assisting people to relearn everyday life skills should be integral to homecare packages. His study found that recipients of conventional homecare packages were 95% more likely to require homecare packages for the rest of their lives. Out of those who received just six weeks of reablement homecare package, almost half the people were found not to require assistance (i.e., were independent with PADL/ IADL two years later).

My professional experience working as an occupational therapist in New Zealand, for the last 12 years, informs me that the restorative or reablement approach is primarily used for acute injury related conditions in New Zealand but not chronic conditions managed in the community. The absence of the requirement to regularly review client goals suggests that although the term "restorative approach" is used in the government literature (Ministry of Health, 2003, 2012; Ministry of Social Development, 2001) a true restorative approach for clients with chronic health problems and disabilities, over the age of 65 years of age, is not being implemented in standard homecare packages. As previously stated, the role of the carer involves minimal training; therefore, it is unclear how a restorative approach can be implemented in a homecare setting that employs untrained carers.

This research aimed to provide insight into the self-perceived benefits of homecare packages funded by a single DHB by exploring whether homecare clients perceived that homecare package provision enabled them to retain life skills with regard to PADL and IADL, and experienced improved QoL.

# **New Zealand Population**

Within the broad outline of the over 65-age group, decades of institutionalised racism, inequality, and poverty have led to poor health outcomes among Māori (Strickland, 2016). Māori experience a higher burden of disease compared to other groups, with a higher proportion experiencing mood disorder, type 2 diabetes, cardiovascular disease, asthma, morbid obesity, respiratory infections, and cancer (Strickland, 2016). Such a disease profile might suggest disproportionate levels of homecare package provision to Māori (Kerse, Lapsley, Moles, Moyes, & Edlin, 2016).

A robustly designed cohort study of older New Zealanders, which was considered to have good transferability to the Māori population, revealed that the majority of older Māori participants lived independently in the community, engaged in voluntary and paid work, and kept close connections with the Marae<sup>1</sup> (Kerse et al., 2016). Active

<sup>&</sup>lt;sup>1</sup> A marae is a traditional Māori tribal meeting place (Collins Dictionary, 2020).

participation and engagement in the community kept older Māori participants more physically active than their non Māori counterparts. Māori, however, were more likely to receive informal care from family, when they required assistance with PADL and IADL, than non Māori. Informal care has resulted in a poor uptake of homecare packages by Māori. The study also confirmed that older adults living in high socioeconomic deprivation were more likely to maintain or improve function than individuals living in low socioeconomic deprivation (Kerse, et al., 2016); although the reasons as to this finding were not provided in the study.

Pacific peoples, the Asian population, and Māori experience higher rates of morbidity than other ethnic groups. Māori experience reduced life expectancy, dying 7.2 years younger than non-Māori (Stats NZ Tatauranga Aotearoa, 2013). While Māori account for 16.5% of the total New Zealand population under the age of 65, this population drops to just 5.6% of the population in the 65 plus age group. The majority of Māori statistically do not survive to 80 years of age; and, as a result, the majority of older adults in New Zealand are of New Zealand European descent resulting in lack of ethnic diversity in the over 65 age group (Stats NZ, Tatauranga Aoteoroa, 2013). The claim for direct targeting of health outcomes for Māori is supported by the Treaty of Waitangi (1840)<sup>2</sup> provisions which necessitate actions to correct old wrongs and address previous inequalities (Strickland, 2016).

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<sup>&</sup>lt;sup>2</sup>The Treaty of Waitangi is the founding document of New Zealand from which all New Zealand legislation stems. On September 6, 1840, 40 Māori chiefs signed the English language version of the agreement, which stated that they ceded sovereignty of New Zealand to Britain and the Crown. In return the Crown had exclusive rights to all Māori land. The Māori translation differs from the English version of the Treaty and has led to ongoing disagreement and dispute (Ministry for Culture and Heritage, 2017).

# **Demographic Statistics of Study Area**

Information provided on the website of the DHB of the geographic region in which this study took place identifies a population level of somewhat less than 200,000 people.<sup>3</sup> There is a slightly higher proportion of older adults than the national average, 11% are between the ages of 60-69, 8% are between the ages of 70-79, 3% between the ages of 80-89, and 1% are 90 years of age or over. The DHB also has a higher proportion of Māori than the national average (20%) and a lower percentage of Pacific Island people (2%). The DHB serves an area of high socioeconomic deprivation, which is greater than the national average. Statistically, deprivation is recorded in quintiles—quintile one being the least deprived, and quintile five the most economically deprived. Of the total DHB population, 26% falls within quintile five.

# The Legislative Context

The WHO's Active Ageing Policy provides a global framework which calls for the active participation of all older adults in community life. Active ageing aspires to extend lifespan, enabling older adults to live healthier, more enriched lives. The WHO (2002b) stated that government policy should support both fit and active older adults without complex health needs, and frail and disabled older adults in need of care. Active ageing focuses on continuing participation of older adults in social, economic, cultural, and spiritual contexts in an attempt to extend healthy life expectancy. The inference is that even frail and disabled older adults can experience improved QoL by remaining in their own homes. The home environment, with correct support services in place, enables the person to be more connected to the community and enables active participation in community life (WHO, 2002b).

<sup>&</sup>lt;sup>3</sup> Reference withheld to mask the location of the study participants.

New Zealand guidelines developed in response to the WHO (2002a) Active Ageing Policy cater for the needs of New Zealanders. The Positive Ageing Strategy's (Ministry of Social Development, 2001) 10 positive ageing goals (see Appendix A) endorse holistic based wellness and ageing in place; and enable, encourage, and support older adults to remain in the community with the provision of services to support their needs. The Positive Ageing Strategy (Ministry of Social Development, 2001) is a guide for successive governments, and action on the strategy is dependent upon the political will of the government in power. The strategy promotes flexible working and transport options, accessible health services, affordable housing and financial support, and encourages the continued and active participation of older adults in the community. See Appendix A which details the Positive Ageing Strategy's 10 positive ageing goals. The policy document "Older New Zealanders healthy, independent, connected and respected," which was developed 12 years after the Positive Ageing Strategy (Ministry of Social Development, 2013), outlines the actions taken by government to fulfil promises made by the government in the Positive Ageing Strategy. Appendix B details actions taken by the Government to fulfil each of the four goals. These actions include homecare packages to assist older adults to live independently at home, increased support to family carers, respite options for older adults, and falls prevention programmes to reduce falls and hospital admissions.

The Ministry of Health (2003), Home Support Services National Service Specifications, promote the understanding that care recipients control how and by whom the care is administered. The older adult living at home is positioned as being in charge of his or her daily routine and able to maintain his or her life roles and normal daily routines. According to service specifications, care recipients are not passive receivers of care but are actively involved in how care is delivered. The

annual plan for the DHB involved in this study states that, "People are experts in their own lives and are partners in their health care," and that people with disabilities should have access to choice and control of the support they receive and the lives they lead.

The same service philosophy of clients being in control of their care is also apparent in the age-related care services agreement for residential care services which states that, "Services must be resident centred and that residents should have access to a range of life experiences choices. Services should promote each resident's independence, their quality of life and involve residents in decision-making that affect their daily lives" (Ministry of Health, 2019, p. 41). Personal experience working in a residential care home informs me that not all care homes are meeting the aspirations of the service specifications; regardless of the intended outcomes of the age-related care service agreement, a perception remains that older adults must fit around the institutional needs of the establishment.

Research has shown that older adults living in residential care settings have reduced life expectancy due to apathy (Nijsten et al., 2017). The older adult loses a sense of being in control of his or her life, in being unable to carry out normal daily routines or life roles, and loses motivation to engage or participate. This apathy may be due to loss of control with regard to decision making in the residential care setting.

# Eligibility for homecare package provision

People with long-term disability are eligible for assistance if they meet the Ministry of Health eligibility guidelines (i.e., they have a permanent physical, intellectual, or sensory disability that prevents them from functioning independently). Eligibility and

<sup>&</sup>lt;sup>4</sup> Reference withheld to mask the location of the study participants.

<sup>&</sup>lt;sup>5</sup> Reference withheld to mask the location of the study participants.

access to care services are determined following needs assessment (Ministry of Health, 2017f). Not all individuals with a disability are covered by the Ministry of Health funding or DHB funding. Patients with mental health needs without a physical disability receive funding assistance from the DHB through a different funding stream. Only New Zealand residents are eligible for assistance (Ministry of Health, 2017f). Individuals with disabilities, caused as a result of an accident, are usually covered under the Accident Insurance Act 1998. Services provided are the same regardless of funding stream—Accident Claims Corporation (ACC) or Ministry of Health (Ministry of Health, 2017f).

Home support services are provided when there is no one living in the home available, or able, to provide personal care (Ministry of Health, 2003). Carer support is also provided to assist primary care givers caring for a relative at home. The National Service Framework Home Support Specification does not stipulate or specify the maximum or minimum number of hours of support an individual should receive (Ministry of Health, 2003). Individual DHBs apply their own policy limits on budget, where and how resources are allocated dependent on individual identified need. For the purpose of this study, it was not feasible to compare DHB spending across New Zealand, and how service allocation may or may not differ across DHBs. My professional experience working in New Zealand has informed me that DHBs have attempted to reduce costs by decreasing service provision for homecare. In 2017 Midcentral DHB were accused by the media of a cover up as they failed to identify the number of older adults whose homecare packages had been cut. The DHB stated that the number of people who had had services cut was between 15 and 461. They argued that the absence of specific data was due to a problem with their IT system rather than a deliberate intention to withhold information (McBride, 2017).

#### **Needs assessment**

Homecare packages support the Positive Ageing Strategy of "Ageing in place", and enable older adults to remain living in their own homes. The Needs Assessment and Service Coordination Organisations contracted by Disability Support Services and the Ministry of Health arrange assessments for individuals requiring homecare packages. The needs assessment is used to formulate a plan to support the care needs of the individual. The level of assistance a person receives with Personal Care and Household Management is dependent on the amount of assistance required. An individual may require 3 to 4 visits per day (including a tuck in service) up to 7 days a week. In some cases, the care recipient may require a sleep over service, where the carer is required to assist the disabled person with toileting or personal cares during the night. Needs assessments are undertaken by a variety of professionals across the multidisciplinary team including nurses, social workers, and occupational therapists, and are undertaken prior to hospital discharge or during a home visit assessment. The needs assessor assesses the individual's capability to carry out PADL and IADL.

# InterRAI

International Resident Assessment Instrument (InterRAI) assessment tool was introduced across New Zealand in 2008, to assess clients with complex needs where multi agency involvement is required. The InterRAI needs assessment tool aims to provide comprehensive, standardised, needs assessment across New Zealand. InterRAI is not without its limitations, and some argue that it has been known to identify more needs than DHBs can meet (Parsons et al., 2013). In 2013, it was estimated that 10% of disabled adults have an unmet need for some form of assistance (Stats NZ Tatauranga Aotearoa, 2013).

It has been proposed that the delivery of homecare packages should be as standardised as the needs assessment. An inquiry into homecare provision in 2017 by the Labour and Green Parties found inconsistencies in both the application of InterRai needs assessment and provision of homecare packages across DHBs. The report called for improved outcome-oriented performance measures to improve accountability and the monitoring of health outcomes. They recommended the appointment of an Aged Care Commission and a government-backed system to star rate providers (New Zealand Labour Party, Green Party & Grey Power, 2017).

### **National Service Framework objectives and specifications**

The Ministry of Health service specifications in the National Service Framework (NSF) (Ministry of Health, 2015) aim to meet the policy objectives of Older New Zealanders Healthy, Independent, Connected and Respected by providing homecare packages to enable older adults to remain living at home (Ministry of Social Development). Services aim to be client centred and flexible to suit client needs. The NSF outlines the mandatory support services that DHBs must provide and how these services should be administered by Home Support Services.

The NSF Service Specifications (Ministry of Health, 2015) state that the aim of homecare provision is to maximise the person's independence, improve QoL, self-reliance, and assist a person to retain or maintain functional ability. The service objective is to assist a person's independence through supporting and maintaining his or her current skills while also assisting in the development of new skills. Ministry of Health service objectives, which promote new skill acquisition, suggest that the Ministry of Health is moving towards a rehabilitative or restorative approach to homecare provision (Ministry of Health, 2015).

# Bi-cultural health provision

New Zealand policy aims to ensure positive health outcomes for Māori, to correct past inequalities, to enable Māori to live longer, healthier lives free from disability (Strickland, 2016). It enables Māori to have access to culturally appropriate services and ensures cultural safety (Ministry of Health, 2012). The *Māori Health Strategy: He Korowai Oranga* (Ministry of Health, 2017e) aims to promote Māori health by promoting healthy families, healthy individuals, and healthy envirionments. It ensures that homecare service providers implement an annual plan stating how they will promote Māori health in their service delivery. The aim of Māori Disability Support Services, as defined by the Ministry of Health (2012), is to ensure Māori with disabilities "have an improved level of quality of life and independence" (p. 2).

The Positive Ageing Strategy (Ministry of Social Development, 2001), Home Support Services Specifications (Ministry of Health, 2003), and Māori Disability Support Services (Ministry of Health, 2012) strongly focus on the term independence. Māori believe that interdependence, which primarily refers to being connected to one's whānau (family) or Whānaui (tribal family), is vital to well-being. Collective wellness is more important than individual well-being (Bell, Smith, Hale, Kira, & Tumilty, 2017) or independence. Indigenous peoples often refer to being connected to the land and the rivers as being an essential part of health and well-being (Bell et al., 2017). Bell et al. (2017) argued that to address the health needs of Māori, practitioners need to have a greater understanding of Māori culture and belief systems, and use appropriate terminology and culturally sensitive language. Rather than imposing a westernised model of wellness upon Māori, which can result in poor outcomes. This disjuncture in belief systems may signal a level of discomfort amongst Māori to accept assistance from homecare services.

# **Overview of Thesis**

Chapter 2 will discuss international research that revealed the need for this study in New Zealand; and will discuss ageing at home, the demand for support services, how ageing at home supports maintenance of life skills, activity, health and well-being. I will explore how homecare package provision is said to reduce rates of cognitive decline, promote social connectivity and QoL. I will also detail how homecare services are currently provided worldwide, as well as user perspectives of homecare packages.

Chapter 3 will deliberate on qualitative and quantitative methodology, and the rationale behind this mixed methodology study. I shall explain the ethical processes, participant selection eligibility criteria, qualitative and quantitative data collection, and combined data analysis.

Chapter 4 will present the results. The first section will present participant demographic data. The second section shall describe data from Yesterday Diaries (Gershuny, 2004), recorded during the first and second interview, which details activity undertaken by participants (in 30 minute slots) the previous day. The Yesterday Diary was used to explore any changes in participant activity post care package implementation. The third section presents data from semi-structured interviews on participants' views of homecare packages. I will then integrate both qualitative and quantitative findings.

Chapter 5 will discuss the research findings and the implications of the study. I will outline the strengths and limitations of the study and areas of further research.

# **Chapter 2: Literature Review**

# Introduction

To give context to the research question "Does remaining at home with the assistance of a homecare package promote maintenance of life skills and enhance quality of life?" the literature presented discusses:

- The growing demand for home-based support services worldwide as the population ages.
- How ageing at home helps older adults to maintain life skills, maintain activity levels, and promotes health and well-being.
- How ageing at home is linked to increased QoL and reduced rate of cognitive decline among older adults.
- How ageing at home facilitates social connectivity and improves health outcomes.
- The disagreement that exists around the definition of the term QoL.
- Homecare package provision, users' perspectives of homecare package provision, and how homecare packages are currently evaluated in New Zealand and worldwide.
- How the situation and experiences of people in their own home contrasts with that of people in residential care, given the overarching purpose of provision of homecare services is to maintain people in their own home.

#### Literature Search

To inform the study, I sought literature that would provide a broad overview of homecare provision in New Zealand and internationally. My initial search was conducted in 2017 and extended over a 12-month period. Scopus, Medline, CINAHL, and AMED databases were searched as they include relevant articles from nursing,

allied health, medicine, and psychology journals. I tried to limit the literature search to articles from 2000 to 2020 to ensure the information I was drawing from was both current and offered insight into whether the situation had changed in some way. I used the following search terms in various combinations: elderly or older adult, homecare or homecare package, QoL or QoL measures, Māori health, New Zealand policy, and ageing at home. Older literature included in the literature review has been used as background information.

# **Demand for Support Services**

As mentioned in Chapter 1, New Zealand has an increasing older population with the 65 and over age group set to reach over 1 million by the late 2020s (Stats NZ Tatauranga Aotearoa, 2012). As the older adult population grows, there will be an increase in the number of people experiencing chronic illness and disability, and greater demand for services to support their needs (Inoue & Matsumoto, 2001). Hussein and Manthorpe (2005) conducted an international review of care policies and predicted long-term care workforce shortages from nine European countries, and four non-European countries— Japan, USA, Canada, and Australia (New Zealand was not included in this review). The study revealed that the proportion of the population requiring help with daily care was set to increase by 2020 in developed countries. At the time of Hussein and Manthorpe's report, the UK and USA were experiencing difficulty filling vacancies for homecare workers. Japan, Italy, and Germany also experienced difficulties recruiting care workers, and developed active immigration strategies to recruit staff from overseas to fill unfilled vacancies. There was an evident risk that demand for services could soon outstrip supply (Whitehead et al., 2015). These risks heighten the need for research such as the present study to inform policy decisions about service funding and workforce recruitment and training.

# **Quality of Life**

To examine whether remaining at home with a care package impacts on maintenance of life skills and enhance QoL, it is important to define the term QoL. However, disagreement remains regarding the domains, structures, and meaning of the term (Carpenter & Suto, 2008; Vanleerberghe et al., 2017). While there is general acknowledgement that QoL is individually defined, many experts have tried to quantify the non-quantifiable.

The WHO defined QoL as a person's individual perception of their position in life, in the context of their culture and society values, the person's life goals, expectations, standards and concerns. QoL, according to the WHO (2018), encompasses a person's physical health, psychological health, belief systems, social relationships, and relationship with the environment.

QoL measures collect objective and subjective data, and are used in a number of fields, including healthcare, politics, employment, and international development. One such measure is Flanagan's Quality of Life Measure which encompasses five concepts: material and physical well-being, relationships, community/civic activities, personal development/ fulfilment, and recreation (Burckhardt, Anderson, Archenholtz, & Hägg, 2003). These five concepts are promoted in New Zealand's Positive Ageing Strategy (Ministry of Social Development, 2001) and reflect some of the commonly accepted meanings attached to the term QoL. For the purpose of the present study I have extended Flanagan's Quality of Life Measure of fulfilment to include having fun. Therefore the working definition of Quality of Life in the present study is material and physical well-being, relationships, participating within the community, personal growth and development and having fun.

However Vanleerberghe et al. (2017) argued that the lack of consensus on the definition of the term QoL has contributed to the fact that there is no suitable instrument to assess the QoL of older adults 'ageing in place'; despite the numerous QoL measures available for use with older adults. One commonly used measure is the WHO's (2006) QoL questionnaire-version for older adults (WHOQOL-OLD) which uses a Likert scale to assess older adult's self-perceived satisfaction in sensory abilities, autonomy, past present and future activities, social participation, and concerns regarding death and dying, and intimacy. The WHOQOL-OLD is a generic assessment for older adults and is not specific to homecare recipients. Vanleerberghe et al. postulated that the absence of a suitable QoL measure to evaluate ageing in place could threaten the QoL of older adults living in the community.

# Quality of life and social connectivity

Despite on-going debate over the precise meaning of QoL, research indicates that adults remaining at home are more likely to experience better QoL than those living in residential care (Nikmat, Al-Mashoor, & Hawthorne, 2013). Haustein and Siren's (2014) Danish study involved 3962 participants who were 70 years of age, and used the Pearlin Mastery Scale (Pearlin & Schooler, 1978), the Centre for Epidemiologic Studies Depression Scale (CES-D) (Radloff, 1977), and a self-rated health and well-being questionnaire to measure QoL. The study found that remaining socially connected within the community enhanced QoL, independence, and empowerment in the study participants (Haustein & Siren, 2014; Holt-Lunstad et al., 2010). Research has shown that socialising with family and friends, financial status, relationship with children, as well as participation in the education and upbringing of grandchildren were important for older adults (Kerse et al., 2016; Kjersti Vik & Eide, 2014; Nikmat et al., 2013). Some argued that socialising was more important to older adults than leaving the house (Kjersti Vik & Eide, 2014). However, as many older adults

regarded the use of media as participation, this point of view illustrates how modern technology has enabled many older adults to remain socially connected to family and friends without the need to leave their homes (Mars, Kempen, Mesters, Proot, & Van Eijk, 2008).

The importance of social contact and its positive impact upon health is well established (Arslantas, Adana, Abacigil, Kayar, & Acar, 2015; Holt-Lunstad et al., 2010). For example, Holt-Lundstad's study (2010) found that people with stronger social relationships had a 50% higher likelihood of living longer than those with fewer weaker relationships. Older adults who were not socially connected were more likely to experience loneliness, which studies link to reduced QoL, psychosocial well-being, and poor health outcomes (Arslantas et al., 2015; Xavier, Ferraz, Marc, Escosteguy, & Moriguchi, 2003).

It was believed that close relationships helped individuals to manage and adapt to stressful life events by promoting adaptive behaviour and boosting the individual's immune system. Older adults who had less self-resilience when dealing with stressful life events experienced lowered immune systems and the increased likelihood of ill health (Holt-Lunstad et al., 2010).

The influence of reduced physical and psychological health, and the relationship the person has with the environment, are indicators of reduced QoL according to the WHO (2018) definition. These findings support Inoue and Matsumo's (2001) recommendation that social relationships should be used within treatment planning to enhance both QoL and increase survival rates of patients (Arslantas et al., 2015; Holt-Lunstad et al., 2010; Xavier et al., 2003).

There is an assumption that remaining at home avoids the problems associated with institutional care delivery and prevents isolation as it is believed to facilitate social

connectivity in the community. However, there is no evidence that if a person has a chronic illness, remaining at home will improve social connectivity more than living in residential care. A key factor in remaining socially connected to the community and loved ones is being able to access transport. New Zealand policy, the Positive Ageing Strategy, attempts to promote social connectivity, by providing older adults with affordable and flexible transport options (Ministry of Social Development, 2013). Mobility and being able to leave the home are an important part of life for older adults living in the community (Haustein & Siren, 2014; Iwarsson et al., 2007).

Although Government legislation supports older drivers to remain driving for as long as they are medically fit to do so (Ministry of Social Development, 2013), there will come a time when the ageing process, combined with chronic health conditions, naturally impact upon an individual's ability to drive safely (Carter, 2006). The cognitive and physical decline can have several impacts; including, the individual's ability to drive safely, cause the older driver to retire from driving, and reduce the person's ability to access public transport (Carter, 2006). Consequently, cognitive and physical decline increases the likelihood of housebound status (Haustein & Siren, 2014). However, enabling older adults to remain socially connected through the provision of accessible public transport which aims to assist ageing in place (Ministry of Social Development, 2001), is only part of the solution. Both recent and earlier studies have found that accessible public transport fails to prevent some older adults from becoming housebound and experiencing increased isolation, reduced independence, and a lower QoL (Haustein & Siren, 2014; Inoue & Matsumoto, 2001). However, as the research does not clearly distinguish between older people who find accessible transport options as an effective solution and those who do not, the reasons why accessible transport is not suitable for some older adults remains unclear.

Health related quality of life and social connectivity

Memory deficit is part of the normal ageing process. In contrast, cognitive decline is associated with lowered QoL, and decline in functional independence (Tabbarah et al., 2002). Nonetheless, research by James et al. (2011) and Nikmat, Al-Mashoor and Hawthorne (2013) have shown that older adults who remain living at home experience reduced levels of cognitive decline and in the early stages of dementia perform better in their home environment than in residential care, again supporting the provision of care in the home. Older adults with cognitive impairment, affecting short-term memory, planning and processing, rely on entrenched habits to complete familiar tasks, IADL and PADL in their home environment (Chronopolus & Golden, 1998). When older adults with cognitive impairment are admitted to hospital or residential care, they are often no longer able to complete simple familiar tasks and are at increased risk of experiencing increased isolation, loneliness, alienation, and reduced physical functioning (Ball et al., 2000).

Extending those findings, research indicates significant differences in QoL, health related QOL, and social connectedness among people with dementia remaining at home. This finding was demonstrated by Nikmat et al. (2013), whose study recruited 49 adults between the ages of 60 and 89 years; 30 were from nursing homes and 19 were living at home with homecare packages. Prospective participants were assessed using the fourth version of the diagnostic and statistical manual of mental disorders (DSM–IV) and the Short Mini Mental State Examination (SMMSE). Participants who met the diagnosis criteria for dementia were included in the study. Researchers conducted face-to-face interviews and assessed participants' depression levels, cognitive impairment, independence with ADL, and social connectedness. Older adult nursing home residents' duration of stay varied between 1 and 204 months. No

significant differences were found in cognitive functioning, depression levels, or comorbidities between each group.

The study found that older adults in receipt of homecare packages reported higher health related QoL scores and greater social connectivity than their counterparts. Those who remained at home attained higher scores on the Barthel Index, had greater physical functioning, and greater autonomy and participation in ADL than the nursing home participants. The research supports evidence of the health benefits of older people (in the early stages of dementia) who remain at home with support services, as it enables them to remain socially connected to the community—maintain their life roles, autonomy, and social contacts.

# Physical and Cognitive Impact of Social Connectivity

Active participation in the community and family roles has been shown to have the associated health promoting benefits of reduced functional decline and increased longevity (Glass, 1999; Holt-Lunstad, Smith, & Layton, 2010; Kerse et al., 2016; Mendes de Leon, Glass, & Berkman, 2003; Resnick, 2012). Remaining socially connected impacts physical health and is also associated with reduction in cognitive decline. This was demonstrated by James et al. (2011) who examined the social interaction and cognitive functioning every year of 1,100 older adults over a 5-12 year period. James et al. found that older adults (free from dementia at the start of the study) who were socially active, experienced reduced rates of cognitive decline (over a five year period) than participants who were less socially active.

Although research suggests that remaining at home enables the older person to remain active and socially connected to the community (James et al., 2011a; Nikmat et al., 2013), Iwarsson et al. (2007) argued that remaining at home does not necessarily facilitate social connectivity or enable older adults to lead active lifestyles. Studies

suggest that older adults with reduced physical functioning are more likely to experience loneliness and social isolation (Holt-Lunstad et al., 2010; Inoue & Matsumoto, 2001). For instance, Inoue and Matsumoto (2001) interviewed 866 older adults over the age of 65 living in the mountain region of Japan. They assessed older adults' ability to perform ADL, PADL, and mobility levels. The study relied on self-reported information by participants. Out of the total number of participants interviewed, 310 were considered homebound, defined as having impairment in all ADL as well as being unable to access permanent toilet facilities (relying on a commode). Key factors associated with reduced activity levels (ADL) were increased age, visual impairment, and age related disability among participants. In particular, older adult residents with reduced range of movement in their lower limbs were more likely to become housebound; in addition to experiencing chronic health conditions, nutritional disorder, cognitive impairment, depression and functional decline, and social isolation (Inoue & Matsumoto, 2001).

Nikmat et al. (2013) found that loneliness was also prevalent in nursing home residents. The study showed a correlation between living in a nursing home, and increased isolation and reduced QoL. Nikmat et al. thought the finding for increased loneliness for nursing home residents was due to reasons other than living in the nursing home environment. This is supported by Russel et al. (1997), who earlier found that older people who experienced high levels of loneliness had an increased likelihood of being admitted to nursing home level care. Therefore, the loneliness experienced by nursing home residents may not be as a direct consequence of being admitted to nursing home care, as the individual may have already experienced social isolation and loneliness in the community.

American and UK studies that have quantified the amount of time that older people spend in their own homes have found that 80% of them (50-90+ years of age) spend

time at home doing sedentary activity rather than going out (Davis, Fox & Hillsdon, 2001; Mathews, Chen & Freedson, 2008). Results such as these suggest that older people living at home with a disability may find it difficult to lead active lifestyles and remain socially connected to the community; and, therefore, are at increased risk of becoming housebound and socially isolated (Inoue & Matsumoto, 2001; Iwarsson et al., 2007). Further research is required to explore how housebound status impacts upon morbidity and disability. The outcome of this type of research may guide the design of future homecare service provision.

## Ageing at Home and Maintenance of Life Skills

Despite the historic bias towards institutional care (Hennessy & Hennessy, 1990), research suggests that older people prefer to stay in their own homes. Older adults' preference to remain living in the community is well founded, given the evidence generated into the impact of residential care. As Ball et al. (2000) observed, the negative effects of living in long-term care institutions (in the higher end spectrum of care) including institutionalisation, depression, alienation, and decreased functional ability are widely documented. That may be because many of the everyday activities that make up people's daily routines in community settings, which are usually performed in the home environment and close surroundings, are not available in residential care settings (Hocking & O'Sullivan, 2005; Iwarsson et al., 2007).

One of the concerns expressed has been that the approach of 'doing for the older adult' deprives older adults of the opportunity to maintain their functional abilities (Ball et al., 2000). Doing for a person, rather than assisting an individual to participate in PADL and IADL, is known to lead to decreased range of movement, reduction in functional ability, muscle deconditioning, and decline in overall physical functioning and functional independence (Metzelthin et al., 2017; Resnick, 2012; Tabbarah,

Crimmins, & Seeman, 2002). There is much about New Zealand homecare service provision that we still do not know. Does it improve QoL and help people to maintain their life skills? The present study addresses the lack of New Zealand research on the benefits of homecare package provision with regard to maintenance of life skills and QoL.

### Ageing at home and activity

International and New Zealand studies indicate that participation in occupations, leisure activities, physical activity, maintaining life roles, and life skills are important to older adults remaining at home (Kerse et al., 2016; Kjersti Vik & Eide, 2014). This finding has been supported by research that shows meaningful activity provides the individual with a sense of security and sense of worth (Kielhofner, 2004). Engagement in activity and meaningful occupation is promoted as having a substantial positive impact on the QoL, well-being, physical and mental health of older adults (Dorrestein, 2006; O'Sullivan, 2004; Wenborn, 2005).

Despite the known health benefits of activity, research indicates that participation in meaningful activity declines with age, with opportunities for participation in activity reduced (Andrew & Halcomb, 2006b; Barnes, 1991; Hasson & Arnetz, 2011; Metzelthin et al., 2017; Kjersti Vik & Eide, 2014). In particular, research suggests that the older adults' motivation to participate in activity is driven by the choice of activities on offer and the amount of control that the individual has over the activity, with many older adults preferring to participate in occupations that they had previously been involved in (Kjersti Vik & Eide, 2014).

A possible reason for reduced activity among older adults is suggested by Vik and Eide (2014) who referred to older adults who receive assistance with homecare packages as "passive receivers of care" (p. 140). Vik and Eide found that older adults

who remain at home, have reduced physical functioning and are dependent, may lose motivation to participate in activity as they have reduced physical control over their environment and little or no control over the type of activity undertaken. Dependency can lead to a lack of motivation to participate in both physical and daily activity, due to a lack of belief in the benefits of activity, and can increase the likelihood of experiencing anxiety and depression (Metzelthin et al., 2017). The present study hopes to explore whether the provision of homecare enables homecare recipients in New Zealand to participate in occupations, physical and leisure activity.

#### Ageing at home, health and well-being

A common theme in the literature was that remaining at home has health benefits; that it alleviates illness and decline in health (James, Wilson, Barnes, & Bennett, 2011a). Where an individual resides, has been shown to play an important role in healthy ageing. To support that assertion, illustrative research findings from large-scale studies that have explored the link between home and healthy ageing, functional independence, well-being and mental health are outlined below.

The Enable-Age project interviewed 1,918 older adults between the ages of 75 and 89 years of age, from five European countries, at two time periods (spaced a year apart) to explore the link between the home environment and healthy ageing (Oswald & Fleischmann, 1985). For the purpose of this study, health was defined as independence in daily activities (ADL). Participant independence in ADL was assessed using Katz's ADL index (Katz, Ford, Moskowitz, Jackson, & Jaffe, 1963), as well as the participants' self-perceived level of independence using self-evaluation measures from the Neuropsychological Ageing Inventory (Oswald & Fleischmann, 1985).

Well-being was assessed using self-evaluation measures: the Psychological Well Being Questionnaire (Ryff, 1989) and the Geriatric Depression Scale (Yesavage et al., 1983). The study results supported the opinion that participants well-being and healthy ageing are not dependent on participants' actual physical ability to perform ADL or overcome environmental barriers around the home; rather, the participants' self-perceived level of functional independence and mastery over the environment. This study also found that participants who were positive about their abilities, felt independent and in control of their environment, and had mastery over their environment, experienced increased well-being and lower levels of depression (Oswald et al., 2007). The satisfaction experienced from having mastery over one's environment and the familiarity of home surroundings may be a reason why many older adults prefer to remain in their own homes (Duppen et al., 2019).

Studies show that strong cognitive ties are formed with the older person and their home environment; it is a place of memories and belonging (Cipriani et al., 2009; Iwarsson et al., 2007; Whitmore, 2001). The objects and possessions that older adults surround themselves with connect them to the environment; provide reminiscence of emotional connections, their relationships to others, connections to past and present events, connections to a higher power and or past occupations (Cipriani et al., 2009). Home is made up of objects. When a person is in his or her home, it is the objects and personal possessions, which make it their home (Cipriani et al., 2009; Whitmore, 2001). Moving into a residential care context means the emotionally painful process of shedding loved possessions, and for many older adults represents the final part of their life, their final residency (Cipriani et al., 2009).

The importance of staying in one's own home, despite increasing illness and disability, is supported by Dutch research (Nijsten et al., 2017). This study explored the correlation between apathy and mortality risk. It recruited 731 National Health

patients, 341 from Somatic Care (SC) units and 371 participants from Dementia Special Care Units (DSC). The average age of participants from the SC unit was 77 years and the average age of participants from DSC was 83 years. Participants were assessed every 4 months over a 20-month period using the 10 item Abbreviated Apathy Evaluation Scale (AES), the Cornell Depression Scale, and the Mini Mental State Examination (MMSE). Researchers found that 50% of all participants experienced apathy which was linked to increased mortality rates in both types of care facility. Participants in the SC unit achieved higher cognitive scores (less cognitive impairment) than participants from the SDC unit. However, no correlation was found between the level of cognitive impairment and apathy levels as both groups of participants experienced similar levels of apathy and depression. As this study only assessed participants in nursing care units, it is not possible to determine whether similar levels of apathy were experienced by older adults living in the community. Nijsten's (2017) study highlighted the negative effect of living in a nursing care setting and supports the view that remaining at home with a care package is preferable to living in residential care. That view is supported by Iwarsson et al.'s (2007) earlier study which found that relocation and upheaval impacted negatively upon the health and well-being of older adults. Iwarsson et al. argued that preventing re-location is one of the greatest needs of older adults, a perspective that supports homecare services.

#### **Provision of Homecare Services**

When reviewing the literature on homecare for the older adults, there were four reoccurring themes; future measures required to meet the growing demand for carers,
standards of care, service user safety, and the development of measures that capture the
outcomes of the homecare service (Robinson & Griffiths, 2010; Socol, 2006; Thornley,
2000; Yamada, 2002a). Studies reveal that homecare package provision has increased

worldwide due to greater understanding of the health benefits of ageing in place and remaining at home (Hennessy & Hennessy, 1990; Hussein & Manthorpe, 2005; Kjersti Vik & Eide, 2014). Harwood, Sayer, and Hirschfeld (2004) predicted that the proportion of older adults requiring daily care and dependent people (the dependency ratio) in Australia, Canada, Denmark, France, Finland, Germany, Hungary, Japan, Netherlands, Spain, Sweden, UK, and USA will continue to rise. The study focused on the needs of younger disabled people from the ages of 15 to 59 years rather than older adults, and did not quantify the numbers of older dependent adults requiring daily care. However, it is reasonable to assume that the care needs of younger disabled adults will continue as they grow older; and, as a consequence, the number of older adults requiring daily care will continue to rise.

In New Zealand, it is believed that once the baby boom generation reach old age there will be a void in available carers (Kerse et al., 2016; Yamada, 2002a). Turn-over of homecare workers is high due to low wages (Yamada, 2002b). The future shortage of potential home carers may be one of the reasons why the New Zealand Government increased the minimum wage of carers in 2018 to make the role more attractive to those wanting to enter employment in this sector.

Another complexity is the risk that future increase in demand for carers could result in a decrease in the quality of available care staff. One review of the literature found that lack of regulation has resulted in carers who have previously been dismissed from health care positions (in the USA) being re-employed as home carers (King et al., 2012; Socol, 2006). Further, Socol (2006) discovered that care recipients who hired their own homecare workers (for privately funded homecare pacakges) were at increased risk of abuse and fraud. This result was because care recipients did not have the protection of an agency to vet candidates and, as a result, carers were not adequately screened (Socol, 2006).

An additional complication, identified in the early 1990s, was the absence of a unified approach to homecare provision and differing care standards (Beaulieu, 1991). Whitehead et al.'s (2015) study, which reviewed 13 studies worldwide of 3907 recipients of homecare packages, revealed significant differences in how services are delivered and how service outcomes were measured, indicating that little has changed in homecare provision since those earlier studies.

A further consideration is that the role of home carer has evolved and extended beyond basic home help and personal care tasks. It now includes tasks usually performed by health professionals such as taking blood pressure and giving medication (Thornley, 2000). As the role of the carer has evolved to include more complex tasks, professional registration by a regulatory body may be required to provide carers with boundaries for their scope of practice, standardised training, and defined nationally agreed competencies (Robinson & Griffiths, 2010).

One response to the growing demand and ever-increasing costs of homecare packages has been to change the way services are delivered worldwide with the introduction of Reablement Programmes (Metzelthin et al., 2017; Whitehead et al., 2015). Many countries have opted for time-limited reablement homecare packages, which promote independence in PADL and IADL and aim to reduce the long-term costs associated with care provision (Ministry of Health, 2017b). Reablement programmes have moved away from the traditional approach of homecare which involves doing for the client and can create client dependency. Instead, reablement programmes aim to enable, facilitate, and empower homecare recipients. The underlying philosophy behind reablement programmes is to promote functional ability, independence and improve the QoL of the individual (Resnick, 2012).

Reablement programmes provide a team approach. They involve the service of an occupational therapist, nurse, physiotherapist, and case manager. Reablement programmes utilise a client centred holistic approach and assist homecare recipients to set long and short-term goals. They provide homecare recipient and carer education, assist homecare recipients with IADL and PADL, as well as provide recipients with training and practice in IADL and PADL (Whitehead et al., 2015). Some reablement programmes also run falls prevention programmes, exercise classes, and activities (Metzelthin et al., 2017; Pool, 1993; Whitehead et al., 2015).

Carer training is considered the key to the success of Reablement programmes. Carer training programmes have been implemented alongside Reablement programmes, in order to change the way that carers perceive their role, and how they perform their role and responsibilities. Self-reflection enabled carers to reflect on the terminology they used such as "getting the patient dressed", "getting them out of bed". Terms which described care tasks as doing for the patient, as opposed to doing with the patient, were common (Baker, Harrison, & Low, 2016; Metzelthin et al., 2017; Pool, 1993; Whitehead et al., 2015). Many carers believed that enabling independence was contrary to their role (Pool, 1993). Self-reflective practice is required to facilitate behavioural change in how care was delivered but research suggests that the carers' role changed from carer to facilitator which involves working collaboratively with the homecare recipient (Baker, Harrison, & Low, 2016). Recent studies show that adopting a reablement approach was popular amongst care staff. King et al.'s study (2012) found that workers who were involved in implementing a restorative approach to homecare received increased levels of support, experienced greater flexibility in the work place, and greater job satisfaction than carers employed in standard homecare services. All of which may have been contributing factors to the reduced staff turnover rates evident in restorative homecare providers (King et al., 2012).

Although the literature revealed the popularity of both the restorative and reablement approach to homecare, this approach has its limitations and some question its effectiveness for a client group with chronic health conditions (Vernon & Qureshi, 2000). Although, New Zealand Ministry of Health guidelines for homecare provision promote a restorative approach to homecare (Ministry of Health, 2003, 2012; Ministry of Social Development 2001), New Zealand does not appear to have adopted a restorative approach to homecare provision for the over 65 age group similar to the approach implemented in the UK by Pilkington (2011) which involved a time limited and target driven intervention using a multidisciplinary approach. The reasons for this are not evident, as the topic has not been subject to research.

Worldwide, studies revealed increased levels of job satisfaction amongst carers who worked in restorative homecare (rather than standard homecare) and improved service outcomes amongst home care recipients. In the future it may be necessary for homecare agencies in New Zealand to adopt a restorative approach to homecare in order to improve the desirability of the role of carer as well as retain existing carers so that the supply of carers is able to meet the increasing demand for homecare.

### User perspectives of homecare services

Service user empowerment and control is a common theme in the literature. Vernon and Qureshi's (2002) study found that service users who received direct payments to employ their own carers experienced greater levels of satisfaction than those provided with standard care packages. Homecare recipients felt more in control of their lives, as they could organise how, by whom, and when care was provided. Vernon and Qureshi interviewed 127 homecare recipients. They found that "An ideal service was identified as one in which people had a say in how things were done, and if desired had assistance to perform tasks themselves" (Vernon & Qureshi, 2000, p. 268). Being in control and

having control over how care is administered is a theme echoed in later research by Vik and Eide (2014).

In contrast, service provision which causes the homecare recipient to feel disempowered or disengaged may have led to the development of engagement measures to evaluate the effectiveness of homecare. For instance, in Baker et al.'s study (2016), the Homecare Measures of Engagement Staff questionnaire (HoMe-S) was used to assess attention, attitude, appropriateness, engagement, duration, and passivity of 84 homecare recipients in New South Wales. Care workers interviewed homecare recipients, recipients' families, and conducted cognitive assessments which assessed agitation, dysphoria, apathy, and cognitive functioning. Baker and colleagues found that homecare recipients who were the most apathetic, least responsive, and failed to engage did not have English as a first language. These findings were supported by other research which revealed that culture and cultural identity play a large part in service user satisfaction (Baker et al., 2016; Inoue & Matsumoto, 2001; Oswald et al., 2007).

Baker et al.'s (2016) study discovered that non-English speaking clients were also less responsive to strategies employed by care workers to engage homecare recipients to participate in their care. Although the research recommended that strengthening the relationship between care worker and client increased client engagement, it was unclear how the carer and client relationship could be strengthened with non-English speaking clients. No recommendation was made of the requirement to employ carers who spoke the native language of the clients. In many cultures, there is an expectation that family members will provide care for older adult relatives, and both the family and the older adult may feel "let down" if help is provided by outside agencies (Marjoribanks, 1982). It is possible that non-English speaking service users in Baker's study may have felt unreceptive and unhappy about receiving care from outside agencies as opposed to

family members, were unable to verbally communicate with their carers in their own language and, as a result, became more disengaged.

In New Zealand, Māori Health Services ensure that their clients are cared for by Māori carers to ensure cultural safely and to ensure Tikanga Māori (Ministry of Health, 2012).<sup>6</sup> It is unclear what specific care provision with regard to homecare has been made to facilitate cultural safety for other ethnic groups in New Zealand, who do not have English as a first language, to ensure the cultural safety of all homecare recipients and to ensure user satisfaction.

### **Evaluation of homecare services**

Remaining at home is no longer perceived as a cheaper alternative to residential care; therefore, it has become necessary (in order to justify public spending) to reconceptualise the benefits of long-term care in the community with greater attention placed upon the psychosocial benefits for older adults (Hennessy & Hennessy, 1990). There has been an organisational shift in how service providers measure service outcomes.

Historically, functional assessment tools have been widely used to evaluate service outcomes (Hennessy & Hennessy, 1990). Public service providers worldwide have needed to carefully consider how to accurately measure service outcomes in older adults with chronic health conditions and on-going decline which can lead to poor outcomes (Vernon & Qureshi, 2000). Greater emphasis is accordingly placed on evaluating the improved QoL of homecare recipients, as well as their physical functioning and independence (Vernon & Qureshi, 2000). To evaluate these benefits of homecare, some

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<sup>&</sup>lt;sup>6</sup> Tikanga Māori "Has many meanings it refers to culture, custom, ethic, etiquette, fashion, formality, lore, manner, meaning, mechanism, method, protocol, style. In general terms it means "the Māori way of doing things", it is derived from the Māori word tika meaning 'right' or 'correct'" (Collins Dictionary, 2020).

have argued that service providers needed to listen to the lived experiences and subjective views of homecare recipients (Hennessy & Hennessy, 1990; Vernon & Qureshi, 2000).

Vernon and Qureshi (2000) suggested that while service providers preferred independence as a service objective, as it implies lower and decreasing service costs, terms such as autonomy and independence need to be redefined with regard to homecare provision. They proposed that the focus of homecare provision should be on the autonomy of the recipient, as this is a more consumer-based objective. According to Vernon and Quereshi (2000) care providers should meet the needs of care recipients holistically, without the condition or proviso of getting better or becoming independent. In addition, they promoted the view that service provision should be needs and not cost led. Underpinning this perspective, Vernon and Qureshi (2000) asserted that homecare enabled recipients to have increased control over their life and live the life they wish to live.

Refuelling this debate, the literature review revealed that there were many different tools to evaluate the effectiveness of homecare. Some services used a combination of standardised QoL assessments, ADL assessment, and depression scales to evaluate service outcomes (Hennessy & Hennessy, 1990; Vernon & Qureshi, 2000; Whitehead et al., 2015). As previously discussed in Chapter 1, in New Zealand the RBA Framework specifies the use of client satisfaction surveys to evaluate whether client needs have been met. Significant differences exist worldwide with regard to service provision; therefore, it is not possible to compare services or draw conclusions as to the overall effectiveness of any particular approach to homecare provision due to the absence of a standardised approach and differences in evaluation (Baker, Harrison & Low, 2016; Metzelthin et al., 2017; Whitehead et al., 2015). Equally, it is not possible

to determine how worldwide studies compare to provision of homecare in New Zealand.

## **Summary**

The literature undertaken to inform the question, "Does remaining at home with the assistance of a care package impact on maintenance of life skills and quality of life?" revealed that older adults who remain at home have greater physical functioning completing IADL and PADL than older adults who live in nursing homes (Katz et al., 1963). Older adults who remain at home are able to maintain their life roles, and remain more socially connected to the community (Glass, 1999; Holt-Lunstad et al., 2010). Remaining at home has been linked to increased QoL and well-being (Nikmat et al., 2013). These complimentary findings support the dual focus of the present study, in attending to how homecare effects both life skills and QoL. The literature revealed differences in how homecare services are provided worldwide and differences in home carer training. A lack of New Zealand research was found in this field; it is thus difficult to ascertain how the literature reflects homecare package provision or the experiences of homecare users. It is therefore important to undertake research on this topic in New Zealand to explore whether homecare enables older adults to maintain their life skills and experience improved QoL.

# **Chapter 3: Methodology and Methods**

This chapter details the methodology, the research design, and ethical considerations used to answer the question "Does remaining at home with a homecare package impact on maintenance of life skills and quality of life?" I also discuss the philosophical background behind qualitative, quantitative, and mixed methods research. Mixed methods research combines qualitative and quantitative research paradigms, and integrates data in order to support the research question. Due the variability of data collected, this method improves validity of research findings (Polit & Beck, 2012). The study relies heavily on qualitative rather than quantitative methods and takes a constructivist rather than a post-positivist stance. In outlining the methodology and the methods, I first address the qualitative component then quantitative component; next, the ethical issues involved in the research process; and finally, discuss how the findings were brought together.

# **Philosophy**

The word philosophy means love of wisdom (Florida State University, n.d). Wisdom is the ability to use your experience and knowledge in order to make sensible decisions or judgements (Collins dictionary, 2020). Assumptions or ideas help to form belief systems. Theorists define beliefs as true; these convictions help to create the building blocks for a framework of thinking which are called philosophical frameworks (Rogers, 1982; Yerxa, 1998). Every profession has its own philosophy which has at least three categories—ontology, epistemology, and axiology (Wilcock, 1999). The occupational therapy philosophical framework helped to guide the formation of the research question and which I will discuss in further detail later.

### **Ontology – beliefs about reality**

Ontology is a philosophical belief system about the nature of reality that is concerned about what exists and what there is to know (Lincoln & Guba, 1985). It is the study of being or existence, and the development of concepts of reality (Carpenter & Suto, 2008; Lincoln & Guba, 1985; Kjersti Vik & Eide, 2014). It answers the question, "What is most real?" (Hooper & Wood, 2002). In the context of this study, it asks, "What is the daily reality of participants living at home who receive homecare packages?"

The ontology of relativism theorises that there is no universal truth. Each viewpoint is based on an individual's perceptions of reality or truth (Collins Dictionary, 2020). The relativist view point is that human experiences can only be fully understood if examined in the context in which people live or exist in a naturalistic setting (Creswell, 1998; Lincoln & Guba, 1985). Experiences are time and place dependent, and the environment and context in which these experiences occur will impact upon the lived experiences of the participants. This viewpoint is also central to the occupational therapy belief that human beings are best understood in the context of their own environment (Wood & Hooper, 2013). According to Kielhofner, "The unity of the human system with the social environment is not a platitude but an essential part of the human condition" (Kielhofner & Burke, 1983, p. 76).

The ontology of relativism guided this research as it allowed me to examine multiple realities holistically in the environment in which they occurred; in this case, 12 older adults receiving care packages who were interviewed in their own homes. Interviewing participants in their own home enhanced the trustworthiness of the data gathered as it provided a true picture of participants lived realities. Interviewing participants in their own homes provided contextual cues to both older adults in receiving home care packages and myself as the interviewer. It also enabled additional information to be

provided by family members which helped to verifying (or not) events recalled by participants.

Relativism underpins the interpretive-constructive paradigm (Denzin & Lincoln, 2000). The interpretive/constructivist approach aims to understand the "World of human experience" (Cohen & Manion, 1994, p. 36). This approach relies on "participants' views of the situation being studied" (Creswell, 2003, p. 8). Individual experiences are deemed by some theorists as "approximations"; however, sooner or later these individually constructed realities converge as similarities emerge (Lincoln & Guba, 1985).

Creswell (2003) argued that unlike post-positivists, constructivists do not begin with a theory but "generate or inductively develop a theory or pattern of meanings" (p. 9) during the research process. I hoped that similarities between individual participants' experiences of homecare would emerge from the research. A central occupational therapy ontological assumption which helped to form the question, "Does remaining at home with a homecare package influence maintenance of life skills and quality of life?" is that human beings require occupation in their daily lives for their survival, health and well-being, and personal growth. Furthermore, that maintenance of life skills assists people to undertake life roles and activities of daily living which, too, are essential to health, well-being, and QoL (Wilcock, 1999; Wood, 1993; Yerxa, 1998). Occupation is perceived as a biological need, through which people transform as they act on and interact with their environment (Hooper & Wood, 2013). In occupational therapy, health is not regarded as a biological absence of disease but the ability to engage in meaningful occupation which, in turn, leads to maintaining optimum functional capacity and increased OoL (Hasselkus, 2011).

### **Epistemology**

Epistemologies are theories of knowledge and beliefs which question what knowledge is, how it can be attained, and whether or not it is valid (Cameron, 2014). The epistemology underpinning the interpretive constructivist paradigm is transactional and subjective (Creswell, 2014). Experiences are viewed as time and place dependent, and the environment and context in which these experiences occur is understood to impact upon the lived experiences of the participants. The context of my research acknowledges the subjective experiences of participants, and that experiences may vary from participant to participant but are of equal value and importance to this scientific enquiry. Although commonality is likely to exist between participant experiences, the paradigm of interpretive-constructivism accepts that previous knowledge of the phenomenon will have no effect on emerging patterns or theories due to the uniqueness of each individual enquiry. Lincoln and Guba (1985) argued that interviewing multiple participants enables enquiry into multiple realities, and it is not possible to predict an outcome.

#### Axiology

Axiology (Given, 2008) is defined as a philosophy that studies values or concepts of worth. It can be used as a collective term for ethics, and philosophical fields which are founded on these notions of worth or values. In the context of my study, axiology asks what is important or of value in occupational therapy and, based on occupational therapy's beliefs about reality and knowledge, how will these be applied to practice (Hooper & Wood, 2013). Occupational therapists regularly assess patients for homecare packages and this study explores an aspect of the value and worth of homecare packages to the individual.

### What is Qualitative Research?

Qualitative research is an umbrella term for a set of concepts, assumptions, methods and research traditions used to generate knowledge (Denzin & Lincoln, 2005). It is historically linked to anthropology, sociology, psychology, and education; and some believe that it has no theory or paradigm that is distinctly its own (Denzin & Lincoln, 2005). Qualitative research lends itself well to examining the perceptions and beliefs of participants and "assumes no single reality" (Mark, 1996, p. 61). Qualitative research has become popular to guide service provision as it investigates complex issues, client experiences, and QoL in real life contexts over the client's life span (Carpenter & Suto, 2008). It is subjective in nature as it explores the subjective reality and meanings of participants in their natural setting (Skivington, Lifshen, & Mustard, 2016). I chose this type of research as each participant's situation, experience of homecare, array of life skills, and sense of QoL would be unique to them as an individual.

### **Qualitative methodology**

The inductive approach used in qualitative research is suited to generating new hypotheses and theories on how people create meaning from their circumstances (Neergaard, 2009). My specific methodological choice was qualitative descriptive methodology which relies on low-level inferences and presents findings in everyday language which is easy to understand (Magilvy & Thomas, 2009; Neergaard, Olesen, Andersen, & Sondergaard, 2009; Sandelowski, 2010).

# Naturalistic inquiry approach

Naturalistic inquiry is an approach used in qualitative research where "the researcher observes, describes, and interprets the experiences and actions of specific people and groups in societal and cultural context" (Salkind, 2010, p. 880). This approach was utilised within the study. A strength of naturalistic inquiry is that it is committed to conducting inquiries with minimal disruption in the natural setting; therefore, it is

hoped that it will provide the researcher with a greater understanding of the phenomenon and to provide an accurate representation of this understanding in the research findings (Lincoln & Guba, 1985). From this perspective, reality is constructed through social interactions, human relationships, and experiences. Naturalistic inquiry ensures that the research design and question formation evolve through inductive reasoning, so that the interviewing process evolves as the researcher collects rich data, and patterns and themes emerge. Accordingly, theorists propose that naturalistic inquiry helps to keep researcher bias under control (Lincoln, & Guba, 1985).

# **Transferability**

Unlike quantitative research, naturalistic studies aim to "maximise information and not facilitate generalization" (Lincoln & Guba, 1985, p. 202). The body of data gathered is considered to have importance in its own right, and holds its own unique value. Transferability of data is dependent on the context in which the data were gathered. The reliability of the data or truth value is dependent upon the accurate representation of the multiple constructions of reality (Lincoln & Guba, 1985).

### What is Quantitative Research?

In realism, the perspective taken is that the real world can be described and analysed, explained and predicted. The paradigm for quantitative research, termed positivist or post-positivist is a "formal, objective, systematic process in which numerical data are used to obtain information about the world, to describe a variable" (Burns & Grove, 2005, p. 23). Within this paradigm, researchers measure variables which are statistical impersonal, causal, and contrived (Cameron, 2014).

Quantitative research involving human subjects typically uses standardised questionnaires to collect numerical data (Polit & Beck, 2012). This type of research provides scientific rigour by being objective in its approach and quantifying measurable

facts; and is thus valued by researchers for its accuracy (Rutberg & Bouikidis, 2018). Quantitative research answers "when", "how much" and "how many" questions (Carpenter & Suto, 2008; Stanley & Nayar, 2014); thus, is suited to problem quantification and testing theories, interventions and new treatments. Polit and Beck (2012) defined the three commonly used quantitative research designs: experimental, quasi experimental, and non-experimental. Experimental design examines the phenomena in a laboratory under controlled conditions and involves a control group and experimental group. Quasi experimental involves an intervention, does not always involve a control group and is not randomised. Non experimental does not involve the manipulation of variables but observes phenomena to see if relationships exist. In this study I collected data directly from participants in their own homes. I did not observe participants undertaking activity, and did not conduct an intervention but relied on the participants' ability to recall activities they had undertaken the previous day.

# **Post-positivism**

Post-positivism is a model of scientific enquiry commonly used in mixed methods research (Creswell, Fetters, & Ivankova, 2004). Like positivists, post-positivists believe that reality can be studied and exists independent of consciousness (Creswell, 2014). It also acknowledges that the beliefs held by the researcher and the researcher's background and knowledge of the subject matter can influence the research findings (Creswell, 2014). Post-positivists argue against the limitation of traditional scientific inquiry used in the field of health and social research as it does not explore the lived experiences of individuals (Grant & Giddings, 2002). Post-positivism has inherited the viewpoints of "empirical observation and measurement" from positivism (Creswell, 2014, pp. 35-36). These viewpoints were applied in the research and are further discussed in the sections that follow.

Post-positivism acknowledges that there is not just a singular reality but multiple realities or truths (Lincoln & Guba, 1985). In this study, each participant was likely to have his or her own unique experience of homecare, as they had different carers, different care packages and differing needs, and different expectations.

# **Mixed Methodology**

The question "Does remaining at home with the assistance of a homecare package impact on maintenance of life skills and quality of life?" informed the methodological approach and research design. Mixed method research involves collecting, analysing, and interpreting both quantitative and qualitative data in a single study. Post-positivism utilises reductionism, which refers to studying the parts to support development of an understanding of the whole. It supports the objectivist view of the use of scientific measurement and observation as a necessary part of mixed methodology (Creswell, 2014).

Polit and Beck (2012) argued that using mixed methods increases the validity of research findings due to the variability of methods and multiple types of data gathered, which complement each other. The philosophical assumption was that combining both methods would provide a better understanding of the research problem than a single approach (Creswell & Plano Clark, 2007). Mixed methodology allows for the deductive reasoning used in quantitative research and the inductive reasoning used in qualitative research to generate questions and hypotheses. I used a mixed methodology approach to utilise the strengths of both (Andrew & Halcomb, 2006a).

For this study, the quantitative component measured objective phenomena; that is, participant activity over a 24-hour period divided into 30-minute time slots, as well as demographic data which included age, gender, ethnicity, living situation, and diagnosis. The qualitative component explored the subjective experiences of participants in receipt

of homecare. The goal was to triangulate the data using a mixed method approach to gain a more rounded understanding of older people's experience of receiving homecare services.

Combining methods allowed for the integration of both qualitative and quantitative data to support the original research question. Applying both methodologies enabled me to explore the type of daily activities people participated in, whether activities were ADL or PADL, the time spent undertaking each type of activity, and whether activity was undertaken at home or in the community. Repeating the Yesterday Diary six weeks following the initial interview was expected to reveal whether there were changes in participant activity following the care package implementation. The qualitative component of the research—the participant interviews—enabled me to gather participants' perceptions on homecare at the start of their homecare package and explore any changes in participant perceptions six weeks post care package implementation. The research design in this study, interviewing (most) participants twice, facilitated rigour and trustworthiness as it enabled me to follow-up on issues detailed in the previous interview. The rich data gathered contributed to answer the question of whether the provision of homecare helps older adults who remain at home to maintain their life skills and QoL.

### **Question formation**

The qualitative component of this study answered the what and how questions (Carpenter & Suto, 2008). In qualitative descriptive research, semi-structured interviews are commonly used to gather data. In depth questions were used to focus on activities of everyday life (Fontana & Frey, 2000). In this research, I wanted to explore the benefits of homecare, in relation to any self-reported beneficial impact on recipients' life skills, as a result of homecare intervention and whether it had improved their QoL. The research question directly addresses these concerns.

Lincoln and Guba (1985) theorised that the researcher's own values and belief systems guide and initiate the questions asked, and that researchers will select a topic of enquiry and methodology to reinforce their own personal belief system. They argued that it was also likely that the enquiry would serve a social agenda (Lincoln & Guba, 1985). In the context of this study, as I was currently not employed to set up homecare packages in the community, the study did not serve a personal agenda but was intended to generate knowledge that would usefully inform provision of homecare thus serving a social agenda.

### **Quantitative methods**

The literature review had revealed that people lose their functional capacity if the approach, when providing personal care, is one of doing for rather than doing with the care recipient (Metzelthin et al., 2017; Pool, 1993; Vik & Eide, 2014). I hoped to see if participants in my study experienced any changes in activity levels post care package implementation or whether a homecare package enabled participants to be active participants in the care process and maintain their life skills.

In addition, and possibly linked, to the reduction in range of movement identified in homecare recipients, the literature review revealed that older adults living at home tend to spend up to 62% of the day participating in sedentary activities (Schlaff, Baruth, Boggs, & Hutto, 2017). It was hoped that the Yesterday Diary would support findings from previous studies. Most of the literature is from abroad; therefore, it was important to see whether older New Zealanders in receipt of homecare packages spent the majority of time indoors at home participating in sedentary activity rather than more active pastimes. Examining the division of activities, that is, whether the activity was IADL or PADL, would quantify the amount of time that participants spent undertaking meaningful activity or occupation rather than self-care activities as well as explore changing activity level.

A Yesterday Diary see Figure 1. (Gershuny, 2004), was the chosen quantitative method used in the research project to measure changes in homecare recipients' activity levels post care package implementation (Gershuny, 2004), as a proxy measure of maintenance or improvement of life skills related to the services being provided.

A Yesterday Diary was used to facilitate rigour and trustworthiness of the quantitative data gathering. Yesterday Diary studies are deemed reliable and are commonly used to measure time and frequency of activity, "They enable investigation of activity sequences and times of the day when activities occur" (Gershuny, 2004, p. 1127).

Figure 1. Yesterday diary

Time	Activity	Was activity new Y/N	Alone or with assistance/or company	Where performed? H/C	Difficult or Easy
6.30am- 7.00am					
7.00am- 7.30am					
7.30am- 8.00am					
8.00am- 8.30am					
8.30am- 9.00am					
9.00am- 9.30am					
9.30am- 10.00am					
10.00am- 10.30am					
10.30am- 11.00am					
11.00am- 11.30am					
11.30am- 12.00pm					

Time	Activity	Was activity new Y/N	Alone or with assistance?	Where performed?	Difficult or easy?
12.00pm- 12.30pm					
12.30pm- 1.00pm					
1.30pm- 2.00pm					
2.00pm- 2.30pm					
2.30pm- 3.00pm					
3.00pm- 3.30pm					
3.30pm- 4.00pm					
4.00pm- 4.30pm					
4.30pm- 5.00pm					
5.00pm- 5.30pm					
5.30pm- 6.00pm					

Record the main activities in each time period, along with pertinent information relating to where it was performed (home/community), if there was someone else there – noting if they were doing something different, and satisfaction with performance (difficult/easy).

**Key:** Home = H, Community = C, Alone = A, With Assistance = WA, Company= Co, Yes = Y, N = No

Participants were asked to complete a Yesterday Diary with me, as part of the interview, by describing in 30-minute slots what activities they had undertaken, how long they spent doing the activity and whether it was performed at home or in the community. They were also asked whether they required assistance to undertake the activity and whether the activity was difficulty or easy. The Yesterday Diary was repeated six weeks later at the second interview. The diaries detailed participant function which had potential to make them identifiable; therefore, participants are numbered 1-12 rather than given pseudonyms. Three participants were unable to complete a Yesterday Diary (two participants died and one was unable to participate due to decline in health). Data extracted from the first and second Yesterday Diary were combined. Where it was not possible to complete a second Yesterday Diary, data from the first diary were taken as representative of both.

### Mātauranga Māori Ethics Committee

I consulted with the Mātauranga Māori Ethics Committee (Appendix C) as part of my legal obligations as a researcher under the Te Tiriti O Waitangi, and to seek advice on the research design to ensure that the research followed the "Māori ethics framework of the four tikanga based principles whakapapa (relationships), tika (research design), manaakitanga (cultural and social responsibility) and mana (justice and equity) as the primary ethical principles" (Hudson, 2010. p. 4).

# Participant recruitment

The committee suggested targeting specific geographical areas within the DHB catchment area to recruit Māori to guarantee maximum participation by Māori, due to low numbers of Māori over 65 years of age compared to Pākehā<sup>7</sup>. It was essential to know the number of Māori receiving homecare in each geographical area so that I

<sup>&</sup>lt;sup>7</sup> Pākehā is Māori for New Zealanders of European descent or any non-Māori New Zealander (Collins Dictionary, 2020).

could calculate the proportion of Māori participants to try to recruit, rather than just those over the age of 65 years. However, this was not possible as the DHB chosen for the research had 3% Māori population within the age criteria.

As previously discussed, Māori well-being is linked to interdependence. Māori traditionally value help from family and reciprocal relationships (Bell et al., 2017). Therefore, it was possible that values of interdependence might result in Māori refraining from accessing services. Cultural differences may also affect how Māori perceive homecare packages. The number of Māori participants might be further reduced as they may choose to use services that adopt a Kauapapa Māori<sup>8</sup> approach. In addition, as interdependence is important to Māori, it was suggested that using the word independence in the title was not culturally akin to Māori belief systems and could cause confusion.

## Changes implemented following Mātauranga Māori Committee consultation

The advice provided by the Māori committee made me realise that recruiting Māori participants would not be as straight forward as I had anticipated. The research area chosen for this study covers three geographical areas in which only 3% of Māori fall within the 65-84 age group (Anonymous DHB, 2015). Following advice from the Mātauranga Māori Committee, I enrolled on the Tikanga Māori research course to improve my networks within Māori Health Services and to learn more about Tikanga.

As a Pākehā, I had used the term independence in the title of the research as my professional training and the medical model that occupational therapy falls under values the ideology of independence with regard to PADL and IADL; however, it is an assumption that independence is universally valued across cultures (Reindal, 1999). To

<sup>&</sup>lt;sup>8</sup> Kaupapa Māori refers to "Māori customary practice, Māori principles, Māori ideology - a philosophical doctrine, incorporating the knowledge, skills, attitudes and values of Māori society" (Moorfield, 2003).

<sup>&</sup>lt;sup>9</sup> Tikanga Māori means "custom, or the Māori way of doing things" (Collins Dictionary, 2020).

prevent confusion and to respect the different cultural beliefs of both Pākehā and Māori I changed the focus of the research from independence to QoL.

#### **Ethics**

This study involved interviewing patients who had recently had a homecare package implemented. To be able to interview service users I first had to gain ethical approval from Auckland University of Technology Ethics Committee (Appendix D) and District Health Board X (Appendix E).

# **Auckland University of Technology Ethics Committee**

The research proposal was reviewed by the Auckland University of Technology Ethics Committee to ensure scientific integrity and to uphold the four ethical principles of respect for autonomy, non-maleficence, beneficence, and justice (Beauchamp & Childress, 2001). To adhere to the ethical principle of non-maleficence, participants were given ID numbers which linked both interviews together to protect their identity. Equally, the name of the DHB involved in the study is not revealed in the findings so as to protect its identity. Following consultation with the ethics committee, minor procedural changes were made.

### DHB approval

I contacted two DHBs to seek ethics approval. The first DHB did not have the staffing resources to support the research. I therefore approached the second DHB and met with a needs assessment care coordination team who organised homecare assessments and homecare packages for people with disabilities living within the DHB. The second DHB provided approval for the research to commence once a care coordination service had provided their approval (Appendix E). Participants were given ID numbers which linked both interviews together. The identity of all participants including the identity of the homecare agency remained anonymous.

### Māori research review group DHB

To protect the identity of any Māori participants, I agreed that demographic data would not be connected to research findings.

# **Participant Recruitment**

As stated, I met with a care coordination service that organised homecare assessments and homecare packages for people with disabilities living within the DHB utilised in the study. I asked that a worker elected by the care coordination service approach potential participants who fitted the following criteria of being above 65 years of age and above 50 years for Māori who did not have a diagnosis of cognitive impairment, who were able to provide informed consent and who had just had a care package put in place. The Care Coordination Service provided potential participants with a copy of an information sheet detailing the purpose of the research, as well as a consent form (see Appendix H). Participants were selected to be as diverse as possible and capture a breadth of views representative of the community, and provide rich in depth data.

Given the objective of the study, I decided to use purposive sampling to select participants. Purposive sampling is also referred to as subjective, selective, judgemental, and non-probability sampling; and means that participants would be selected based on key demographic characteristics including their age and living situation. Purposive sampling is deemed a strength of qualitative research (Patton, 2002; Stanley & Nayar, 2014). It aimed to ensure, where possible, that participant selection reflected the ethnic makeup or demographic of the community. The agency selecting participants was asked to actively recruit Māori to encourage maximum participation.

Initially, it was intended that participants would be over the age of 65 years on the assumption that most participants may have retired, were no longer responsible for the care of young children and have different life roles than those under 65 years of age. To

ensure rigour I discussed prospective participants with my academic supervisors to ensure that they met the inclusion criteria of the study. I used the aims of the study to guide the decision making process. The age range for Māori was supposed to be 50 years and over. However, as the number of Māori participants was low, one 49 year old Māori participant was accepted onto the study as they were eligible for care coordination.

For ease of recruitment, the plan was to select participants from a single homecare agency. However, the care coordination service employed the services of more than one homecare agency, so participants in this study received homecare from different agencies. It took four months to recruit and complete two interviews for each of the 12 participants, with data collection beginning in October 2018 and completing in January 2019. The total number of participants recruited was limited to 12 due to the time taken for recruitment. The number of participants, although low, was adequate to gather meaningful data. Research suggests that as few as eight participants are sufficient to generate new knowledge (Murphy, Hocking, & Reed, 2008). The hope was that data gathered in the research may be used to steer future larger research projects.

### **Qualitative Data**

# Formulating interview questions

Prior to the interviews, questions were formulated which explored the nature of reality of the participants' lives. These questions were informed by my professional assumptions and information from the literature about the possible benefits from homecare intervention, the belief that homecare enables people to remain at home, maintain their life roles, life skills, and remain socially connected to the local community.

I do not deny that my personal interest in this subject stems from my own belief system; that it is better to remain at home with a care package (if possible) than to reside in institutional care. However, I am aware of my own biases and this enabled me not to impose my own values and belief systems, professional assumptions or prior knowledge upon the research process. Personal beliefs which I held on homecare prior to this study were:

- Homecare provided the bare essentials of care to sustain people in their own home.
- Home carers were provided with insufficient time to complete their tasks and completed bare essentials.
- Home carers received minimal training.

It was important to self-reflect when formulating questions, to avoid steering or prompting participants or influencing questions which involved my own personal biases to maximise scientific integrity (Gabard & Martin, 2003). I used the Ministry of Social Development's "Positive Ageing Strategy Goals" (2001) of holistic wellness, feeling safe and secure, and ageing in place to guide initial semi structured interviews, and used open ended questions that enabled participants to discuss their personal views rather than respond to predefined questions. The interviews became a personal narrative of participants' experience of homecare.

The interview questions that I initially formulated aimed to create a picture of each participant's daily life since the homecare package commenced. Questions aimed to explore:

- What assistance the person received from homecare and family
- The participant's prior experiences of homecare (if any)
- The individual's expectations and hopes following homecare
- Concerns the participants had regarding homecare

- How the homecare and assistance is provided
- How or if the older adult participated in the care
- How the person managed tasks when a formal carer was not present

Follow up interview questions aimed to explore:

- Whether homecare increased participant energy levels
- Whether homecare allowed the person to feel safer in their home and become more actively involved in the community
- The specific benefits of homecare to the individual in relation to how or if it improved their QoL

In the second interview, questions responded to the themes that had come up in each participant's first interview. Consequently, interviews were individually tailored to each participant with many questions evolving from participant's own responses.

Initial interviews and follow up interviews took place at participants' homes. All interviews were conducted on weekdays at a time convenient to the participant, and follow up interviews were booked where possible on the same day of the week as the first interview. Interviews took approximately 45 minutes. If care recipients lived with a spouse or parent who was their primary care giver they were asked to sign a consent form (Appendix H) if they wished to participate and air their views in the research. Three primary care givers contributed to the data collated. The initial plan was to conduct interviews within the first week of a homecare package being implemented. This was not always possible as 75% of participants had already had their homecare package in place for a number of weeks. Participants signed the consent form at the meeting for the initial interview. Interviews were voice recorded and transcribed within four days. Once the initial interviews were transcribed, participants were offered the opportunity to read the interview transcripts and could then decide whether they wished to proceed with the second interview six weeks later. One initial interview failed to

record correctly due to equipment malfunction so was unable to be transcribed. Instead, I made detailed notes from memory to capture the data. Only one participant requested a copy of the transcript for the interview and no changes or omissions were requested. Repeating the interview six weeks later enabled me to explore participants' views on how provision of a homecare package had impacted their lives.

Qualitative inquiry enabled an exploratory and inductive approach. An inductive approach aims to generate new theories from emerging data when interviewing participants (Gabriel, n.d.). To learn from older adults experiences, it was essential not to rely on my own professional assumptions with regard to homecare; that is, the belief that older adults lives' were enriched as a result of homecare provision. It was important to listen to each participant's experiences, to explore those feelings while gathering the data during the interview process. As the interviews progressed, patterns and themes emerged which helped to guide and steer future questions. One question concerned the number of carers individuals had and the carers' reliability and perceived experience.

Establishing a relationship between participant and researcher is vital to gathering rich data. However, this can impact both positively and negatively on the data gathered. When conducting the interviews I found it necessary to adapt my interview style to each individual. For example, some of the male participants were less chatty than the women and gave closed answer responses which posed a challenge when trying to get participants to discuss their feelings about homecare. It was also important to hear family members' opinions (where possible) of homecare to provide a broader perspective of the impact of services. In addition, it was important to be aware that family members' opinions may not reflect those of the participant and that family members did not speak on behalf of the participant. When trying to elicit further information it was essential for me not to steer questions, or to try and elicit a response to match my own belief systems. I received early feedback on my interviewing skills

from my academic supervisors. Receiving feedback on my interviewing skills helped me to hone the questions I asked to elicit rich information. Having acted on that feedback, I was then able to immerse myself in the data. To ensure trustworthiness and rigour in the study methodology I engaged in regular supervisory discussions with my academic supervisors to challenge and extend my interpretation of qualitative data. I felt I developed a good rapport with the majority of the participants which enabled them to discuss matters openly with me.

## Qualitative data analysis

Analysis of the interview data was initiated immediately after the first interview was transcribed and continued concurrently with data collection. It was important when analysing data that this was done to limit bias. To gain a deeper knowledge of the data I chose to transcribe each interview myself to facilitate immersion in the data and gain a deeper understanding of the text and meanings behind individual responses. Carpenter and Suto (2008) described the three phases of qualitative data analysis as "data reduction, data display, conclusion drawing and verification" (p. 114).

In the data reduction phase, it was important that I identify emerging themes accurately without bias. Thematic content analysis of the transcript was used to identify emerging themes in the qualitative data. I undertook a manual analysis of all data. An iterative approach was used, which involved reading small sections of the text back to the whole text and linking the text back again. As described by Stanley and Nayar (2014), this assisted me to identify themes and patterns within the context of the whole text and provided a deeper understanding of the text and interview.

I used conventional content analysis to look for emerging themes, and grouped initial codes into "meaningful clusters" (Hsieh & Shannon, 2005). Data excerpts from each participant were colour coded to enable me to keep track of whom to attribute the

quotes. Identified codes within the transcript were reduced down, grouped, and then reduced further into broad categories or themes. Each participant's initial interview was compared with findings from his/her second interview six weeks later. This interpretive descriptive approach relies on inductive reasoning. Neergaard (2009) described this as a process where the researcher gathers data and provides an in depth description and understanding of the data. This process automatically involves some level of interpretation by the researcher (Sandelowski, 2010).

### **Quantitative Data**

#### **Quantitative data collection**

At the start of the interview I gathered demographic details for each participant. I asked participants the following questions:

- Their gender—male or female
- Their ethnic group
- Whom they lived with
- Date of birth
- How many home visits they receive each day
- How many days a week of homecare they receive
- Whether they receive additional help from family members or unpaid or paid carers
- Whether this was their first homecare package
- How the homecare package was funded

At the end of each interview, using the Yesterday Diary, I asked participants to detail everything they had done during the previous day in 30-minute time intervals. The intention was to log participant activity in their waking hours, on average this covered from 6am until 2am in the morning. To improve accuracy, I tried to schedule the follow up visit on the same day of the week so as not to introduce a new variable (e.g., it could

be assumed that participants may be more active at the weekend if family members take them out). However, it was not always possible to schedule appointments on the same day due to participant prior commitments; therefore, this could affect the accuracy of the findings. See example of Yesterday Diary findings Appendix I. Completion of the Yesterday Diary was not as straightforward or as scientific as I had intended it to be. The process was time consuming and many participants provided generalised responses as to how they had spent their time the day before.

Quantitative data analysis/descriptive statistics is termed a portrait of "actual data" and is defined as "not inferential, no multivariate, or not causal" (Vogt, Vogt, Gardner, & Haeffele, 2014, p. 206). Following the interviews, demographic data for each variable were collated and displayed in Table 1. "Participant Demographics", relating to each variable. Care was taken that demographic data from individual participants was only reported in an aggregated form to protect participants' identities.

The quantitative data from the first and second Yesterday Diaries were coded into types of activities (i.e., PADL and IADL); whether activity was completed with assistance, alone or with company; whether participants regarded the activity as difficult or easy; and whether it was completed at home or in the community.

The results from individual participants' first diary were qualitatively compared with their second Yesterday Diary to look for indications of any increase or decrease in the individual's activity levels, functioning, or time spent with others following homecare package implementation. I engaged in discussions with academic supervisors for advice about strategies to elicit greater detail to complete the diaries as the data elicited from participants were found to lack precision regarding the amount of time allocated to specific activities. We discussed how to present the quantitative data when it became clear that numerical measures of changes in time spent in different occupations would

not be feasible. Increases or decreases in time spent in various activities could not be numerically calculated as had been intended. As there was no observable increase or decrease in time spent in identified activities in which participants engaged, and little change in observed functioning levels, location, or who was present when activities were completed, data from the initial and second Yesterday Diary were compiled for reporting purposes.

The quantitative data were collated and displayed in tables. A log was kept of all discussions with the supervisors and all changes made to the original research design as a result of those changes.

## **Combined Data Analysis**

This study used a convergent parallel design (Creswell, 2014), during data collection. Both quantitative and qualitative data were collected concurrently during the first and second interviews. Both types of data were analysed and interpreted separately then compared. Combining both types of data helped to provide a broad picture of how participants spent their time. Qualitative data answered the nature of the help provided (e.g., self-care tasks, housework), how people's lives had changed as a result of the provision of homecare, and generated a descriptive account of how their activities, time use, relationships, and satisfaction with care provision affected their QoL. Quantitative data from the Yesterday Diary quantified, to some extent, the part being a care recipient played in their day-to-day lives. It also helped to inform and enrich the qualitative data by showing participant activity levels with regard to IADL and PADL post care package implementation. It provided a picture of the participants' division of time and how much time they spent at home versus accessing the community. When considered together, in relation to policy statements about homecare provision, the qualitative and quantitative data generated insights into the impact of homecare provision on life skills and QoL.

## Conclusion

A combined approach using quantitative data to support qualitative data was implemented to answer the question "Does remaining at home with the assistance of a homecare package promote maintenance of life skills and quality of life?" I interviewed 12 participants 49 years of age and over without known cognitive impairment, from a single DHB in the North Island of New Zealand, using semi structured individual interviews in their own homes, close to the time when their homecare package commenced and six weeks later.

Demographic data were collected at the start of the initial interview. Quantitative data in the form of a Yesterday Diary were collected at the conclusion of the initial and second interviews, to examine participant activity levels post care package implementation. Quantifying how participants spent their time would provide information as to how people spent their day and the division of time spent completing PADL or IADL, and that Yesterday Diaries aimed to reveal whether participants were able to maintain life skills and remain active and socially connected to the community. Objective numerical data from the diaries aimed to support and provide increased validity to the subjective lived experiences of individual participants and reveal whether assistance from homecare enabled older adults to maintain life skills and experience enriched lives and increased QoL. Chapter 4 details the research findings.

# **Chapter 4: Research Findings**

In this chapter, findings derived from both quantitative and qualitative data are reported. Quantitative data will be presented first; that is, the participant demographics and findings from Yesterday Diaries. Qualitative data from participant interviews will then be presented and encompass the following themes: control, the importance of social connections, and the benefits of homecare. I will then provide a summary of the research findings, integrating the understandings derived from the quantitative and qualitative data. In the following chapter, the findings are interpreted in relation to the research question, "Does remaining at home with the assistance of a homecare package promote maintenance of life skills and enhance quality of life."

# **Participant Demographics**

Participants ranged between 49 to 90 years of age (the youngest being 49); most were between 70 and 90 years of age (Table 1). The majority identified as being New Zealand European, and lived alone. The remainder lived with a spouse or family member. There was an equal ratio of male and female participants. The majority reported as having heart disease or cancer as their primary diagnosis and, like the others in the survey population they had mobility and functional deficits.

All homecare packages were funded by the DHB. It was the first homecare package for 11 of the participants. Four of the participants received homecare seven days per week, indicating that they had high care needs; of which only one participant received three visits a day as the other participants received assistance from their primary care giver. The majority of the participants received one to five days per week of care. Ten of the participants received one home visit per day. Ten older participants received assistance

with personal care, washing, and dressing. Only two participants received assistance with cleaning.

**Table 1. Participant Demographics** 

Participant Characteristic	Frequency %							
Age								
40-50	8.3%							
50-60	8.3%							
60-70								
70-80	42%							
80-90	42%							
Gender								
Female	50%							
Male	50%							
Ethnicity								
New Zealand or New Zealand European	50%							
<b>.</b>	0.207							
European	8.3%							
Māori	8.3%							
Samoan	8.3%							
English	8.3%							
Australian	8.3%							
Declined	8.3%							
Living Situation								
Lives alone	50%							
Lives with spouse	33%							
Lives with parent	8.3%							
Lives with child	8.3%							
Diagnosis								
Visual impairment	8.3%							
Heart disease/ heart problems	33%							
Cancer	33%							
Cerebral vascular accident	8.3%							
Osteoarthritis	8.3%							
Heart and kidney problems	8.3%							

A great deal of of unpaid help was provided by family and friends to assist older participants to remain at home. Without this extra assistance it is questionable as to how they would manage. Eleven participants required transport assistance from family and friends. Other unpaid help provided by family and friends was shopping, cooking, personal care, home maintenance, and helping with finances. The minority of older participants in the study funded their own gardeners and cleaners and received assistance from outside agencies. See Table 2 (p. 67).

**Table 2. Formal Care Provision from a Homecare Service** 

Home visits per day	Frequency %
1	83%
2	8.3%
3	8.3%
Days per week	
1	17%
2	
3	17%
4	8.3%
5	25%
6	
7	42%
How is the care package funded	
DHB	100%
Type of care provided	
Cleaning	17%
Personal care/washing dressing/assistance	83%
with meal preparation where required	
Unpaid help from family and friends	
Shopping	75%
Gardening	50%
Personal care	33%
Cooking	50%
Bringing in firewood	25%
Transport	91%
House maintenance	17%
Bringing prepared food	17%
Managing finances	17%
Laundry	17%
Housework	25%
Self-funded assistance	
Gardener	25%
Cleaner	17%
First care package	
Yes	91%
No	8.3%
Other help from charities such as RSA / Vete	•
Washing the house/ outside windows	17%
Cleaning	8.3%
Gardener	8.3%
Transport	25%

Key: RSA = Returned Servicemen's Association

## **Findings from Yesterday Diaries**

All 12 participants completed a Yesterday Diary during the initial interview. Three participants were unable to complete a Yesterday Diary (two participants died and one was unable to participate due to decline in health). Data extracted from the first and second Yesterday Diary were combined as described in the methodology chapter. Where it was not possible to complete a second Yesterday Diary, data from the first diary were taken as representative of both. In Tables 3 and 4 (below), PADL and IADL are reported separately. As the diaries detailed participant function and this had potential to make them identifiable, participants are numbered 1-12. PADL and IADL are reported separately.

When an activity differed from the first Yesterday Diary to the second Yesterday Diary this is indicated in the Table 4 as duplicate ratings (occurred/did not occur/or did not occur due to decline in function). For example, participant 1 in his first Yesterday Diary reported that he had completed chair exercises the previous day. However, in his follow up Yesterday Diary (six weeks later) he had not completed chair exercises due to decline in physical functioning. Accordingly,  $\checkmark$ < is entered in that column. Similarly, participant 12's follow up Yesterday Diary revealed that he did not got out of bed or get washed and dressed the previous day due to decline in physical functioning but had reported these things at the first interview.

The older participants (Table 4.) spent most of their time at home in sedentary activity. Many spent protracted hours watching television between one and three times a day. A minority completed indoor hobbies such as reading books or the newspaper, knitting, playing on the i-pad and doing jigsaws. When not engaged in sedentary activity, their lives revolved around mealtime, meal preparation, and IADL. The majority of activity undertaken however focused on PADL activities (e.g., getting in and out of bed,

washing and dressing, eating meals). Eighty-three percent required assistance with washing and dressing. Only 17% were able to wash and dress independently and Anne prepared lunch independently during the first Yesterday Diary but required assistance on the second occasion due to decline in health.

Table 3. Data Extracted from Participants' Combined Yesterday Diaries (PADL)

Participants	Chair exercises	Getting	out of bed	Getting	into bed		ning and essing	Eating Breakfast	Eating Lunch	Eating Dinner	Eating Snacks	Mid afternoon nap
	l	ı	AS	1	AS	1	AS	I	1	l	l	l
Harold	<b>√</b> <		$\checkmark$		$\checkmark$		$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	X	X
Chris	X	$\checkmark$		$\checkmark$			$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	x✓	X
Betty	X	$\checkmark$		$\checkmark$			$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	X	X
Judy	X	$\checkmark$		$\checkmark$			$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	X	X
Harvey*	X	$\checkmark$		$\checkmark$			$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$
Anne	X	$\checkmark$		$\checkmark$			$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	X	X
Clare*	X	$\checkmark$		$\checkmark$			$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	X	X
John	X	$\checkmark$		$\checkmark$			$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	X	$\checkmark$
Arnold*	X	$\checkmark$		$\checkmark$			$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	X	X
Maud	X	$\checkmark$		$\checkmark$		$\checkmark$		$\checkmark$	$\checkmark$	$\checkmark$	X	X
lvy	X	$\checkmark$		$\checkmark$		$\checkmark$		$\checkmark$	$\checkmark$	$\checkmark$	X	✓
George	X		<b>√</b> <		$\checkmark$		<b>√</b> <	✓	$\checkmark$	$\checkmark$	X	X

I = Independent AS= Assisted ✓ Activity completed ✓ Activity not completed x Activity not completed due to decline in function < \* First Yesterday Diary only.

Participants commonly made their own breakfast, drinks, and snacks and required assistance with meal preparation for lunch and dinner. This was possibly because breakfast (usually) does not require any cooking (Table 4).

Fifty percent of the participants had family and friends visit them in their homes rather than go out, with just a quarter of participants leaving their homes to access the community. Accessing the community involved visiting a rest home, attending a hospital appointment, going for walks, and walking on the beach. Ninety-one percent of participants were dependent of family and friends for transport to access the community. Only 25% of the interviewees used technology to remain socially connected to family and friends and the community.

Only three participants showed an increase in sedentary activity six weeks after their homecare package commenced. Judy and Ivy increased their television viewing time and Chris ate and prepared a snack.

Table 4. Data Extracted from Participants' Combined Yesterday Diaries (IADL)

Participants	TV	TV Sitting in activity / TV AM TV PM evening lounge hobbies		ity /	preparation preparation		eal ration nch	ation preparation		Snack preparation and drinks		Shopping		Accessing Community		Family or friends visit	Using technology remain connected							
	I	со	- 1	СО	I	ı	СО	I	СО	I	AS	ı	As	I	AS	I	AS	I	AS	I	AS	I	I	I
Harold	Х		Х		х	Х		Х	✓		✓		✓		✓		✓		x√		х√	х	Х	х
Chris	Х	✓	Х	✓	Х	Х		Х		✓			✓		✓	✓		Х		Х		х	Х	Х
Betty	Х		✓		Х	Х		✓		✓			✓		✓	✓		Х		Х		✓	Х	х
Judy	х√		✓		x✓	✓	✓	√x		✓			✓		✓		✓	Х		Х		х	Х	х
Harvey	Х		Х		Х	✓		Х		✓			✓	✓		✓		Х		Х		х	✓	х
Anne	✓		Х		✓	Х		✓		✓		✓	✓	✓		✓		Х		Х		✓	✓	х
Clare	Х		Х		х	Х		Х			✓		✓		✓		✓	Х		Х		✓	Х	х
John	Х		✓		х	Х		✓			✓		✓		✓		✓	Х		Х		✓	Х	х
Arnold	Х		Х		х	Х		х		✓		✓		✓		✓		Х			✓	х	Х	✓
Maud	Х		Х		х	Х		х		✓				✓		✓		Х		х		х	✓	х
lvy	✓		✓		x✓	Х		х		✓		✓		✓		✓		Х		✓		✓	✓	х
George	Х		Х		Х	✓		х			✓		✓		✓		✓	Х			✓	✓	Х	х

I = Independent AS= Assisted Activity completed ✓ Activity not completed X Activity not completed due to decline in function <

## **Participant Interviews**

I manually analysed data from the first and second interviews concurrently. As explained previously, of the 12 participants only 9 completed a second interview. Therefore, data from the Yesterday Diaries is incomplete. The data were reduced down into the following themes;

- Feeling in control: Participant control over PADL, and IADL, control over administrative aspects of care, communication between the agency and care recipients, control over the physical environment and the impact of health upon control. Control or lack of control over differing standards of care,
- Social: The importance of social connections and remaining socially connected.
   The impact of health, and role change on role dynamics.
- Participant perceived benefits of homecare and the benefits of remaining at home.

# **Feeling in Control**

A sense of control is defined as "how much control you feel you have over your life" (Healtheuniversity, n.d). Maintaining a sense of control was important to all except one of the participants. Having control over their bodies, decisions made, how and when and by whom care was administered was important. Allowing strangers into their homes was difficult for some to accept. Arnold, who enjoyed his independence, explained, "I'm not used to people being in the house and people doing things."

### Control over PADL and IADL

One of the ways that the participants wanted to feel in control relates to receiving assistance with PADL. Effective communication between the carer and the care recipient allowed participants to feel like an equal partner in the care process. Being offered and accepting assistance emerged as a reciprocal care process, in which carers

would ask care recipients how they would like to be assisted and recipients voiced their preferences. Harold relied heavily on assistance with PADL and IADL. When asked how he negotiated with his carer regarding his personal care, he replied, "Before she touched me she would ask." Having control over their own bodies was important to care recipients who liked to play an active role and participate in their own personal care. They believed the carer's role was primarily to provide support, maintain their safety, and to wash the parts that they could not reach. Harvey described the caregiver's role as "They are in a supervisory role to watch over me, so I don't fall and just lie there."

Many participants unable to complete a task independently still liked to maintain control over some part of the process. Some wanted to be actively involved in and maintain control over household chores (with caregiver's assistance), rather than relinquishing control and participation in tasks in which they were previously involved. Homecare provision enabled them to remain in control of their environment. Arnold had poor mobility and the task of standing and bending to make a bed was likely to have been a challenge for him. He took pride in the fact that both he and the caregiver changed the sheets on his bed together, "We changed the bed together, did it up how I like it." Participation meant getting the job done to Arnold's exact requirements.

Many participants still enjoyed cooking their own meals. Food choices and control over meal preparation provided enjoyment, health benefits, was important to their daily routines, and provided a sense of accomplishment. Harvey described how he did all his own cooking and chose to steam cook vegetables to enjoy the health benefits. Trying to maintain one's health was important. Betty ordered frozen ready meals which she had delivered to her home. She still wished to participate with meal preparation. Her carer would take Betty's frozen meal out of the freezer, put it onto the kitchen work surface

next to the microwave and Betty would place the meal into the microwave and press the start button.

Judy received assistance with cleaning from a charity organisation. The close relationship that she enjoyed with her cleaner enabled her to feel in control of the service being provided. Judy conjectured, "With my cleaning she comes in and she knows exactly what to do ...she will say what have you got for me today? And I will say could you clean the kitchen windows and she will do that."

## Control over administrative aspects of care

Control over the administrative aspects of care emerged as important as it gave participants a sense of control over their environment. One aspect of being in control is being informed of when things will happen. Some homecare recipients described how the care agencies had asked them what time they would prefer homecare to come, which enabled them to feel in control of their care and when it was provided. Anne had chosen the time that homecare was provided but was considering altering it to a later time. She announced: "I chose the time .. I think if I can I would like to have her come a bit later in the morning ...I might ask if they can change it."

Not everyone was provided with a choice. Although Harvey had been given a choice about the time that homecare could be provided, he was still not happy with the regimentation of living his life around a time schedule provided by homecare. He declared:

With homecare, I've got to be up and about when they arrive and I felt it's alright 5 days a week. That's good cos she doesn't get here till 9.30 ....but at the weekends I want to have a sleep in. I want to do my own thing and not be regimented anymore. I wanted control at the weekends.

The majority of older adults chose not to have homecare over the weekend and manage the task alone or with assistance from family so that they could have more control over how they spent their time.

Clare advised that she let the agency decide the time that care was delivered, "I said I would leave it up to them as I didn't know what to expect. So time was flexible." Most care recipients felt able to express their needs to care coordination to organise care arrangements which worked for them.

Having multiple carers was a common problem for many care recipients when their care packages were first set up, with some individuals receiving a different carer each day. All preferred to have the same carer or the same regular carers as this provided a routine, stability, and security. Harold stated, "The biggie for me was getting the one carer. It's not really nice when you have six or seven different women coming in and you don't know who they are, what they are."

Harvey had altered his daily routine to fit around the needs of the care agency to ensure that he did not have a different carer every day. Originally he had been sent four different carers and had phoned the agency and told them, "I don't want that." He had altered his daily routine to secure a single caregiver of his choice rather than have a multitude of carers come to his house. Three of the participants chose to fit around their caregiver's work arrangements and available work slots to secure their preferred carer.

Choice of carer and whom they allowed into their houses provided a sense of control, even if they had to compromise on the time that care was provided. Having a carer who was flexible to individual's needs was important. For Judy, being able to phone her carer directly was important. That meant she was able to reschedule appointments, and

that her carer could also ring to reschedule if required. "If you can get someone who fits around you like that it's very good!" Judy exclaimed.

From an organisational perspective, it could be hard for care coordination to manage if carers and care recipients make their own arrangements with regard to homecare visits. It is important to have a third party mediate between the care provider and care recipient so that the care agency is fully informed as to the whereabouts of their workers, particularly as a common problem reported by homecare recipients was carers failing to turn up. Maud had problems with her first cleaner who would phone in sick at the last minute, rearrange her appointment and then cancel. "She rang up and she said she couldn't come, and she was coming at 1 o'clock. Then she rang at half past 1 and said 1 can't come, my back's still sore."

John's wife was unhappy when a new carer arrived late, and unexpectedly, at her door. As the primary care giver, she had already helped her husband get out of bed, get washed and dressed. Rather than being a help, the carer's visit had come as an unwelcome intrusion.

She came ...she was very nice. She didn't do anything cos we had got him dressed by then... She came and said do you want me to do anything? Well no, cos I'm not undressing him again. It's dinner time now. So she plonked herself down. She was very pleasant and talking, seemed like an hour.

John's wife informed me that she had phoned the care agency about the incident and was told that her usual carer was on holiday, to which she replied, "I was told nothing about that."

Participants reported different levels of expertise among carers. Betty described one of her carers as rough: "No, one's rougher than the other one." Harold's first carer was less confident in the role and he felt uncomfortable in her presence, "One of the carers

that came on the day, never looked at you. She looked at the side of you. I find that strange," he disclosed. George's wife perceived his carers as understanding of his individual care needs and if he did not want to get out of bed they would wash him in bed. She stated, "They've both been very good and very understanding of what he would like if he doesn't want to get out." Harold's carers also took their time and did not rush when providing care,

they are both very good like that. They both take their time ... She was very kind when I was showing signs of getting breathy or whatever she would say, 'Let's stop. Take your time.' She was totally focused on me, she really was.

Harold's carer requested more time from the office to help him shower because it was a slow process. Harold revealed, "She requested more time from the office to do a shower cos it was taking much longer."

### Communication

Poor communication between carers and agency was a common theme. Harold, who had also experienced multiple carers turning up not sure of what they were supposed to be doing, stated, "I was in management for years and I could sit here now and write a better system than they seem to have." The participants felt more comfortable with carers who were informed of their individual care needs and could focus on required tasks. One of Betty's carers "sat in that chair there and said to me "Oh what shall I do now?" When care recipients had to inform carers of the tasks to be undertaken, this made them feel uncertain of carer's level of competence and expertise. Harold's wife explained, "I don't know whether this is relevant, but each one of them has come to the property and has not known what was the matter and what they were coming to." It was unclear whether carers not knowing the care tasks required was due to an organisational

failure to pass on information about homecare recipients and their care needs or whether further training for carers was required.

The need to vet carers was also apparent. One of Betty's carers used to come to the house and help herself to coffee and something to eat. Betty rang the care agency about the carer, "I rung and said I don't want the lady cos she talked too much. She's supposed to be here an hour and she doesn't do nothing." Another carer wanted Betty to sign her time sheet for work that she had not completed. "This lady come on Sunday and then wanted me to sign the book and had done nothing and she didn't come. She didn't show up and told the care agency she'd been here and I wasn't here." Four of the homecare recipients felt comfortable approaching the agency with difficulties that they were having with carers. Everyone who had difficulties with carers phoned the care agencies to inform them of what had happened and difficulties were resolved.

Some did not know what to expect from homecare, while others were better informed. Harvey was fully informed of what his carers were meant to be doing and showed me the list of chores that needed to be done. He had questioned the time sheet given to him by the homecare agency as he believed it to be incorrect, "It was originally down here per week, so it's in the right column there, but they've got the time muddled up." He believed he was due more care than he was in fact getting.

There were also instances of unmet need among older adults. Some complained of homecare not completing tasks or half-finished jobs. John's carer would hang the washing out but his wife would then have to take it off the line when it was dry. "Hanging it out in the morning is good but she [his wife] still has to try and bring it in in the afternoon." Ivy had assistance with cleaning but still had to do the laundry by herself and struggled with folding sheets; "It a bit of struggle. I manage, which it's a question of manage," she retorted.

## Losing control over their physical environment

Loss of control over their environment, in the sense of not being able to maintain the general upkeep of their homes, caused frustration to some. For instance, Harold was frustrated that he was no longer able to maintain his gardens, "If I was fit, I would eat this place," he declared (a colloquialism for making light work of the jobs to be done).

Loss of control over the environment in some cases was linked to moving into residential care or considering moving into residential care. Ivy was happy living at home and was receiving assistance with cleaning, but lack of transport and difficulty maintaining the up-keep of her home was forcing her towards making the decision to move into a retirement home. She announced, "I am very happy at home. I said to my friend, who is in a rest home, I'm in a luxurious rest home really."

Ivy was worried that if she had to move into residential care that she would have nowhere to house all her possessions. Ivy had told her sons that they could be responsible for getting rid of all her stuff as she could not decide what to keep:

I'm thinking I can't go in a little box. I've got too many things, but time's going on I have boxed some things. My son is going to take them... he says, and I said there are things that I don't know what to do with. You can take them and don't tell me what you do with them. I don't care if they go to the tip. I don't want to know.

Maud was considering going into a retirement village as she too was having difficulty keeping on top of things where she lived. "I used to spend all day out in the garden ….the garden's gone to rack and ruin really," she reported. Leaving the family home was associated with loss, shedding possessions, and memories. Moving into a retirement home, for Maud, meant not only shedding personal possessions but also finding a new home for her cat. She had visited one rest home but had decided against it

saying it felt like a "Boot Camp," "It's almost as though they have complete control over what you do" she conjectured. Remaining at home enabled Maud to feel in control of her environment, and how she spent her time.

Two individuals received assistance with cleaning; others had to fund their own cleaning. Betty, who did not get assistance with cleaning, referred to it as a "very important thing." Those that funded their own cleaning were more satisfied with the service than those who received funded assistance. Judy's (charity funded) cleaner wiped the light switches, the walls in the bathroom, vacuumed, and dusted. Homecare recipients with DHB funded cleaning received a less thorough service and complained about the standard of cleaning. Ivy's cleaner told her that her care agency had told her that cleaners were not allowed to dust. Ivy complained that the cleaner did not clean the inside of the windows, and had used strategies to try to tempt the cleaner to clean the inside of the windows by moving furniture out of the way to make the task easier. "Look, I've made a bit of room for you" she would say. Ivy believed that cleaners should be allowed to use their initiative with regard to cleaning. Unhappy with the standard of cleaning, she described how "I notice things get left. Cloths still in the shower, but it's done." She also joked that she would like to make a video about vacuuming. Ivy was worried about the lack of cleanliness in her home:

I woke up one morning cos there a thing that's been worrying me is cleaning. Literally cobwebs, and I was brought up very strict and I'm not now and I woke up one morning and I thought really what I should do, I'm starting to when the weather is better, adopt a room. (meaning to clean)

Maud's agency did not allow her cleaner to dust. However, she dusted anyway, "I think dusting especially when someone's got respiratory problems is really important...I'm going to ask her to dust today because the bathroom doesn't need doing ...I just said to

her, if you break something, you break something," she declared. Despite the fact that Maud's cleaner dusted, she was not happy with the standard of cleaning. "Sometimes people will come in and they will say, is your cleaner still coming in? And I think they haven't cleaned that very well."

Harvey did not mind that his cleaner did not dust. "You are looking at the health of the person concerned, not only from the dust that they could be raising but whether things slip or depending on what's broken." However, Harvey was unhappy with the infrequency with which his bed linen was changed, only every two weeks. He explained, "I've got to change the linen on my bed once a week."

## The influence of health upon control

The negative impact and loss associated with declining health was evident amongst some. George lived with his wife, whom he relied on heavily to provide his care, meals, company, and transport. For George, decline in health and reduced mobility meant loss of control. He was low in mood on both the occasions that I met him. He informed me, "Control; there's no control in my part." George felt as though he had little control over his life or the activities he could participate in. George's wife, Eve, told me, "George listens to his music, he's happy with that." George's response to this statement was, "Tunes over and over again." I asked George whether there was anything, with regard to homecare, that he would like to see improved. George replied, "I would like to be less disabled and walk without a walker now." George was aware that this desire to be less disabled was not realistic.

Reduced mobility and pain affected ability and motivation to participate in some ADL. Betty received assistance with washing and dressing and experienced daily pain. She was only able to walk short distances with the assistance of a wheeled walker. Betty described how, "It's painful but I still walk." Others complained of low energy levels.

Ivy had planned a strategy to spring clean her house but admitted that, "I'm quick to get exhausted and I have noticed that I really do... I can be enthusiastic for half an hour and then I'm tired and I want to go to bed and sleep for an hour." Decline in health, not being able to control her own level of performance, and the degree with which she relied on others for assistance made Judy feel that she had little control over her life and made her feel like a burden. "It's frustrating for you people having to deal with me, but I try not to be hard."

Some participants played down their need for assistance from homecare and demonstrated a lack of insight into the difficulties they were having prior to their care package. George's wife explained he would "just do the things he could." George replied, "I could say I was managing myself." Anne was admitted to hospital twice before she made the decision to ask for assistance from homecare.

Harold believed he could get out of bed independently. His wife had advised me that she helped him to get out. Harold said, "I'm not fully mobile no." I enquired further and asked him how he got out of bed, to which he replied, "I just get out of bed."

Surrendering control provided empowerment to some. Clare had high care needs, which were taken care of through homecare assistance. Clare's carer taught her breathing techniques and helped her to maintain her balance when getting washed and dressed, which provided her with a sense of security. Clare explained, "I pretty much did it all and now I can't and I have to let it go... I'm not getting anxious with what I can't do." For others, the process of surrendering control by allowing home carers into the home was harder to accept. Arnold declared, "I'm not used to people being in the house and people doing things."

## The Importance of Social Connections

Social connections were vital as they enabled the participants to remain at home. Social connections ranged from family members who acted as carers, friends in the community who assisted with shopping and transport, and neighbours who provided assistance with household maintenance and odd jobs. Many formed close friendships with home carers, some of whom provided unpaid assistance outside of their working hours. Confirming the data from the Yesterday Diaries, the majority of older adults described that they relied heavily on partners and family to assist with shopping, take them to hospital appointments, provide cooked meals, and maintain the gardens. This resulted in changed role dynamics. Some family members travelled considerable distances to provide assistance to their older adult relatives but still visited regularly. Some participants were reluctant to accept help as they did not wish to be a burden to their families, as they realised that their children had commitments and responsibilities to their own families. Betty explained, "My son, he was staying here when I came out of hospital. He stayed here a week, but he's got kids and he's got a business." Some family members provided financial assistance to their parents. Betty's family paid for her meals on wheels and Chris' family helped manage his finances, "She does all the financial things."

All participants who lived with partners referred to them as their primary care giver and extolled the benefit of this care, often in more gushing terms than the terms they used to describe homecare. Anne revealed, "My daughter ...has given me wonderful care." Those who did not have family close by relied on neighbours and friends for assistance. Assistance in some cases was provided by older adult friends with declining health, who were already primary care givers for disabled partners. Betty's friend used to bring her shopping and brought his disabled partner with him:

He's taking me with his partner together, poor man. He looked after me in the back of the car and then he sat in the front and then he had to get out and then they put him out first and then they come around holding the partner in one hand and comes around to help me out with my arm. I said, 'Don't worry about me you look after your partner!'.

Ivy's friend used to give her lifts to the shops but had to stop taking her when she was no longer able to lift Ivy's [wheeled walker] into the boot of her car, "I've got one (wheeled walker) and she got shoulder trouble and between us we can't get the shopping and walker in [the car boot] so I said, 'Leave it, I will get a taxi'." As Ivy no longer had assistance from her friend with shopping, she had just discovered internet shopping. She exclaimed, "I'm definitely going to try some shopping on line." Maud did not have anyone to help with her shopping so she would phone her local supermarket to have her groceries delivered. Harvey could still drive and did his own shopping despite being advised by his family not to drive. "I've got a lot of friends who have offered their help and I am still capable at the moment of doing my own shopping" he explained, determined to retain his independence.

## Role change

Alteration in health and requiring assistance with IADL and PADL changed the role dynamics between individuals, their partners, and their children. George pronounced, "My wife has been my caregiver right from the beginning." Having a spouse as a primary care giver had a negative influence on Judy's relationship, she declared, "We are getting on each other's wick a bit. It's hard to avoid." For others, decline in health made it difficult to perform family roles. For Clare, being "Nana" meant being able to give lots of hugs to her grandkids. She explained, "I know they enjoyed getting hugged. I miss those precious hugs and having them hugging me back." Hugging her

grandchildren may have become too painful and tiring for Clare with her declining health and increased fragility.

### **Social isolation**

Reduced mobility and spending protracted hours alone at home brought loneliness for Arnold who revealed, "I do not have friends, only my ex dancing partner...it's the only contact." He used to be a keen dancer, "I've had to give up dancing, so that was my physical contact, going to the dance. I had people who would say hello to have a conversation with," he revealed. He appeared to be lonely, and apologised for talking too much, "then as I said not really been a talker, somebody comes around and I can't stop talking."

## Remaining socially connected

All those involved in this study relied on family, children, partners, friends, or charities for transport. Judy relied on her husband to drive and said she would be stuck without his help. A common theme was the absence of accessible public transport. Maud exclaimed, "They took the bus stop away...It's just I need to move somewhere else and I just find, up here, I don't drive. It's difficult, if you haven't even got a car." Chris complained that there was not a regular taxi service in the area and that when he last caught a taxi it had cost him \$10 to get to the doctors. Chris was horrified at the cost; however, the fare was reasonable given the distance that he had travelled. His expectations of cheap taxi fares were did not reflect current fares. Ivy explained, "Once your legs have gone, which I mean by losing your car your legs are cut off and you live in a situation where the transport is absolutely pathetic." Ivy complained that catching the local bus which was a long distance away and up a hill was time consuming, "I don't get home till 1 o'clock. It's a full morning."

Not only was reaching the bus stop a challenge, getting onto the bus was also difficult. Ivy's frustration was evident when she described the difficulty she had accessing public transport,

I got on the bus and ...I had a bit of a job hauling myself up and it must have been probably one of these that curtseyed to you...but the bus driver actually reached out and sort of dragged me on and I think, I can't be doing this... I feel it's quite dangerous sometimes.

Although the bus provided disabled access, Ivy still had difficulty getting on and off and worried she might injure her legs. This example illustrates the complexity of providing accessible transport for people with disabilities who have a variety of mobility issues.

Maud was unable to access public transport and relied on taxis, but had a mobility card which provided her with reduced taxi fares. Maud's GP was aware of that but on one occasion felt sorry for her and gave her a lift home, after her appointment, to save her waiting a long time for a taxi. This is yet another example of how social connections, in this instance a GP, provided transport to his older patient as public transport was not adequate to meet her need. This example illustrates that without help from the wider community, remaining at home may not have been possible for many of the participants.

Not all participants relied on public transport. Arnold, who had recently retired from driving, imparted that prior he had changed his driving habits and altered the journeys that he would take. Arnold described how, "When I could drive I would go down myself, park [in the] handicapped parking, and I was going down in the evening when it wasn't quite so busy." Harvey declared,

I've got a car but don't drive very much. Put it this way, I won't drive very far because I know I get very tired quickly so I only go down to the shops. ...I haven't been refused a driving licence although my daughter isn't happy that I drive but I can still override her on that.

Judy had a current driver's licence but chose not to drive. Betty also had a driver's licence and described how she drove occasionally, "I'm not really likely to drive when I got the pain...I drove my car. I was sick after that."

### **Benefits of Homecare**

Remaining at home was important to individuals as it was a place of memories and connections. Betty preferred to stay at home rather than go out, she preferred her own company in the house as it filled her with joy, "You walk around your house and you look at your photographs and your family and you look at flowers...I am very happy in my own home. I hope I can stay as long as I can." Chris, who rarely went out, stated that he had never been a joiner of anything. Ivy too loved living at home, "I honestly love it here and fell in love with it 23 years ago and I've never changed and my view at the back is all mountains and birds. You know it's just the balance." Friends and family had unsuccessfully tried to persuade Ivy to put her name down for a retirement home and told her, "You can't rattle around in that house."

Homecare provided benefits for both service users and primary care givers, as it enabled individuals to have their personal care needs attended to and provided a break for primary care givers. Feeling fresh and clean was important to some. George exclaimed, "I have had breakfast, morning tea, I've had lunch. I've had a wash and a change of clothes, I feel like a new man." Clare described how she had, "An hour in the morning to help me clean up nice little fresh moment." Remaining at home with assistance enabled Clare to enjoy family time, "Yesterday was an awesome day, cos we achieved

many things." Betty was quite happy and thankful for the help she got she exclaimed, "I got the good help."

Homecare enabled many of the care recipients' primary care givers to have a break. George's wife referred to the homecare visit as her hour off, "I can read the paper, do whatever I want" she announced. Many preferred to have assistance from homecare with regard to personal cares as it meant their partners did not have to do it. Harold agreed to have homecare to help his wife "It was for your sake I did it... She's doing everything and she's buggered," he explained. Judy had concerns about the toll that caring for her was having on her husband's health, saying,

He does a lot and he is starting to get tired and you know I watched him ...and he was walking up the drive to check the mail and he's kind of stooped over and he's never been stooped. It's taking its toll. He's getting tired.

Having a good relationship with their carer was important to participants. Maud advised that she did not like her first cleaner, explaining, "There's nothing worse than having someone come in your house that you don't like...I didn't like the woman that came way back."

Many homecare recipients formed close bonds with her carers. They regarded them as friends or like members of the family and enjoyed their company. Judy described how she bought her carers a gift at Christmas:

Christmas came, it wasn't a lot and I bought them a little gift each and they both said, 'You didn't have to do it. I said I didn't have to do it but I wanted to do it to just as a thank you... She is here every day of the week so I've got used to her and I really like her. I've known her for years... they have actually become like part of the family. She always comes in here, 'how are you? What you been up

to?' And takes 5 minutes or just a couple of minutes of her time and says, 'the usual'.

Some participants became dependent on their carers and found it difficult when carers changed jobs and left. Judy's carer was relocating and was no longer able to visit her. Judy commented:

I was quite sad because she is shifting ...I was so apprehensive about getting someone to come to do it and I said to her. 'Ask your boss if you can still come down to do me... I would even be prepared to pay you petrol money to come down'.

Some carers worked beyond their role. Betty's carer visited Betty one weekend to maintain Betty's garden. "On a weekend off she come and clean all the patio. There she put some flowers." The same carer went shopping for Betty in her lunch hour. Ivy's carer brought Ivy's shopping with her on her days off. If professional boundaries are crossed and the professional carer becomes a friend to the homecare recipient, there is a risk that the carer will be placed in vulnerable position and may feel obliged to provide assistance not covered by the homecare package. It also masks deficits not covered by homecare if carers are doing unpaid work in their spare time to assist older care recipients to remain at home.

# Participant views on homecare

Most involved in this study advised that they had been reluctant to accept assistance from homecare. For George, it was "a bit of an ordeal to start with but it has improved yes." Older adult care recipients adapted to change. Judy initially put off having assistance with washing and dressing as she was embarrassed having someone help her with personal care, "I put off having someone coming to shower me for so long... I thought I couldn't bear that" she announced.

Harvey was apprehensive about accepting help with personal care, "I thought this is going to be a bit awkward, but no it works out easily" he mused. Some of his friends had deterred him from accepting assistance as they had had negative experiences. Harvey exclaimed,

I feel from what I have heard only, not experienced, there seems to be some of those home carers should be vetted better they are not all up to the same standard... I've heard different stories. Some home carers can be very domineering, abusive at times. That's what I was prepared to face, but it never eventuated.

George had no preconceived ideas about homecare "I never expected anything and I'm more than satisfied," he declared.

Positive experiences of homecare changed individual's preconceived ideas on homecare. Anne mused,

I'm thinking the important thing for me was having this home help is the person they have sent to me is very good and we get on very well, which is a big help. So that has changed my outlook in having somebody to help.

Equally, Harold's bond with his carer meant that the experience was far better than he had expected.

Although none of the participants knew how old their carers were, some referred to them as "girls". However, the language others used to describe carers inferred that carers were middle aged. Arnold was surprised at the thoroughness and the level of energy his carer had, "She's very good, big lady but she moves. She bought my rubbish bins in from the street, put my rubbish out." Harvey stated, "I don't know how old either lady be, but obviously they are very experienced to know what they are doing." Betty

advised that her carers worked extremely hard but showed signs of tiredness, "It's nice to have people in the house ...but you have to try to help yourself, 'cos I know girls coming in help you but they are getting tired too themselves. They try their best."

## **Integrating Qualitative and Quantitative Findings**

The quantitative and qualitative data, in combination, revealed that participants spent the majority of their time at home in sedentary activity with their lives revolving around meal-time and self-care tasks. The Yesterday Diaries revealed only a quarter of the participants participated in indoor hobbies. The majority of participants spent their leisure time watching television. This could indicate reduced activity levels amongst participants. Participants' friends and family visited them in their homes rather than participants leaving their homes; some kept in contact with relatives via technology such as Skype or the telephone.

Data from the Yesterday Diaries supported interview data and revealed that participants were actively involved in their personal care provided by homecare, rather than passive receivers of care. This finding supports the theory that homecare assists individuals to maintain their life skills with regard to PADL. Many participants still cooked their own meals and made their own beds, some with caregiver assistance, and provided individuals with a sense of achievement and being in control. This reciprocal care process enabled homecare recipients to maintain their life skills and life roles.

Combined data revealed that the care provided by homecare was insufficient in itself to assist participants to remain at home, as participants relied heavily on social connections family, friends, and neighbours to assist them with care tasks, transport, home maintenance, managing finance, shopping, gardening and GP/ hospital appointments. Only two of participants received assistance with cleaning and no assistance was provided with shopping as this is not a service provided by homecare.

### **Summary**

The findings from the study "Does remaining at home with the assistance of a homecare package impact on quality of life and maintenance of life skills?" revealed both positive and negative aspects to remaining at home with the assistance of a homecare package. Quantitative data demonstrated that being at home enabled homecare recipients to maintain/and or participate (with assistance) in PADL and IADL which assisted them in maintaining their life skills. It revealed a decline in physical functioning in two participants due to a decline in health and no significant increase in activity levels were reported by participants. Two participants did increase their activity levels slightly but this was to undertake sedentary activity (i.e., watching the television and preparing/eating a snack). Quantitative data supported qualitative data which showed that being at home enabled most participants to continue their life roles; it enabled spouses to remain living in the same home and remain socially connected to family, and friends. Six participants received visits from family and friends. Quantitative data detailed the level of support provided by family and friends who assisted some participants with PADL, shopping, gardening, and transport. It supported data from the qualitative interviews which showed that without support from family and friends it was questionable as to how many of the participants involved in the study would be able to remain living safely at home.

Qualitative data revealed that home was a place of memories that provided participants with a sense of belonging. Participant interviews detailed how some participants formed close and valued friendships with home caregivers. Participants' sense of control over their personal care and their home environment was a central theme identified in the study. Having mastery over ones environment has been linked to increased QoL (Vernon & Qureshi, 2000). For some participants, reduced health brought a feeling of

loss of control over their environment and a feeling of dependency. Some felt they were a burden on family and friends and this altered the role dynamic of relationships. The feeling of loss of control due to declining health may have resulted in reduced QoL for some homecare recipients. Despite some participants' ailing health, assistance from homecare remained beneficial to participants as it provided primary care givers the opportunity for a break and enabled participants to feel less burdensome to their relatives.

Qualitative data revealed organisational issues (i.e., differing standards of care, poor communication provided by the homecare organisations) and quality issues. Care provided to participants in the study just meet basic needs. All of which may have impacted upon reducing the QoL of the participants.

# **Chapter 5: Discussion**

To answer the research question, "Does remaining at home with the assistance of a homecare package promote maintenance of life skills and enhance quality of life?" I will discuss the researching findings in relation to the literature and legislative context within New Zealand. The QoL literature points to specific aspects of life that comprise this concept. I will be using specific QoL concepts used by Flanagan; that is, physical well-being, relationships, and recreation (Burckhardt et al., 2003), and the WHO (2018) definition of QoL which encompasses physical health, social relationships, and relationship with the environment, to identify how homecare influences QoL of homecare recipients. The discussion is organised under the following headings: Maintenance of life skills, QoL as it relates to sense of control, well-being, social connections, and time use/recreation. I will then discuss the strengths and limitations of the present study and further questions that it revealed.

### **Maintenance of Life Skills**

This study found that remaining at home with homecare services assisted older care recipients to continue to participate in everyday activities and thus supported maintenance of life skills with regard to PADL skills and IADL. Participation in IADL and PADL provided some of the more physically able participants the possibility of having a sense of mastery over their environment which might be considered a life skill in itself. Maintenance of life skills with regard to PADL and IADL is known to promote physical health and well-being and aligns with the WHO (2018) definition of QoL, as well as Flanagan's QoL measure (Burckhardt et al., 2003).

Participants viewed homecare provision as a reciprocal process where the carer assisted them under the participants' guidance, rather than completing tasks for them. In addition to maintaining physical skills, homecare provision supported participants to maintain the organisational and cognitive skills that support independent living in the community. This finding aligns with studies by James et al. (2011) and Nikmat et al. (2013). The practice of doing tasks together contributed to both QoL and maintenance of life skills for those who received assistance with household tasks.

Assisting homecare recipients to complete familiar tasks (i.e., to cook lunch and help them to make their beds the way they liked them) enabled care recipients to maintain their range of movement and physical functioning and allowed participants to feel in control of care tasks and maintain a sense of independence. Earlier studies have shown that completing familiar tasks is important to older people with disabilities as it helps to maintain their sense of identity and roles (Ball, Perkins, & Kemp, 2004; Barken, 2019; Vik & Eide, 2013). The approach to homecare by the care agencies involved in this study aligns with both earlier and recent studies, which have shown that an ideal homecare service is one where care recipients have a say in how things are done and have assistance to perform tasks themselves (Duner et al., 2019; Vik & Eide, 2013).

The present findings did not support an earlier study by Vik and Eide (2011) which showed homecare services contributed to levels of passivity among homecare recipients. This lack of congruence was possibly owing to the fact that the model of homecare employed by the New Zealand based DHB differed from a traditional approach of doing for the person. This is in line with the Ministry of Health (2003) guidelines which promote a restorative approach to homecare.

Maintenance of participants' life skills and promoting ADL is congruent with a rehabilitative approach to homecare; defined by Lewin et al. (2013) as restoring function rather than simply doing things for people. One example drawn from this study was reports of carers providing advice to care recipients on how to maintain their balance in order to maintain mobility, range of movement, promote strength, and

conserve energy. However, as this study only explored participants' perception of homecare, rather than whether carers were trained in a rehabilitative/restorative approach involving support and regular supervision (King, 2012), it is unclear whether the homecare organisations involved in the present study did in fact implement a recognised model of rehabilitative/restorative homecare. It also remains unclear whether implementation of homecare services supported the maintenance of life skills beyond the PADL and IADL tasks that carers directly supported; which had been the intent in collecting data about time use via the Yesterday Diaries.

### **Sense of Control**

Service users maintaining a sense of control was a central theme in the study. Having a sense of being in control is linked to improved QoL. According to Hennessy and Hennessy (1990) "maintaining quality of life to an acceptable level, and maximising the degree of control over the way that life is lived is more desirable...than getting better" (p. 258). The present findings support previous research which revealed that older people wish to be in control of their personal care, and prefer to have control over how and when services are delivered to maintain a sense of independence and control over their everyday lives (Duner, Bjalkerbring, & Johansson, 2019). Participants involved in the present study were similar to those in Duner et al's. (2019) Swedish study of homecare recipients, which revealed that most of the recipients of homecare were actively involved in the decision making of when and by whom care was provided.

Another similarity with Duner's et al. (2019) study was the importance of staff continuity. Inconsistent service provision, which involved a variety of carers who did not keep to regular appointments, resulted in care recipients feeling disempowered, being less actively involved in their care and, according to Duner and colleagues, less

able to achieve a sense of autonomy. Inconsistent care might decrease the possibility of maintaining life skills and improved QoL outcomes for care recipients.

Previous research identified that homecare recipients often adapt their expectations of homecare around the constraints of the service provided (Duner et al., 2019; Gunnarsson, 2009). For most participants in the present study, having a say in how things were done did not always extend to securing their preferred time for when homecare was provided. Studies have shown that not having control over the timing of care can cause frustration for recipients of homecare (Duner et al., 2019). However, the majority of homecare recipients in the present study managed to take back control by securing their preferred carer. This may not be possible in other circumstances and was dependent on the number of carers employed by the particular homecare agencies. Homecare recipients also exerted control over how they spent their time by selecting not to have homecare over the weekend. This level of control, or choice, over which carer to have, has not been previously reported in the literature and has clear implications in relation to organisational life skills older people living at home retain despite increasing physical care needs.

The assistance which carers provided to homecare recipients was not able to compensate for decline in health and mobility, which caused frustration and feelings of disempowerment for some participants. Loss of control has been shown to lead to reduced QoL and is linked to depression and anxiety (Vernon & Qureshi, 2000).

One participant did not feel that he had control over even the smallest activities in his life (i.e., changing channels on the radio or turning it off). This may be a reason why some participants were in denial of their reduced mobility. Some participants reported a higher level of physical ability than their observed abilities. Viewed from the perspective of life skills, such findings suggest that perceived and actual life skills may

not align. This may have been a self-coping mechanism, and supports one study which found that when a person's self-perceived level of independence is higher than their actual ability, it provides the older person with a sense of increased self-worth and well-being, and supports healthy ageing (Oswald & Fleischmann, 1985).

## Quality of life and social connections

Remaining at home supported the present study participants' psychological well-being Participants had formed strong emotional ties to their homes. Possessions provided reminiscence and a sense of belonging; these findings support one study which showed that objects connect the older adult to their environment, family photos remind them of their life roles, connections to others, memories to past and present events (Cipriani et al., 2009). Psychological well-being and the relationship the individual has with their environment is an indication of improved QoL (WHO, 2018).

While social connections in themselves are associated with improved QoL (Burckhardt et al., 2003; WHO, 2006), for the participants with reduced mobility and poor health in the present study, having good support networks were vital for remaining at home. One of the reasons social connections were important to these participants was that all relied heavily on family and friends for assistance. That assistance bridged the gap between unmet need and funded homecare services, and enabled participants to remain living in the community. However, becoming a primary care giver changed the role dynamics in relationships and, in some instances, placed a burden upon the carer.

Lecovich (2011) found that the quality of the relationship between the care recipient and the informal care provider determined whether or not the care provider experienced a sense of carer burden. A close relationship between the carer and care giver was found to reduce the likelihood of carer burden and was linked to increased carer satisfaction. For instance, in the present study, some participants worried about the burden of caring

was having on their spouses health as well as their relationship. The literature revealed that dependency is linked to reduced QoL (Vik & Eide, 2013). Other studies, by Barken (2019), reveal that dependency among recipients of homecare falls into two categories—bodily dependency and dependency due to inadequate support. Hurd et al. (2012) asserted that gender differences affect individual's sense of dependency, with women believing that being able to care for one's self is a moral responsibility. Findings from the present study did not reveal any gender differences between participants as both expressed concerns about being a burden to their spouses. However, one female participant who expressed concern about being a burden to her husband also expressed concern about receiving assistance with personal care from her husband; male participants did not express the same anxiety about a spouse providing personal care. Flanagan's QoL measure uses relationships as a concept to measure QoL. The change in the role dynamic of care recipients' relationships with their spouses could influence the QoL of care recipients.

A part of being socially connected is maintaining life roles. Remaining at home enabled participants of the present study to maintain their life roles and life skills. Studies indicate that participation in life roles is important for adults remaining at home (Kerse et al., 2016; Kjersti Vik & Eide, 2014). Exemplifying this, was Clare's relationship with her grandchildren. When completing the Yesterday Diary she had referred to her day as having been, "awesome" as she had spent special time with her grandchildren who were an important part of her life.

One study by Haustein and Siren, (2014) revealed that older adults who remain at home are likely to experience increased QoL and empowerment in old age (Haustein & Siren, 2014). Active participation in the community has been shown to lead to reduced functional decline and increased longevity (Glass, 1999; Holt-Lunstad et al., 2010;

Kerse et al., 2016; Mendes de Leon et al., 2003; Resnick, 2012), However, it is an assumption that 'ageing in place' assists social connectivity. This study supported previous research findings that remaining at home does not necessarily facilitate social connectivity or enable older adults to lead active life styles (Iwarsson et al., 2007). Inoue and Matsumoto (2001) argued that older adults living at home may find it difficult to lead active lifestyles and remain socially connected, and risk becoming house bound. New Zealand's Positive Ageing Strategy (Ministry of Social Development, 2001) promised to develop and provide affordable and accessible transport options for older adults to remain connected to the community, as well as provide transport to access health services and address the transport needs of older adults living in rural areas. As previously stated, the DHB involved in the study serves an area of high socioeconomic deprivation, which is greater than the national average. Of the total population of the DHB, 26% falls within quintile five which is the most economically deprived (Anonymous DHB, 2019). Therefore, the older adults in the present study may not have been able to afford to use taxis even with the assistance of mobility vouchers and were at increased risk of becoming socially isolated.

Although the present study included a small number of participants, all complained of difficulty accessing public transport due to high costs, lack of services, and physical inaccessibility of public transport vehicles. One of the participants lived in a rural location, the local bus stop had been removed, and she relied solely on taxis for transport which she believed was costly. The majority of participants were dependent on family members for transport to hospital appointments, shopping, and to access the community. Without this assistance there was the risk that participants would become house bound and experience reduced QoL.

Lack of company and lack of activity are two commonly cited unmet needs among the older adults living at home (Miranda-Castillo, Woods, & Orrell, 2013). Studies show that older adults who are not socially connected are more likely to experience loneliness, which studies link to reduced QoL, well-being and poor health outcomes (Arslantas et al., 2015; Xavier et al., 2003). Within the current study, some participants reported being lonely and attributed that to social and occupational losses due to decline in health and reduced mobility, even while they described enjoying their own company and being selective of the company that they kept.

Given the importance of social connection to QoL and well-being, it is perhaps not surprising that participants in the present study had formed close bonds with carers and some regarded them like members of the family. The closeness and frequency of these relationships was possibly due to the limited opportunities that participants had to form social connections and friendships, because they spent most of their time at home. Ayalon et al. (2015) found that the relationship that formed between formal carers and care recipients in homecare situations differed from other care settings (i.e., residential care and hospital settings), as homecare happens in the privacy of the care recipient's home. The strength of the relationship may be explained by the frequency of the visits by the same carer, the carer interaction with the care recipient, and their social connection. Socio-emotional selectivity theory (Carstensen et al., 2003), which proposes that as people grow older they prefer to develop close intimate relationships rather than more superficial relationships, may also play a significant part in the carer and care recipient relationship. Therefore, relationships formed between the care recipient and their carer can be of deep significance to the older adult.

Viewed from the carers' perspective, studies by Lechovich (2011) have found that a friendly sense of connection and quality of relationship with people to whom they

provide care enhances caregiver satisfaction, reduces caregiver burden, and increases caregiver productivity. Reduction in caregiver burden is also experienced by family members who provide care. Findings from the current study support the recommendation made by Inuoue and Matsumoto (2001) that older adults who remain at home should be provided with social networking opportunities (with transport), and that social relationships should be used in treatment planning to enhance older adults' QoL and longevity (Inoue & Matsumoto, 2001). In contrast, the present study revealed that strong bonds that formed between the homecare recipient and the homecare worker were at risk due to poor organisation (i.e., home carers turning up late, carers not being informed of the tasks they are meant to be completing, and homecare recipients having multiple carers).

## **Differing Standards of Care**

Participants in the present study reported different levels of perceived expertise among carers. Some carers were reported as very kind, others as being rougher, and some were uniformed as to their care tasks. It was unclear whether carers not knowing the care tasks required was due to an organisational failure to pass on information about homecare recipients and their care needs, or whether further training for carers was required. Previous literature has also identified a non-unified approach and differing standards were identified across international studies (Beaulieu, 1991; Whitehead et al., 2015). Participants reported different levels of perceived expertise among carers in care delivery, supporting the call for standardised training and regulation of homecare assistants (Yamada, 2002b).

In addition, across participants of the current study who received DHB funded domestic help and those who self-funded a cleaner, concern was expressed regarding domestic help and domestic help not meeting client expectations. Having a clean house has been shown to improve QoL for homecare recipients. In Vik and Eide's (2014) study, a homecare recipient expressed concern about the lack of domestic help provided; to her QoL was not having to look at dusty surfaces.

## Quality of life and time use/recreation

Meaningful occupation is known to have a substantial impact on QoL, well-being, and the physical and mental health of older adults, and provides them with a sense of security and self-worth (Dorrestein, 2006; Kielhofner, 2004; Wenborn, 2005). Hooper and Wood (2006) perceived occupation as a biological need. In contrast, the present study supports literature which revealed the association between housebound status, depression, and functional decline (Inoue & Matsumoto, 2001). Those participants in the present study with poor mobility, in particular who spent protracted periods of time either in their bed or a chair, were low in mood. Across all participants, this study found that the majority punctuated their days with passive pass times (watching the TV, listening to the radio) and completing PADL. Reduced levels of meaningful activity among participants supports previous studies which demonstrated that participation in meaningful activity declines with age as opportunities for participation in activity are reduced (Andrew & Halcomb, 2006a; Barnes, Wilson, De Leon, & Bennett, 2006; Metzelthin et al., 2017; Vik & Eide, 2014). One previous study by Vik and Eide (2014) revealed that a person's motivation to participate in activity is driven by the choice of activities on offer and the amount of control the individual has over the activity (Vik & Eide, 2014). Reduced levels of meaningful activity or leisure activity among participants in the present study may have been due to the combination of poor health, poor mobility, and limited opportunities, combined with an absence of accessible transport.

In addition, few of the participants spent time going out of their homes. Rather, friends and family visited them in their homes. This reflects findings from UK and US studies which found that 80% of older people spend their time at home doing sedentary activity rather than going out (Davis et al., 2001; Mathews et al., 2008). A number of studies have extolled the health benefits of participation in leisure activity which has been shown to alleviate loneliness and depression (Dahan-Oliel, Gélinas, & Mazer, 2008; Stav, Hallenen, Lane, & Arbesman, 2012). As previously stated, recreation is a QoL indicator used in Flanagan's QoL measure (Burckhardt et al., 2003). Therefore, reduced participation in recreational activities leads to diminish QoL. Other authors contest that the benefits of sedentary activity, such as watching the television, need to be also acknowledged, as watching television can enable older adults to engage in everyday life and provide them with a sense of belonging (Vik & Eide, 2014). This supports previous studies which indicate that older adults use technology (TV, computer, telephone) to remain socially connected to the community (Mars et al., 2008). Only a quarter of participants however, in the present study used mobile phones, iPads or computers to remain socially connected to family and the community (Mars et al., 2008).

## **Study Strengths and Limitations**

The study had both strength and limitations. Literature revealed that most studies have been undertaken abroad; therefore, a strength of the study is that it is New Zealand specific. Of note, this was the first homecare package that most participants had received and most of the participants had no preconceived ideas about what to expect. Some, however, did have preconceived ideas as their friends had told them of their own negative experiences of homecare. Another strength of the study was the methodology used. Polit and Beck (2012) argued that combined methodology results in enhanced variability of data which results in increased validity of results. The broad focus of the

study facilitated participant issues of concern to surface; and the combination of qualitative and quantitative data collection allowed participants reports of receiving homecare services to be viewed in relation to daily routines shaped around basic PADL and IADL tasks, visits from the paid carers and health concerns. Findings from the study revealed the time use and participation in occupations of the 12 participants who received home care in New Zealand was limited.

A limitation to the study was the small number of participants and the fact that the study only included participants from a single DHB. Thus, findings may not reflect the experiences of homecare recipients from other DHBs. However, as previously discussed, data gathered from qualitative research has its own importance, and tells each individual's unique story. The reality of the findings is dependent on the accurate representation of the data (Lincoln & Guba, 19885). In this study, although the participant numbers were low, I was able to gather rich data of participants' experiences of homecare which are valid in their own right.

Furthermore, to address one of the major limitations of the study, future researchers will

need to consider strategies to assist with recruitment of Māori participants such as employing the services of a Māori research assistant. Another limitation to the study is that participant mood was not evaluated pre and post care package implementation. Mood level is commonly used as an indicator in QoL measures and could have been useful in determining participants improved QoL post care package implementation. The Yesterday Diary did not provide the detailed data anticipated. It was difficult to administer and provided insufficient data on whether there was an increase or decrease in client functionality/activity levels. Participants provided only general information about how they spent their time. Additionally, only nine Yesterday Diaries were

completed during the second interview phase, as two care recipients died prior to the

second interview and one participant was too ill to complete a second interview. Therefore, data from the diaries are incomplete. Acknowledging the difficulty of reporting the details of a routine day punctuated by care, meals, and passive activities other data gathering strategies are indicated. For example, future researchers might observe participant activity over a 24-hour period, (this would not have been possible within the scope of the current study) or assess participants utilising ADL assessments pre and post care package implementation to assess for increase or decrease in activity levels. Information provided in the diaries did however allow us to describe the constrained occupations of this group of older adults and infirm care recipients.

Another limitation to the study was that I was only able to recruit one Māori participant, which does not reflect the national demographic and, therefore, provides poor representation. This was unavoidable due to the scope of the study and absence of existing relationship with the Māori community or funding to promote the uptake of Māori participants.

## **Implications of the Research**

The study has a number of implications and highlighted areas for future study in relation to QoL, protection for homecare recipients, transport and accessing the community. It supported previous research by Vik and Eide (2012) which identified the importance of care recipients feeling a sense of control over their environment and their bodies and being in control when receiving assistance from homecare. The link drawn between QoL and having a sense of control reveals this to be an important finding. Enabling participants to feel in control of their homecare packages was particularly pertinent to planning and implementing homecare packages.

Exploration of the QoL of older homecare services was, however, hampered by the absence of specific standardised assessment tool to assess QoL among care recipients

who remain at home. Further study needs to be undertaken to devise an assessment tool to quantify QoL among homecare recipients as current tools which assess QoL in older adults e.g. WHOQOL-OLD are not specific to homecare recipients. In addition, researchers could follow on from previous studies and assess participant depression levels pre and post care package implementation to assist in assessing the QoL of participants.

The study also revealed an absence of protection for homecare recipients. Participants expressed concern about carers turning up to properties unprepared and unaware of their care needs. Lack of training and poor communication by the care agency could increase the risk of abuse of the system. One carer asked a participant to sign a time sheet without having completed any work. These unwelcome experiences have clear implications for QoL as well as maintenance of life skills, in that unfamiliar and unprepared carers are not in a position to learn from care recipients about how to best support them to participate in their own care. However, this study only explored participants' perception of homecare rather than whether carers were trained in a rehabilitative/restorative approach involving support and regular supervision (King, 2012). Further research could be undertaken to evaluate whether homecare agencies in general have adopted a rehabilitative approach as government guidelines suggest (Ministry of Health, 2015).

The study also revealed a poverty of meaningful activity in many of the participants' lives; participants reported spending most of their time indoors and not venturing into the community. While it was not a direct focus of the study, the participants raised the issue of accessible public transport. Although previous research has demonstrated that provision of accessible public transport fails to prevent some older adults from becoming housebound and experiencing increased isolation (Haustein & Siren, 2014),

all of the participants in this study complained about its absence. Further research is required to look at what can be done to enable older adults to remain socially connected; thus supporting QoL, maintenance of life skills, life roles, and longevity.

The identified purposes of providing homecare packages do not include providing social connections for older adults who remain at home. Nonetheless, the present study found that carers formed close relationships with care recipients and the regular visits by home carers seemed to provide essential social contact for care recipients. Although this enhanced participants' QoL, the potential risks or negative impact associated with role blurring warrants future study. In addition, some older adults experienced having multiple caregivers which risked continuity of care and impacted close relationships being formed.

The Yesterday Diary revealed a reduction in meaningful occupation or hobby type activity among participants. The majority of participants spent sedentary time watching the television. Although it is important not to underestimate the importance of watching television for participants, studies show that reduced occupation is linked to decreased mental health (Dorrestein, 2006; O'Sullivan, 2004; Wenborn, 2005); therefore, activity planning, frequency and variety of occupations need to be considered in future home care provision.

Beyond supporting the QoL and life skills of care recipients, the study also illustrated the importance of homecare to both the homecare recipients' and primary care givers. It revealed that without informal assistance it would be difficult for many of the participants to remain at home. Further study would be useful to explore how caregivers benefit from homecare provision and what can be done to optimise these benefits. Evaluating the importance of homecare to both carer and care recipient may assist in stemming the current trend by DHBs of reducing homecare services to older adults.

As noted, a limitation to the study was the Yesterday Diary which was difficult to administer and provided insufficient data on whether there was an increase or decrease in care recipient's functionality/ activity levels. Domestic assistance is linked to perceived QoL. Only two participants received assistance with domestic services. Both participants had specific expectations and anticipated a specific standard of cleaning (e.g., both participants believed that cleaning should include dusting). Future research could explore the importance of domestic assistance to homecare recipients as there is limited studies on this subject and how this service can best meet both client need and expectations. In addition, how Māori perceive homecare may also be a topic for future study.

## Conclusion

Remaining at home with the assistance of a homecare package enabled the majority of participants in this study to maintain their life skills with regard to PADL and IADL, albeit over the relatively short period of the study, and enhanced their QoL. The majority of participants perceived care as a reciprocal process, and participating in their care process enabled participants to maintain range of movement, life skills, and feel in control of the care provided within their homes.

Remaining at home also provided QoL for many of the participants, as remaining at home provided them with a sense of belonging, connected them to their memories, and enabled them to maintain life roles and remain socially connected to family, friends, and the community. Care recipients formed close relationships with their carers which also enhanced their QoL.

However, the study findings supported my personal beliefs with regard to homecare providing just the bare-essentials. If provision only meets basic needs, this raises

important questions regarding the QoL of participants if some services such as cleaning and shopping are not being provided. The study also revealed a poverty of meaningful activity in many of the participants' lives; participants reported spending most of their time indoors and not venturing into the community, suggesting that more needs to be done to address to the needs of older adults living in the community to enable them to remain socially connected, with all the benefits that implies for QoL, life skills, life roles, and longevity.

## References

- Abaogulu, H., Cesim, O. B., Kars, S., Celik, Z. (2017). Life skills in occupational therapy. In M. Huri (Ed.). *Occupational therapy: Occupation focused holistic practice in rehabilitation*. https://doi.org/10.5772/intechopen.68462
- Andrew, S., & Halcomb, E. J. (2006). Mixed methods research is an effective method of enquiry for community health research. *Contemporary Nurse*, *23*(2), 145-153. https://doi.org/10.5172/conu.2006.23.2.145
- Anonymous DHB. (2019). *Annual plan*. Retrieved from http://www.anonymous.govt.nz/Publications/AllPublications/Documents/anonymousDHB%20Annual%20Plan%202018-19.pdf
- Arslantas, H., Adana, F, Abacigil, E. F., Kayar, D., & Acar, G. (2015). Loneliness in elderly people, associated factors and its correlation with quality of life: A field study from Western Turkey. *Iranian Journal of Public Health*, *44*(1), 43-50. http://ijph.tums.ac.ir/index.php/ijph
- Baker, J. R., Harrison, F., & Low, L.F. (2016). Development of two measures of client engagement for use in home aged care. *Health & Social Care in the Community*, 24(3), 363-374. https://doi.org/10.1111/hsc.12213
- Ball, M. M., Perkins, M., & Kemp, C.(2004). Independence in assisted living. *Journal of Ageing Studies*, 18(4), 467-483. https://doi.org/10.1016/j.jaging.2004.06.002
- Ball, M. M., Whittington, F. J., Perkins, M. M., Patterson, V. L., Hollingsworth, C., King, S. V., & Combs, B. L. (2000). Quality of life in assisted living facilities: Viewpoints of residents. *Journal of Applied Gerontology*, 19(3), 304-325. https://doi.org/10.1177/073346480001900304
- Barken, R. (2019). Independence among older people receiving support at home: The meaning of daily care practices. *Ageing and Society, 39*, 518-540. https://doi.org/10/1017/5014468x17001039
- Barnes, C. (1991). Disabled people in Britain and discrimination. A case for antidiscrimination legislation. London, England: Hurst & Co.
- Barnes, L., Wilson, R., De Leon, C. F. M., & Bennett, D. (2006). The relation of lifetime cognitive activity and lifetime access to resources to late-life cognitive function in older African Americans. *Ageing, Neuropsychology, and Cognition,* 13(3-4), 516-528. https://doi.org/10.1080/138255890969519
- Beauchamp, T. L., & Childress, J. F. (2001). *Principles of biomedical ethics* (5<sup>th</sup> ed.)

  New York, NY: Oxford University Press.

- Beaulieu, J. (1991). The quality of home and community-based services. *Journal of Applied Gerontology, 10*(1), 88-102. https://doi.org/10.1177/073346489101000107
- Bell, R., Smith, C., Hale, L., Kira, G., & Tumilty, S. (2017). Understanding obesity in the context of an indigenous population: A qualitative study. *Obesity Research* & Clinical Practice, 11, 558-566. https://doi.org/10.1016/j.orcp.2017.04.006
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77-101. https://doi.org/10.1191/1478088706qp063oa
- Burckhardt, C. S., Anderson, K. L., Archenholtz, B., & Hägg, O. (2003). The Flanagan quality of life scale: Evidence of construct validity. *Health and Quality of Life Outcomes 1*(1), 59. https://doi.org/10.1186/1477-7525-1-59
- Burns, N., & Grove, S. K. (2005). *The practice of nursing research: Conduct, critique, and utilization* (5<sup>th</sup> ed.). St. Louis, MO: Elsevier/Saunders.
- Cameron, R. (2014). *Mixed methods research*. Retrieved October 23, 2019, from https://www.deakin.edu.au/\_\_data/assets/pdf\_file/0020/681023/Dr-r-cameron\_mixed-methodology.pdf
- Carpenter, C., & Suto, M. (2008). *Qualitative research for occupational and physical therapists: A practical guide*. Ames, Iowa: Blackwell Pub.
- Carter, T. (2006). *Ftiness to drive*. Oxford, England: Royal Society of Medicine Press Limited.
- Carstensen, L. L., Fung, H. H., & Charles, S. T. (2003). Socioemotional selectivity theory and the regulation of emotion in the second half of life. *Motivation and Emotion*, 27(2), 103-123. https://doi.org/10.1023/A:1024569803230
- Chakra, A., (2016). A life skills approach to adolescent development. *International Journal of Home Science*, 2(1) 234-238. Retrieved from http://www.homesciencejournal.com/archives/2016/vol2issue1/PartD/2-1-46-353.pdf
- Charmaz, K. (2002, winter). The self as habit: The reconstrucion of self in chronic illness. *The Occupational Therapy Journal of Research*, *22*, 315-415. https://doi.org/10.1177%2F15394492020220S105

- Cipriani, J., Kreider, M., Sapulak, K., Jacobson, M., Skrypski, M., & Sprau, K. (2009). Understanding object attachment and meaning for nursing home residents: An exploratory study, including implications for occupational therapy. *Physical & Occupational Therapy in Geriatrics*, 27(6), 405-422. https://doi.org/10.3109/02703180903183164
- Cohen, L., & Manion, L. (1994). *Research methods in education*. https://books.google.co.nz/books?id=geTBQgAACAAJ
- Collins, K. M., & O'Cathain, A. (2009). Introduction: Ten points about mixed methods research to be considered by the novice researcher. *International Journal of Multiple Research Approaches*, 3(1), 2-7. https://doi.org/10.5172/mra.455.3.1.2
- Collins Dictionary.(2020). *Wisdom*. Retrieved June 7, 2020, from https://www.collinsdictionary.com/dictionary/english/wisdom
- Collins Dictionary. (2020). *Marae*. From https://collinsdictionary.com/dictionary/english/marae
- Collins Dictionary. (2020). *Pākehā*. From https://www.collinsdictionary.com/dictionary/english/pakeha
- Collins Dictionary. (2020.) *Relativism*. Retrieved from https://www.collinsdictionary.com/dictionary/english/relativism
- Collins Dictionary. (2020). *Tikanga* Retrieved from https://www.collinsdictionary.com/dictionary/english/tikanga
- Collins Dictionary.(2020). *Wisdom*. Retrieved June 7, 2020, from https://www.collinsdictionary.com/dictionary/english/wisdom
- Elderly Accomodation Council. (2019). *HousingCare.org: Information for older people*. Retrieved November 16, 2019, from https://housingcare.org/jargon-care-plan-c9d36.aspx
- Controller and Auditor General. (2011). *Home bases services for older people*. https://oag.govt.nz/2011/home-based-support/docs/home-based-support.pdf/view
- Creswell, J. W. (1998). *Qualitative inquiry and research design: Choosing among five traditions*. Thousand Oaks, CA: Sage Publications.
- Creswell, J., Fetters, M., & Ivankova, N. (2004). Designing a mixed methods study in primary care. *Annals of Family Medicine*, 2(1), 7-12. https://doi.org/10.1370/afm.104

- Creswell, J. W., & Plano Clark, V. L. (2007). *Designing and conducting mixed methods research*. Thousand Oaks, CA: Sage Publications.
- Creswell, J. W. (2014). *Research design: Qualitative, quantitative and mixed methods approaches* (4<sup>th</sup> ed.). Thousand Oaks, CA: Sage Publications.
- Dahan-Oliel, N., Gélinas, I., & Mazer, B. (2008). Social participation in the elderly:

  What does the literature tell us? *Critical Reviews in Physical & Rehabilitation Medicine*, 20(2), 159-176.

  https://doi.org/10.1615/CritRevPhysRehabilMed.v20.i2.40
- Davis, M. G., Fox, K. R., & Hillsdon M. (2001). Objectively measured physical activity in a diverse sample of older urban UK adults. *Medical Science Sports Exercise*, 43(4) 647-654. https://doi.org/10.1249/MSS.0b013e3181f36196
- Denzin, N. K., & Lincoln, Y. S. (2000). *Handbook of qualitative research*. Thousand Oaks, CA: Sage Publications.
- Denzin, N. K., & Lincoln, Y. S. (2005). *The Sage handbook of qualitative research* (3<sup>rd</sup> ed.). Thousand Oaks, CA: Sage Publications.
- Dorrestein, M. (2006). Leisure activity assessment in residential care: Improving occupational outcomes for residents. *New Zealand Journal of Occupational Therapy*, 53(2), 20-26. https://www.otnz.co.nz/publications/new-zealand-journal-of-occupational-therapy
- Duner, A., Bjalkerbring, P., & Johansson, B. (2019). Merely a rhetorical promise? Older users' opportunities for choice and control in Swedish individualised homecare services. *Ageing and Society*, 39, 771-794. https://doi.org/10.1017/so14468X17001210
- Duppen R. D., Machielse, A., Verté R. D., Dury, S., De Donder, L., & Consortium, D.
  S. (2019). Meaning in life for socially frail older adults. *Journal of Community Health Nursing*, 36(2), 65-77. https://doi.org/10.1080/07370016.2019.1582160
- Fontana, A., & Frey, J. H. (2000). The interview: From structured questions to negotiated text. In N. K. Denzin, & Y. S. Lincoln, (Eds.), *Handbook of qualitative research* (2<sup>nd</sup> ed., pp. 645-672). Thorofare, CA: Sage.
- Florida State University(n.d). What is philosophy?Retrieved June 7, 2020, from https://philosophy.fsu.edu/undergraduate-study/why-philosophy/What-is-Philosophy
- HealtheUniversity. (n.d). *Cardiac college. Stress and sense of control.* Retrieved December 12, 2019, from

- https://www.healtheuniversity.ca/EN/CardiacCollege/Wellbeing/Stress\_And\_S ense\_Of\_Control/Pages/sense-of-control.aspx
- Foti, D., & Koketsu, J. (2013). Activities of daily living. In L.W. Pedretti, H. M. Pendleton, & W. Schultz-Krohn (Eds.), *Pedretti's occupational therapy* (7<sup>th</sup> ed., pp. 157-232). St Louis, MO: Elsevier.
- Gabard, D. L., & Martin, M. W. (2003). *Physical therapy ethics*. Philadelphia, PA: F. A. Davis.
- Gabriel, D. (n.d.). *Inductive and deductive approaches to research*. Retrieved July 30, 2019, from http://deborahgabriel.com/2013/03/17/inductive-and-deductive-approaches-to-research/
- Gershuny, J. (2004). Time measurement. In M. S., Lewi-Beck, B., Bryman, & T. Liao Futing (Eds.), *The Sage encyclopedia of social science research methods* (vol. 3, pp. 1127-1128). London, England: Sage. https://doi.org/10/4135/9781412950589
- Given, L. M. (2008). *The Sage encyclopedia of qualitative research methods*. https://doi.org/10.4135/9781412963909.n31
- Glass, T. (1999). Population based study of social and productive activities as predictors of survival among elderly Americans. *British Medical Journal*, *319*, 478-483. https://doi.org.10.1136/bmj.319.7208.478
- Golden, C. J., & Chronopoulos, A. (1998). Dementia. In M. Hersen, & V. B. Van Hasselt (Eds.), *Handbook of clinical geropsychology* (pp. 113-146). New York, NY: Plenum.
- Grant, B., & Giddings, L. S. (2002). Making sense of methodologies: A paradigm framework for the novice researcher. *Contemporary Nurse*, *13*(1), 10-28. https://doi.org/10.5172/conu.13.1.10
- Gunnarsson, E. (2009). The welfare state, the individual and the need for care: Older people's views. *International Journal of Social Welfare*, 18(3), 252-259. https://doi.org/10.1111/j.1468-2397.2008.00610.x
- Harwood, R. H., Sayer, A. A., & Hirschfeld, M. (2004). Current and future worldwide prevalence of dependency, its relationship to total population, and dependency ratios. *Bulletin of the World Health Organization*, 82(4), 251-258. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2585969/pdf/15259253.pdf
- Hasselkus, B. R. (2011). *The meaning of everyday occupation* (2<sup>nd</sup> ed.). Thorofare, NJ: Slack.

- Hasson, H., & Arnetz, J. (2011). Care recipients' and family members' perceptions of quality of older people care: A comparison of home-based care and nursing homes. *Journal of Clinical Nursing*, 20(9-10), 1423-1435. https://doi.org/10.1111/j.1365-2702.2010.03469.x
- Haustein, S., & Siren, A. (2014). Senior's unmet mobility needs How important is a driving licence? *Journal of Transport Geography*, 41, 45-52. https://doi.org/10.1016/j.jtrangeo.2014.08.001
- Hennessy, C. H., & Hennessy, M. (1990). Community-based long-term care for the elderly: Evaluation practice reconsidered. *Medical Care Review*, 47(2), 221-259. https://doi.org/10.1177/107755879004700205
- Hesse-Biber, S. N., & Leavy, P. (2011). *The practice of qualitative research* (2<sup>nd</sup> ed.). *Technical Communication* 58 (3), 252-253.
- Hocking, C., & O'Sullivan, G. (2005). *Dying for something to do*. Paper presented at the meeting of the Many Faces of Abuse, Auckland, New Zealand.
- Holt-Lunstad, J., Smith, T. B., & Layton, J. B. (2010). Social relationships and mortality risk: A meta-analytic review. *Plos Medicine*, 7(7), 1-23. https://doi.org/10.1371/journal.pmed.1000316
- Hooper, B., & Wood, W. (2002). Pragmatism and structuralism in occupational therapy. The long conversation. *American Journal of Occupational Therapy*, 2002(56), 40-50. https://doi.org/ 10.5014/ajot.56.1.40
- Hooper, B., & Wood, W. (2013). The philosophy of occupational therapy: A framework for practice. In Boyt Schell, B. A., Gillen, G., & Scaffa, M. E. (Eds.) *Willard & Spackman's occupational therapy* (12<sup>th</sup> ed., pp. 35-46). Philadelphia, PA: Lippincott Williams & Wilkins.
- Hsieh, H., & Shannon, S. (2005). Three approaches to qualitative content analysis.

  \*Qualitative Health Research, 15, 1277-1288.

  https://doi.org/10.1177/1049732305276687
- Hudson, M. (2010). Te ara tika: Guidelines for Māori research ethics: A framework for researchers and ethics committee members. Wellington: New Zealand. Health Research Council of New Zealand on behalf of the Pūtaiora Writing Group.
- Hussein, S., & Manthorpe, J. (2005). An international review of the long-term care workforce: Policies and shortages. *Journal of Aging & Social Policy*, 17(4), 75-94. https://doi.org/10.1300/J031v17n04\_05

- Ilinca, S., Rodrigues, R., & Leichsenring, K. (2015). From care in homes to care at home: European experiences with (de)institutionalisation in long-term care.

  Retrieved from https://www.euro.centre.org
- Index Mundi. (2018). *New Zealand demographics profile*. Retrieved February 26, 2018, from www.indexmundi.com /New Zealand/demographic profilehtml
- Inoue, K., & Matsumoto, M. (2001). Homebound status in a community-dwelling elderly population in Japan. *Asia-Pacific Journal of Public Health /Asia-Pacific Academic Consortium for Public Health, 13*(2), 109-115. https://doi.org/10.1177/101053950101300209
- Iwarsson, S., Wahl, H. W., Nygren, C., Oswald, F., Sixsmith, A., Sixsmith, J., & Tomsone, S. (2007). Importance of the home environment for healthy aging: Conceptual and methodological background of the European ENABLE–AGE Project. *The Gerontologist*, 47(1), 78-84. https://doi.org/10.1093/geront/47.1.78
- James, B., Wilson, R., Barnes, L., & Bennett, D. (2011). Late-life social activity and cognitive decline in old age. *Journal of the International Neuropsychological Society*, 17(6), 998-1005. https://doi.org/10.1017/S1355617711000531
- Johnson, R. B., Onwuegbuzie, A. J., & Turner, L. A. (2007). Toward a definition of mixed methods research. *Journal of Mixed Methods Research*, *I*(2), 112-133. https://doi.org/10.1177/1558689806298224
- Katz, S., Ford, A. B., Moskowitz, R. W., Jackson, B. A., & Jaffe, M. W. (1963). Studies of illness in the aged. The index of ADL: A standardised measure of biological and psychological function. *Journal of the American Medical Association*, 185, 914-919. https://doi.org/10.1001/jama.1963.0
- Kerse, N., Lapsley, H., Moles, R., Moyes, S., & Edlin, R. (2016). *Health: Indepedence and care giving in advanced age.* https://www.academia.edu/30773354/Health-Independence-and-Caregiving-in-Advanced-Age.pdf
- Kielhofner, G., & Burke, J. (1983). *Theory and practice in occupational therapy*. Philadephia, PA: F. A. Davis.
- Kielhofner, G. (2004). *Conceptual foundations of occupational therapy* (4<sup>th</sup> ed). Philadelphia, PA: F.A. Davis.
- King, A. I. I., Parsons, M., & Robinson, E. (2012). A restorative homecare intervention in New Zealand: Perceptions of paid caregivers. *Health & Social Care in the Community*, 20(1), 70-79. https://doi.org/10.1111/j.1365-2524.2011.01020.x

- Lewin, G., Allan, J., Patterson, C., Knuiman, M., Boldy, D., & Hendrie, D. (2014). A comparison of the home-care and healthcare service use and costs of older Australian randomised to receive a restorative or a conventional home-care service. *Health and Social Care in the Community*, 22(3), 328-336. https://doi.org/10.1111/hsc.12092
- Latham, C. A. T., & Radomski, M. V. (2002). *Occupational therapy for physical dysfunction*. Philadelphia, PA: Lippincott Williams & Wilkins.
- Lincoln, Y. S., & Guba, E. G. (1985). Naturalistic inquiry. Newbury Park, CA: Sage.
- Magilvy, J. K., & Thomas, E. (2009). A first qualitative project: Qualitative descriptive design for novice researchers. *Journal for Specialists in Pediatric Nursing*, 14(4), 298-300. https://doi.org/10.1111/j.1744-6155.2009.00212.x
- Marjoribanks, S. D. (1982). Care of the elderly at home: Serving the family in the community. *Canadian Journal of Occupational Therapy*, 49(5), 163-167. https://doi.org/10.1177%2F000841748204900505
- Mark, R. (1996). Research made simple for social workers. London, England: Sage.
- Mars, G. M., Kempen, G. I., Mesters, I., Proot, I. M., & Van Eijk, J. T. (2008). Characteristics of social participation as defined by older adults with chronic physical illness. *Disability and Rehabilitation*, 30(17), 1298-1308. https://doi.org/10.1080/09638280701623554
- Mathews, C. E., Chen K. Y., & Freedson, P. S. (2008). Amount of time spent in sedentary behaviours in the United States. *American Journal of Epidemiology*, 167(7), 875-881. https://doi-org.10.1093/aje/kwm390
- McBride, N. (March, 2017). DHB accused of cover-up after failing to reveal cuts to elderly homecare. *Stuff*. Retrieved November 15, 2019, from https://www.stuff.co.nz/national/health/89829959/dhb-accused-of-coverup-after-failing-to-reveal-cuts-to-elderly-homecare
- Mendes de Leon, C. F., Glass, T. A., & Berkman, L. F. (2003). Social engagement and disability in a community population of older adults: The New Haven EPESE. *American Journal of Epidemiology, 157*(7), 633-642. https://doi.org/10.1093/aje/kwg028
- Metzelthin, S. F., Zijlstra, G. A. R., Van Rossum, E., Kempen, G. I. J. M., De Man-Van Ginkel, J. M., Resnick, B., & Parsons, M. (2017). 'Doing with ... ' rather than 'doing for ... ' older adults: Rationale and content of the 'Stay active at home'

- programme. *Clinical Rehabilitation*, *31*(11), 1419-1430. https://doi.org/10.1177/0269215517698733
- Miller, E.K., (2012). Occupational therapists' intervention approaches in secondary transition services for students with disabilities. Unpublished Doctoral dissertation. Eastern Kentucky University, Kentucky. Retrieved from https://pdfs.semanticscholar.org/5465/5c3f643f26659d552eac2af90dac98c7511b.pdf
- Ministry for Culture and Heritage. (2017). *The treaty in brief*. Retrieved March 19, 2018, from https://nzhistory.govt.nz/politics/treaty/treaty-faqs
- Ministry of Health. (2003). *Home support services personal care and home help*.

  Retrieved August 8, 2017, from https://nsfl.health.govt.nz/service-specifications/current-service-specifications/community-health-transitional-and-support
- Ministry of Health. (2012). *Māori disability support services*. Retrieved August 8, 2019, from https://nsfl.health.govt.nz/service-specifications/current-service-specifications/m%C4%81ori-health-service-specifications
- Ministry of Health.(2013). What you can expect from home support services. Retrieved November 21, 2019, from https://www.health.govt.nz/system/files/documents/topic\_sheets/what-to-expect-from-home-support-services.pdf
- Ministry of Health. (2015). Community residential support services for people with chronic health conditions. Retrieved August 8, 2017, from http://NSFL.health.govt.nz/service-specifications/current-service-specifications/community-health-transitional-and-support
- Ministry of Health. (2017a). Auditing requirements: Home and community support sector standard. NZS 8158:2012. Retrieved March 19, 2018, from www.health.govt/publications/auditing-requirements-home-and-community-support-sector
- Ministry of Health. (2017b). *Care and support workers pay equity settlement*. Retrieved April 11, 2018, from https://health.govt.nz/new-zealand-health-system/care-and-support-workers-pay-equity-settlement
- Ministry of Health. (2017c). *DHB spending on services for older people*. Retrieved August 15, 2017, from http://www.health.govt.nz/nz-health-statistics-and-data-sets/older-peoples-health-data-and-stats/dhb-spending-services-older-people

- Ministry of Health. (2017d). *He korowai oranga*. Retrieved February 9, 2018, from https://www.health.govt.nz/our-work/populations/māori-health/he-korowai-oranga
- Ministry of Health. (2017e). *Needs assessment and service coordination services*.

  Retrieved August 8, 2017, from http://health.govt.nz/you-heatlh/services-and-support/disability-services/getting-support-disability/needs-assessment
- Ministry of Health. (2018). *Care and support workers pay equity settlement*. Retrieved Sepember 25, 2019, from https://www.health.govt.nz/new-zealand-health-system/pay-equity-settlements
- Ministry of Health. (2019) *Age related residential services agreement*. Retrieved from https://www.health.govt.nz/our-work/life-stages/health-older-people/long-term-residential-care/age-related-residential-care-services-agreement
- Ministry of Social Development. (2001). New Zealand positive ageing strategy.

  Retrieved April 14, 2017, http://msd.govt.nz/about-msd-and-ourwork/publications-resources/planning-strategy/positive-ageing/goals-and-actions-html
- Ministry of Social Development. (2013). *Older New Zealanders healthy, independent,* connected and respected. Retrieved May 17, 2017, https://msd.govt.nz/documents/what-can-we-do/seniorcitizens/positive-ageing/older-new-zealanders
- Miranda-Castillo, C., Woods, B., & Orrell, M. (2013). The needs of people with dementia living at home from user, caregiver and professional perspectives: A cross-sectional survey. *BMC Health Services Research*, *13*(1), 43. https://doi.org/10.1186/1472-6963-13-43
- Moorfield, J. (2003). *Te Aka Māori on line dictionary*. Retrieved April 8, 2019, from https://māoridictionary.co.nz
- Murphy, J., Hocking, C., & Reed, K. (2008). *Strategies older New Zealanders use to participate in day-to-day occupations*. http://hdl.handle.net/10292/684
- Neergaard, M. A., Olesen, F., Andersen, R. S., & Sondergaard, J. (2009). Qualitative description the poor cousin of health research? *BMC Medical Research Methodology*, 9, 52-52. https://doi.org/10.1186/1471-2288-9-52
- New Zealand Labour Party, Green Party & Grey Power. (2017). *Inquiry into aged care*.

  Retrieved from https://www.greens.org.nz/sites/default/files/policy-pdfs/Aged%20Care%20Report%20Sep17.pdf

- Nijsten, J. M. H., Leontjevas, R., Pat-El, R., Smalbrugge, M., Koopmans, R. T. C. M., & Gerritsen, D. L. (2017). Apathy: Risk factor for mortality in nursing home patients. *Journal of the American Geriatrics Society*, 65(10), 2182-2189. https://doi.org/10.1111/jgs.15007
- Nikmat, A. W., Al-Mashoor, S. H., & Hawthorne, G. (2013). The comparison of quality of life among people with mild dementia in nursing home and homecare- a preliminary report. *Dementia*, *14*(1), 114-125. https://doi.org/10.1177/14713001213494509
- O'Sullivan, G. (2004). Leisure activity programming: Promoting life satisfaction and quality of life for residents in long-term care. *New Zealand Journal of Occupational Therapy*, 51(2), 33-38. https://www.otnz.co.nz/publications/new-zealand-journal-of-occupational-therapy
- Oswald, F., Wahl, H. W., Schilling, O., Nygren, C., Fänge, A., Sixsmith, A., & Iwarsson, S. (2007). Relationships between housing and healthy ageing in very old age. *Gerontologist*, 47(1), 96-107. https://doi.org/10.1093/geront/47.1.96
- Oswald, W. D., & Fleischmann, U. M. (1985). Psychometrics in ageing and dementia: Advances in geropsychological assessments. *Archives Of Gerontology And Geriatrics*, 4(4), 299-309. https://doi.org/10.1016/0167-4943(85)90037-8
- Oxford living dictionary. (n.d). *Control*. Retrieved from https://en.oxforddictionaries.com/definition/control
- Patton, M. Q. (2002). *Qualitative research and evaluation methods* (3<sup>rd</sup> ed.). Thousand Oaks, CA: Sage.
- Parsons, M., Senior, H., Mei-Hu Chen, X., Jacobs, S., Parsons, J., Sheridan, N., & Kenealy, T. (2013). Assessment without action: A randomised evaluation of the interRAI homecare compared to a national assessment tool on identification of needs and service provision for older people in New Zealand. *Health & Social Care in the Community*, 21(5), 536-544. https://doi.org/10.1111/hsc.12045
- Pearlin, L., & Schooler, C. (1978). The structure of coping. *Journal of Health and Social Behavior*, 19(1), 2-21. https://doi.org/10.2307/2136319
- Pilkington, G., (2011, August 3). *Home and community health Association. UK expert says help people relearn skills for everyday life.* Retrieved from http://www.hcha.org.nz/page-15/uk-expert-says-help-people-re-learn-skills-for-everyday-life

- Polit, D. F., & Beck, C. T. (2012). *Nursing research: Generating and assessing evidence for nursing practice* (9<sup>th</sup> ed.). Philadelphia, PA: Lippincott, Williams & Wilkins.
- Pool, J. (1993). The care approach to enabling independence. *British Journal of Occupational Therapy*, 56(4), 120-122. https://doi.org/10.1177/030802269305600404
- Radloff, L. S. (1977). The CES-D Scale: A self-report depression scale for research in the general population. *Applied Psychological Measurement*, 1(3), 385-401. https://doi.org/10.1177/014662167700100306
- Reindal, S. M. (1999). Independence, dependence, interdependence: Some reflections on the subject and personal autonomy. *Disability and Society*, *4*(56), 120-122. https://doi.org/10.1177/030802269305600404
- Resnick, B. (2012). Restorative care nursing for older adults: A guide for all care settings (2<sup>nd</sup> ed.). New York, NY: Springer.
- Robinson, S., & Griffiths, P. (2010). Support worker regulation: The NNRU report explained. *British Journal of Healthcare Assistants*, *4*(11), 548-550. https://www.magonlinelibrary.com/journal/bjha
- Rogers, J. C. (1982). The spirit of independence. The evolution of a philosophy. *American Journal of Occupational Therapy*, *36*, 709-715. https://doi.org/10.5014/ajot.36.11.709
- Russell, D., Cutrona, C., De la Mora, A., & Wallace, R. (1997). Loneliness and nursing home admission among rural older adults. *Psychology and Aging, 12*(4), 574-589. https://ovidsp.dc2.ovid.com.
- Rutberg, S., & Bouikidis, C. D. (2018). Focusing on the fundamentals: A simplistic differentiation between qualitative and quantitative research. *Nephrology Nursing Journal*, 45(2), 209-213.
  - https://www.annanurse.org/resources/products/nephrology-nursing-journal
- Ryff, C. D. (1989). Beyond ponce de leon and life satisfaction: New directions in quest of successful ageing. *International Journal of Behavioural Development, 12*, 35-55. https://doi.org//10.1177/016502548901200102
- Salkind, N. J. (Ed.). (2010). *Encyclopedia of research design*. Thousand Oaks, CA: Sage. http://doi.org./10.4135/9781412961288
- Sandelowski, M. (2010). What's in a name? Qualitative description revisited. *Research* in *Nursing & Health*, 33(1), 77-84. https://doi.org/10.1002/nur.20362

- Schlaff, R. A., Baruth, M., Boggs, A., & Hutto, B. (2017). Patterns of sedentary behavior in older adults. *American Journal of Health Behavior*, 41(4), 411-418. https://doi.org/10.5993/AJHB.41.4.5
- Skivington, K., Lifshen, M., & Mustard, C. (2016). Implementing a collaborative return-to-work program: Lessons from a qualitative study in a large Canadian healthcare organization. *Work*, *55*(3), 613-624. https://doi.org/10.3233/WOR-162437
- Socol, C. (2006). Protecting consumers from the pitfalls of homecare. *Home Health Care Management & Practice*, 18(2), 98. https://doi.org/10.117/1084822305281028
- Stanley, M., & Nayar, S. (2014). Methodological rigour: Ensuring quality in occupational therapy qualitative research. *New Zealand Journal of Occupational Therapy*, 61(1), 6-12. https://www.otnz.co.nz/publications/new-zealand-journal-of-occupational-therapy
- Stats NZ Tatauranga Aotearoa. (2012). *National population projections: 2011(base)*2061- Media release. Retrieved March 20, 2017, from http://stats.govt.nz/tools-and-services/media-centre/media-releases-2017/more-support-needed-for-disabled-peope-aspx
- Stats NZ Tatauranga Aotearoa. (2013). *More support needed for disabled people*.

  Retrieved August 15, 2017, from

  http://www.stats.govt.nz/tools\_and\_services?meida-centre/media-releases2017/more-support-needed-for-disable-people.aspx
- Stats NZ Tatauranga Aotearoa. (2017). *Labour force will grow and age*. Retrieved November 21, 2019, from https://www.stats.govt.nz/news/labour-force-will-grow-and-age
- Stav, W. B., Hallenen, T., Lane, J., & Arbesman, M. (2012). Systematic review of occupational engagement and health outcomes among community-dwelling older adults. *American Journal of Occupational Therapy*, 66(3), 301-310. https://doi.org/10.5014/ajot.2012.003707
- Strickland, B. (2016). *Homecare medical, well-being strategy for priority populations*. Retrieved February 8, 2018, from http://www.homecaremedical.co.nz
- Tabbarah, M., Crimmins, E. M., & Seeman, T. E. (2002). The relationship between cognitive and physical performance: MacArthur studies of successful aging.

- Journals of Gerontology Series A: Biological Sciences and Medical Sciences, 57(4), M228-M235. https://doi.org/10.1093/gerona/57.4.M228
- Thornley, C. (2000). A question of competence? Re-evaluating the roles of the nursing auxiliary and health care assistant in the NHS. *Journal of Clinical Nursing*, 9(3), 451-458. https://doi.org/10.1046/j.1365-2702.2000.00398.x
- Vanleerberghe, P., Witte, N., Claes, C., Schalock, R., Verté, D., De Witte, N., & Schalock, R. L. (2017). The quality of life of older people aging in place: A literature review. *Quality of Life Research*, 26(11), 2899-2907. https://doi.org/10.1007/s11136-017-1651-0
- Vernon, A., & Qureshi, H. (2000). Community care and independence: Self-sufficiency or empowerment. *Critical Social Policy*, 20(2) 255-276. https://doi.org/10.1177/026101830002000204
- Vik, K., & Eide, A. H. (2013). Older adults who receive home-based services, on the verge of passivity: The perspective of service providers. *International Journal of Older People Nursing*, 8(2), 123-130. https://doi.org/10.1111/j.1748-3743.2011.00305.x
- Vik, K., & Eide, A. H. (2014). Evaluation of participation in occupations of older adults receiving home-based services. *The British Journal of Occupational Therapy*, 77(3), 139-146. https://doi.org/10.4276/030802214X1394103626654
- Vogt, W. P., Vogt, E. R., Gardner, D. C., & Haeffele, L. M. (2014). Selecting the right analysis for your data. Quantitative, qualitative and mixed methods. New York, NY: Guildford Press.
- Wenborn, J. (2005). Making occupation matter for older people in care homes. *British Journal of Occupational Therapy*, 68(8), 337-337. https://doi.org/10.1177/030802260506800801
- Whitehead, P. J., Worthington, E. J., Parry, R., Walker, M. F., & Drummond, A. E. R. (2015). Interventions to reduce dependency in personal activities of daily living in community dwelling adults who use homecare services: A systematic review. *Clinical Rehabilitation*, 29(11), 1064-1076. https://doi.org/10.1177/0269215514564894
- Whitmore, H. (2001). Value that marketing cannot manufacture: Cherished possessions as links to identity and wisdom. *Generations*, 25(3), 57-63. https://www.asaging.org

- Wilcock, A. A. (1999). The Doris Sym memorial lecture: Developing a philosophy of occupation for health. *British Journal of Occupational Therapy*, *62*, 192-198. https://doi.org/10.1177/030802269906200503
- Wood, W. (1993). Occupation and the relevenace of primatology to occupational therapy. *American Journal of Occupational Therapy*, 47, 515-522. https://doi.org/10.5014/ajot.47.6.515
- World Health Organization. (1999). Partners in life skills education: Conclusions from a United Nations inter-agency meeting. Geneva, Switzerland: Department of Mental Health, World Health Organization. Retrieved from https://www.who.int/mental\_health/media/en/30.pdf
- World Health Organization. (2002a). *Active ageing a policy framework*. Retrieved March 23, 2018, from <a href="http://www.who.int/ageing/publications/active ageing/en/">http://www.who.int/ageing/publications/active ageing/en/</a>
- World Health Organization. (2002b). *Ageing and life course*. Retrieved February 8, 2018, from http://jpw.int/ageing/active\_ageing/en
- World Health Organization. (2006). WHOQOL-OLD manual. Retrieved from https://www.who.int/mental\_health/evidence/WHOQOL\_OLD\_Manual.pdf?ua =1
- World Health Organization. (2018). *Measuring quality of life*. Retrieved March 31, 2018, from http://www.who.int/healthinfo/survey/whoqol-qualityoflife/en/
- World Health Organization. (2019). *Constitution*. Retrieved October 10, 2019, from https://www.who.int/about/who-we-are/constitution
- Xavier, F. M., Ferraz, M. P. T., Marc, N., Escosteguy, N., & Moriguchi, E. H. (2003).
  Elderly people's definition of quality of life. *Brazilian Journal of Psychiatry*,
  25(1), 31-39. https://doi.org/10.1590/S1516-44462003000100007
- Yamada, Y. (2002). Profile of homecare aides, nursing home aides, and hospital aides: Historical changes and data recommendations. *The Gerontologist*, 42(2), 199-206. https://doi.org/10.1093/geront/42.2.199
- Yerxa, E. J. (1998). Health and the human spirit for occupation. *American Journal of Occupational Therapy*, 52, 412-418. https://doi.org/10.5014/ajot.52.6.412
- Yesavage, J. A., Brink, T. L., Rose, T. L., Lum, O., Huang, V., & Adey, M. & Leirer, V. O. (1983). Development and validation of a geriatric depression screening scale: A preliminary report. *Journal of Psychiatric Research*, *17*, 37-49. https://doi-org./10.1016/0022-3956(82)90033-4

# Appendices

# **Appendix A: Ten Positive Ageing Goals**

Goal	Aims
1. Income	Secure adequate income for older adults to enable them to have an adequate standard of living.
2. Health	Provide accessible and affordable health services for older adults (of equal quality) regardless of where the individual lives.
	Provide health care that caters holistically for the needs of the older adult. Provide health promotion to keep older adults well.
	Develop integrated primary and secondary health services for older adults and provide funding for residential and community support services to enable older people to remain living in the community.
3. Housing	Provide affordable and appropriate housing options for older people
4. Transport	Provide affordable and accessible transport options for older adults. Driver licencing based on Medical Fitness to Drive, and the driver's ability rather than the person's age. Provide transport options to access health services.
5. Ageing in place	Help older people feel safe living in the community. Provide services that support older adults to stay at home. Provide safety awareness programs for older adults such as falls prevention programs.

6. Cultural Diversity	Services designed to meet the needs of all members of the community. Increase the number of services provided for and by Māori, as well as Pacific peoples. Liaise with older adults from different ethnic backgrounds to develop services which meet the cultural needs of the community.
7. Rural	Ensure that older adults living in rural areas have the same access to services as those living in urban areas. Develop options to address the transport needs of older adults, living in rural areas, needing to access services and the community in general.
8. Attitudes	Promote a positive attitude towards ageing and older adults, by ensuring that advertising campaigns present older adults in a positive light.
	Promote involvement of older adults in schools and communities, as well as fostering collaboration in the community, business, central and local government.
9. Employment	Prevent ageism in the work place. Encourage older adults to remain in employment, and provide flexible working arrangements for those caring for older adults. Recognize the skills that older adults possess, and promote public awareness of these skills, and how these can be utilized.
10. Opportunities	Provide increased opportunity for older adults to actively engage in the community, e.g. adult education and retraining courses, as well as the participation of older adults in voluntary organizations

(Ministry of Social Development, 2001).

# Appendix B: Older New Zealanders Healthy, Independent, Connected and Respected

Goal	Actions Taken
Healthy	Non- means tested high use health card. High use users pay lower prescription charges and reduced GP fares. Greater pharmaceutical choices and funded hearing aids.
	Nutrition and physical activity guidelines provided to support health professionals and care givers when offering advice to older adults on healthy eating and exercise. Workshops on oral hygiene, to assist caregivers to help frail older adults to maintain good oral hygiene.
	Falls awareness programs, to reduce the number of falls among older adults, and reduce falls related hospital admissions. Vitamin D supplements given to older adults living in residential care, to help them to maintain good bone health and reduce the severity of fractures from falls.
	Screening programs for cardiovascular disease and diabetes, for over 65's. Reduced waiting time for cancer treatment programs, and increase in non- urgent, elective surgeries. Increased funding of dementia care services and provision of community based Geriatric services.
Independent	New Zealand Superannuation scheme. Financial support increased for war veterans, special needs grants provided for older adults experiencing financial hardship. Extended flexible working arrangements to enabler older workers to remain at work.
	Home care packages to assist older adults to live independently at home. Increased support to family carers, respite options for older adults, standard respite care, short-term residential care. Community rehabilitation provided to assist the transition from hospital back into the community to prevent hospital readmission.
	Access to affordable housing options. Increased social housing. Tenancy services, home ownership support, and rates rebates for those on low income. Universal housing design that provides accessibility around the home for older adults. Number of front line police increased to reduce the crime rate and enable older adults to feel safer in their own homes.

## Connected Flexible transport options. Accessible parking options, adapted road signage to enable older adults to read the signs, accessible buses and trains with priority seating, transport cards provided for free off peak travel for older adults, Total Mobility Scheme, for subsidised taxis and vehicle modification. Support for families and carers, and carer's strategy plan. Going digital programme started in 2010 provided access to digital television for older adults 75 years and older in receipt of a community services card, to enable them to keep connected with the community and current affairs. Planning for inclusive towns and cities. Age friendly cities. Many local councils set up their own advisory groups, made up of older adults, who play an essential role in developing the Positive Ageing strategy and policy implementation. Respected Financial literacy support for older adults. Age concern and other government agencies work to prevent abuse and neglect of older

adults. Government literature provided in a variety of languages to

(Ministry of Social Development, 2013)

ensure cultural safety.

# Appendix C: Mātauranga Māori Consultation

## School of Clinical Sciences Verification of Māori Consultation Processes

This document provides verification that the research project named below was discussed with the School of Clinical Sciences Mātauranga Māori Committee, AUT University. Specific comments and recommendations are indicated below.



Research Title:  Does remaining at home with the assistance of a homecare package promote maintenance of life skills and independence? (Masters research)				
Researcher(s): Julie Roberts	Date: 6/7/2017			
Discussion Areas	Addressed	Comments/ Recommendations		
Whakapapa: Relationships				
Researcher experience in field	×	C1		
Consultation with local stakeholders	×	R1, R3, R11		
Consenting process				
Clarity of data usage				
Dissemination of findings	X			
Benefits to participants				
Tika: Validity of the research				
Clear purpose of project	X	C1, C3		
Relevance to Māori	X	R2, R3, R5		
Likely outcome for participants, communities, other stakeholders				
Participant recruitment methods	Х	C1, C2, R3, R14		
Māori involvement in project (participants, researchers, etc.)	X	R1, R6 R8, R9, R12		
Manaakitanga: Responsibility and respect	.,	,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,		
Participants' access to appropriate advice	X	R2, R6 R7, R10, R15		
Participants treated with dignity and respect	X	R7, R9, R11, R13, R14		
Privacy and confidentiality	X	R3		
Whānau support	X	R7, R9		
Transparency of research process		,		
Mana tangata: Power & Authority				
Reciprocity (acknowledgements, compensation, gifts)	X	R15		
Risks of participation identified	X	R7, R8		
Ownership of outcomes		,		
Informed consent process				

#### Comments

- The researcher is an experienced self-employed Occupational Therapist, and for her project she plans to have fifteen (15) participants over the age of 65 who have undergone needs assessment and have just started receiving homecare support.
- Homecare support packages are initiated by the participant's DHB (through a needs
  assessment process that can involve the DHB's occupational therapists, social workers,
  etc., or private agencies employing such clinicians). The researcher will look at how the
  participants feel that their homecare package has enriched their lives.
- 3. No particular ethnicities will be targeted the first 15 people who agree to participate will be accepted
- 4. The researcher will ask some structured questions for example, how their lives have changed since the introduction of the homecare package and will also introduce a 'yesterday's diary' which looks at activity levels and how they may have changed following the introduction of the homecare package.
- The researcher has chosen participants over the age of 65 because the focus of the
  research will be on life processes and life roles. Below that age, issues of work and caring
  for children, etc., could complicate the data. Whānau can also be involved in the
  interview, if appropriate.
- 6. To ensure cultural safety, the researcher will not make any assumptions about any participants and their needs.

#### Recommendations

- Involvement of someone who is Māori in the Needs Assessment Team (NAT) that is recruiting participants would be beneficial for recruiting Māori participants.
- 2. It was difficult to determine whether any cultural practices are taken into consideration in the way the homecare package is delivered. The Ministry of Health website does offer Māori and non-Māori with disability the opportunity to access organisations who use the kaupapa Māori approach. Are these organisations included in the study?
- It would be beneficial to determine the percentage of current clients receiving care
  packages in the CCDHB who are Māori. Māori may prefer to seek help through iwi, Māori
  health practices, or traditional healers, rather than seeking support from DHB services.
- 4. A committee member recommended reading an article titled 'Understanding Obesity in Māori', which highlights that medical staff often have quite a different perspective on the needs of patients who are Māori compared to non-Māori. A copy of the article has been forwarded to your supervisor. Cultural differences may also affect how Māori perceive the care package. The Ministry of Health also provides a Whāia Te Ao Mārama: The Māori Disability Action Plan. This may also provide you with more insight into Māori with disability. Click the following link for detail <a href="http://www.health.govt.nz/our-work/disability-services/maori-disability-support-services/whaia-te-ao-marama-maori-disability-action-plan">http://www.health.govt.nz/our-work/disability-services/maori-disability-support-services/whaia-te-ao-marama-maori-disability-action-plan</a>
- 5. Aiming for individual independence may not be a goal for Māori. Interdependence may be a more culturally appropriate aim, with extended whānau being involved in the support, discussions and decision making. For example, the Ministry of Health He Korowai Oranga Maori Health strategy states the need for "the health and disability sectors to recognise the interdependence of people, that health and wellbeing are influenced and affected by the 'collective' as well as the individual, and the importance of working with people in their social contexts, not just with their physical symptoms". Click the following link for detail <a href="http://www.health.govt.nz/publication/he-korowai-oranga-maori-health-strategy">http://www.health.govt.nz/publication/he-korowai-oranga-maori-health-strategy</a>.

- 6. Involving Māori in the project would likely provide a better representation of the population who have major disabilities over the age of 65. The latest Ministry of Health statistics indicate that Māori have a significantly higher disability rate than non-Māori. For example, 73% of Māori males over the age of 65 have been identified as having a disability compared 55% of non-Māori males. Recruiting Māori will also provide different perspectives, and has the potential to contribute some very useful information for the services that work with Māori. For example, life roles at 65 may be quite different between Māori and non-Māori, and therefore influence the impact of the care package. More information related to this is available in Will Edwards' PhD thesis.
- 7. If whānau or others are involved in the interview, the researcher may need to be mindful that the patient may defer to others for responses i.e., the answer may not be a true reflection of how the patient feels about the service, or even whether they want the service to be offered.
- 8. It is important that the participant knows that the interview is completely confidential, and that there is no risk of services being removed as a result of something they have said.
- Māori participants may provide more in-depth and honest responses if they are interviewed by someone who is Māori, or if a Māori support person is present.
- 10. Grants may be available to cover the cost of paying Maori interviewers, so they are worth identifying and applying for. One possible source of interview support might be the University of Otago students at the Wellington campus, or grants from OT New Zealand.
- 11. A kaumātua may be available at the DHB, and perhaps could be accessed as a support person for participants. Alternatively, the DHB's cultural advisor may know of someone within the community who could provide the participant support.
- 12. The percentage of participants who are Māori should at least match the percentage of Māori in the general population. It may be necessary to specifically target areas of higher Māori population. For example, the last census and Wellington City ethnicity data indicate that 7.6% of the Wellington City population identify as Maori compared to nearly 20% of the Porirua population.
- 13. Given the personal nature of the interview questions, the committee recommends that the interviewers ask the participants what sorts of questions they would be happy to answer, and which not.
- 14. As recruitment will be through the NAT organisations, it would be important to inform potential participants that any current or future care will not be influenced by whether or not they participate in the project. One of the factors that may limit access to Māori is that a number of Māori may use organisations that use the kaupapa Māori approach. We have contacted Lynda Kirkman (a Māori physiotherapist at the Laura Fergusson Trust, Naenae, Lower Hutt 5011). She works with people with high levels of disability, and mentioned nearly half of the patients they see are Māori or Pasifika. Lynda and her team leader (an occupational therapist) have a good understanding of disability services provided in the Wellington area, and would be a good contact for linking with Māori with disabilities. She has kindly forwarded her email contact address.

  Lynda.kirkman@lft.org.nz
- 15. It is recommended that the researcher provide some compensation (koha) for the participants involved in the study, e.g. petrol or supermarket vouchers, baking.

Feedback on these comments and recommendations may be requested 12 months following the meeting.

Signature:

Date: 7/9/17

**Grant Mawston** 

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## **Appendix D: AUT Ethics Approval**



Auckland University of Technology D-88, WU406 Level 4 WU Building City Campus T: +64 9 921 9999 ext. 8316 E: ethics@aut.ac.nz www.aut.ac.nz/researchethics

27 September 2017

Clare Hocking Faculty of Health and Environmental Sciences

Dear Clare

Re Ethics Application: 17/2

17/282 Does remaining at home with the assistance of a homecare package promote maintenance of life skills and independence

Thank you for providing evidence as requested, which satisfies the points raised by the Auckland University of Technology Ethics Committee (AUTEC).

Your ethics application has been approved for three years until 27 September 2020.

#### Standard Conditions of Approval

- A progress report is due annually on the anniversary of the approval date, using form EA2, which is available online through <a href="http://www.aut.ac.nz/researchethics">http://www.aut.ac.nz/researchethics</a>.
- A final report is due at the expiration of the approval period, or, upon completion of project, using form EA3, which is available online through <a href="http://www.aut.ac.nz/researchethics.">http://www.aut.ac.nz/researchethics.</a>
- 3. Any amendments to the project must be approved by AUTEC prior to being implemented. Amendments can be requested using the EA2 form: <a href="http://www.aut.ac.nz/researchethics">http://www.aut.ac.nz/researchethics</a>.
- 4. Any serious or unexpected adverse events must be reported to AUTEC Secretariat as a matter of priority.
- Any unforeseen events that might affect continued ethical acceptability of the project should also be reported to the AUTEC Secretariat as a matter of priority.

Please quote the application number and title on all future correspondence related to this project.

AUTEC grants ethical approval only. If you require management approval for access for your research from another institution or organisation then you are responsible for obtaining it. You are reminded that it is your responsibility to ensure that the spelling and grammar of documents being provided to participants or external organisations is of a high standard.

For any enquiries, please contact ethics@aut.ac.nz

1 Cours

Yours sincerely,

Kate O'Connor Executive Manager

**Auckland University of Technology Ethics Committee** 

Tēnā koe i tau pānui i tāua pēpā pārongo na.

Approved by the Auckland University of Technology Ethics Committee on 27/09/2017 AUTEC Reference number 17/282

# **Appendix E: DHB Approval**

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	Policy	for Health Research	
APPR	OVAL FORM FOR LOW RISK RESEAR	CH ACTIVITY	
Use this form if your a	application is for:		-10,200
A cost-neutral study	(no budget required at : AND EITHER		
An audit or minimal	l risk study that does not qualify for review by a Health and Disa		
A low risk observation     except when any	onal study reviewed by a Health and Disability Ethics Committe y participants will receive non-standard care as part of the resea	e via the expedited pathway irch <b>OR</b>	,
A low risk study by a		ımittee	
	Research ID (RSO to complete) 2018.	01.001	
	Section 1: General		
Full Project Title	Does remaining at home with a home care package impact on main quality of life.	itenance of life skills and enhar	ice
Principle Investigator	Julie Roberts		
MDHB Service Area	Designation Occupational The	erapist	
Address			
Phone			
Email	julie@reable.co.nz		
Elliali	Julie@reable.co.nz		
Job Title	Team Leader Phone No.	3	
Service	Email	- o p, tilisks.o	15,1
For student projects (	(e.g. summer, masters and doctoral), please provide na	ame of ? clinical	
	nt to the contact person (above).		
Clinical Supervisor Name	Signature o.		
Job Title	Phone No.		
Service	Email		
Other Contact Name	Phone No.		
Other contact mane	Email		
Student Led?	Yes		
Clinical supervisor: In	n relation to this student and this project I take the res ppropriately advised on clinical safety and correct processes in , and in the interests of	ponsibility to ensure: The patient the interests of the patient Yes/N	S
	Section2: Proposal		
			2 9 %
http://ethics.health.govt.nz Low risk mixed methodology in service user's homes. The implementation.	r to: Standard Operating Procedures for Health and Disability Ethics z/operating-procedures y research. The qualitative component is interpretive, naturalistic enq he quantitative component uses a yesterday diary to measure change.	uiry using semi-structured inter	view :kage
	study question (hypothesis) that your study will examine?		
My interest in this study st	tems from my experience working in the community as an Occupa	tional Therapist	

Implementation.

Briefly, what is the principal study question (hypothesis) that your study will examine?

My interest in this study stems from my experience working in the community as an Occupational Therapist

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Page 1 of 6

Version: 6

Policy for Health Research

There are 15 participants so 5 hours of initial contact phone calls will be required in total (allowing for 20 minutes per phone call). Final Reporting Mechanism

On completion of this study, a summary of the research findings will be forwarded to participants who have requested this. The home care provider will be provided with a copy of the findings, and findings will be presented by means of presentation to

The research may be published in a professional journal.

Section 3: Ethical considerations

Complete Section 3 if you HAVE NOT completed an application to the Health and Disability Ethics Committee. If you have completed a HDEC application, do not complete Section 3, but submit the application/approval letter along with this form. If you have submitted an application for ethical approval to an institutional ethics committee(e.g. A University ethics committee), complete Section 3 and also submit the ethics application along with this form

1. What benefits do you expect the study to provide?

#### **Participants**

 The benefit to the participants is in making a contribution to long-term development of service provision that aligns with the legislation. Participation may encourage reflection by the recipient of home care, which may prompt future decision-making and actions of the participants.

#### The Researcher

 The benefit to the researcher is continuing professional development and this work contributes to a Masters of Philosophy

#### The Wider Community

- Fund holders and Service providers will be able to use the research as a benchmark in relation to whether currently funded service provision meets the goals laid out by current NZ legislation.
- It is hoped that the research will inform future research and examine home care provision nationally.
- 2. What risks do you expect the study to pose?
  - Risk to me as the researcher when entering service users' homes unknown to myself. Potential
    environmental Hazards within the home- houses in poor repair, dangerous dogs, service users
    who may have anger management issues, enduring mental health problems, or sexually
    inappropriate behaviour.
  - Risk that patients may feel distressed by the research process.
- 3. What steps will you take to minimise expected risk?
  - As an Occupational Therapist I am used to working in service users' homes, and managing risks associated with the working in new environments. It is highly unlikely that anyone identified as having risky behaviour will be approached to participate in the study but this will be addressed in negotiations with organisations assisting with recruitment. I will provide my work supervisor with a sealed envelope containing information of my where abouts and ring once I have finished the interview. If I fail to text in following the visit, my supervisor will call my family to check that I am safe.
  - It is not likely that the topic discussed will cause any distress. In the unlikely event, that counselling is required, a local counselling provider would have to be provided upon the instruction of AUT counselling services.

<ol> <li>Will you be collecting information dire</li> </ol>	ectly from i	ndividuals?
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YES

Doc. Code:

## Policy for Health Research

If YES, explain how will you identify and/or approach potential participants?	
Participants will be selected and approached by Community Support Links	
5. Will you be collecting information about individuals from a third party? If so, a) what is the party's relationship to the participants, and b) why is it appropriate to gain the information from that person?	YES
organise homecare assessments. Providing a third party to act as a go bet	ween means that
data protection is adhered to. It also means that participants can be screened as to their suitability t research given the exclusion criteria. This will facilitate informed consent.	o participate in the
6. Will you be obtaining information from health records (patient clinical records)?	NO
7. Will you be accessing health information about identifiable or potentially identifiable individuals (this means you – the researcher - will or might be able to tell the identity of the individuals)? (if NO go straight to Section 4)	YES
8. If participants will be identifiable or potentially identifiable, will you obtain the consent of the individuals concerned?	YES
9. If your study involves entering patient data into a registry or database and you will NOT b process of informed consent, describe what information you will be giving to patients about h will be used and if they will have an option to "opt out" Not applicable	
10. Justify the collection and use of patient information without consent for this study Not applicable.	
11. Explain all measures taken to preserve the confidentiality of the patient information, inclustored, which study personnel will have access, and for how long it will be stored before destricted.	iding how it is ruction.
All data pertaining to the research will remain confidential and stored as per AUT guidelines stored for 6 years after completion on a password protected computer file stored in the prima office. Data will be deleted after this time. Individuals having access to the consent forms and research are Julie Roberts OT Researcher, the Primary Supervisor, Clare Hocking and Secon Melissa Evans. Any one contracted to work to transcribe interviews will have to sign a confid agreement. Participant contact details will not be stored or used for future use.	ary supervisor's l data from the dary Supervisor,
IMPORTANT - If you will not be obtaining informed consent to use identified patient information, an of the below apply, you will need ethical approval from a Health and Disability Ethics Committee  • You are not employed by or contracted to	d any combination
<ul> <li>You are not employed by or contracted to</li> <li>You will be retaining unique identifiers (e.g. NHI) in your dataset that could link to other data</li> <li>You will be obtaining health information from other health care organisations in addition to</li> </ul>	bases/registries

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	30/08/2018
YES	
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# Appendix F: DHB Māori Research Review Group Approval

Date: 8 <sup>th</sup> March 2018
Julie Roberts
Study Title: <b>Does remaining at home with a home care package impact on maintenance of life skills and enhance quality of life.</b>
Tēnā koe Julie
Māori Research Review Group met on the 26 of February 2018 to discuss your re-submitted research proposal.
Comments:
As stated in our previous letter, the group feels your project will add value to the well-being of our population within the DHB. We were pleased to receive your re-submitted proposal and thank you for addressing the all of the issues we raised with your earlier application.
On behalf of the Māori Research Review Group your study has been endorsed to commence at this DHB. We wish you well with your research.
Whaowhia te kete mātauranga
Fill the basket of knowledge.
Heoi ano

On behal	f of the Māori Research Review Committee
This proje	ect has been discussed with the following groups:
	Manawhenua Hauora Te Roopu Mangai Kaumatua (Advisory group to the Māori Health Unit) Other

## **Appendix G: Participant Information Sheet**



#### Kia Ora

### **Participant Information Sheet**

Date Information Sheet Produced: 17/07/2017

#### **Project Title**

Does remaining at home with a home care package impact on maintenance of life skills and enhance quality of life?

#### An Invitation

I have been working as an Occupational Therapist for the last 17 years setting up care packages for younger and older adults who wish to live in their own home in the community. Please accept my invitation to participate in this study of what people expect from the home care they receive and how it works out for them.

## What is the purpose of this research?

To explore the impact of home care for individuals living in the community. I hope that this research will lead to a larger research project in the future to guide home care service provision.

## How was I identified for the study?

You have been invited to participate in the study because you are just starting to receive homecare, and have not previously received it.

#### What will happen in the research?

I would like visit your home to chat with you about your experiences. This will involve two interviews. The first visit will be when home care starts and the second will be six weeks later. During both visits, we will fill out a diary of all the things you did the day before. That will help me gauge how busy and active you were, when you started receiving help and when it has been in place for a few weeks.

You are welcome to have a support person with you. Each interview should be no more than about 40 minutes and will be audiotaped.

## Are there possible discomforts and risks involved in this research?

Receiving a care package is a new life stage, and talking about it might upset some people. You can choose not to answer any of the interview questions. You can also choose to stop the recording or withdraw from the interview should you wish. You do not have to explain your choice and there are no penalties for withdrawing. If you need support, I will help you identify counselling services in your area.

#### What are the benefits?

There are no immediate benefits for you taking part. However, the research may help to guide home care service provision in the future, so it is important for current home care recipients to talk about their views. Your participation in this study will assist my own continuing professional development as well as contribute toward my Masters of Philosophy degree. It is hoped that the research will be published in a professional journal or presented at a conference.

## How will my privacy be protected?

Audio recordings and transcripts will only be accessed by the research team who have all signed confidentiality agreements. The typist transcribing the interviews will have also signed a confidentiality contract and will type onto a computer which is password protected. Your name will not be used in any publication or presentation of the findings. All participants will be referred to using a pseudonym (false name) and any identifying information will be altered. The home care provider will also not be identified.

Your demographic information will be stored separately from transcripts in locked cabinets at AUT for six years following the completion of the research and then destroyed.

#### How do I agree to participate in this research?

By expressing your interest to the health professional who told you about the study, who will give me your contact details, or by contacting me yourself. See the bottom of this form.

### Will I receive feedback on the results of this research?

On completion of this study, a summary of the research findings will be forwarded to you if you wish. Your home care provider will receive the same information.

#### What happens if I wish to withdraw from the study?

Taking part in this study is your choice and should you wish to withdraw from the study at any time you may do so without being disadvantaged in any way. You will be offered the choice of having any data collected during the interview process removed and not be used in the research findings should you wish. However once findings have been produced, removal of data may not be possible.

#### I would like to read the transcripts of the interview.

If you wish to read the transcript for your interview once, it has been typed up- you are welcome to do so. You will need to tell me at our initial meeting so I can arrange to get a copy of this to you.

#### What do I do if I have concerns about this research?

Any concerns regarding the nature of this project should be notified in the first instance to the Project Supervisor, Professor Clare Hocking by email: <a href="mailto:clare.hocking@aut.ac.nz">clare.hocking@aut.ac.nz</a> or phone: 09 921 9162.

Concerns regarding the conduct of the research should be notified to the Executive Secretary of AUTEC, Kate O'Connor, *ethics@aut.ac.nz*, 09 921 9999 ext. 6038.

## Whom do I contact for further information about this research?

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

#### Researcher Contact Details: Julie@reable.co.nz

Project Supervisor Contact Details: Professor Clare Hocking clare.hocking@aut.ac.nz

Ph: 09 921 916

If you require Māori cultural support, you may like to talk to your whānau in the first instance. Alternatively you may contact:

Pae Ora Māori Health Directorate

## **Appendix H: Participant Consent Form**

Date sheet produced: 17/07/2017

*Project title:* Does remaining at home with a homecare package promote maintenance of life skills and quality of life?

Project Supervisor: Professor Clare Hocking

Researcher: Julie Roberts

- I have read and understood the information provided about this research project in the participant Information Sheet.
- I have had an opportunity to ask questions and to have them answered.
- I understand that notes will be taken during the interviews and that they will also be audio-taped and transcribed.
- I understand that taking part in this study is voluntary and I may withdraw myself or any information that I have provided for this project at any time prior to the start of data analysis.
- If I withdraw, I understand that all relevant information including tapes and transcripts, or parts thereof, will be destroyed. However, once the finding have been produced removal of the data may not be possible.
- I agree to take part in this research
- I wish to receive a summary of research findings. Please circle Yes/ No.

Participant's signature:
Participant's name:
Participant's Contact Details:
Date:

Approved by the Auckland University of Technology Ethics Committee on type the date on which the final approval was granted AUTEC Reference number type the AUTEC reference number

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

## **Appendix I: Yesterday Diary**

## Figure 2.

Participant Pseudonym : Ivy Date: First yesterday diary.

Information supplied by client

Record the main activities in each time period, along with pertinent information relating to where it was performed (home/community), if there was someone else there – noting if they were doing something different, and satisfaction with performance (difficult/easy).

## **Codes used**

Home= H
Community = C
Alone= A
With Assistance= AS
Company= Co
Yes = Y
No= N

Time	Activity	Was Activity new Y/N	Alone or with assistance/ or company	Where performed?	Difficult or Easy or
6.30am-					
7.00am					
7.00am-					
7.30am					_
7.30am-	Got Up	N	A	Н	Е
8.00am					
8.00am-	Took pills had shower	N	A	Н	E
8.30am					_
8.30am-	Had Breakfast watched	N	A	Н	E
9.00am	TV				
9.00am-		N	A	С	Е
9.30am	Went for walk				
9.30am-					
10.00am					
10.00am-					
10.30am					
10.30am-					
11.00am					
11.00am-					
11.30am					
11.30am-	Had a sleep	N	A	Н	E
12.00pm					
12.00pm-	Walked to beach	N	A	С	E
12.30pm					
12.30pm-	Lunch	N	A	Н	E
1.00pm					
1.00pm-					
1.30pm					

Time	Activity		Alone or with assistance?	Where performed?	Difficult or
					easy?
1.30pm- 2.00pm	Watched TV	N	A	Н	Е
2.00pm- 2.30pm					
2.30pm-					
3.00pm					
3.00pm-	Sleep	N	A	Н	Е
3.30pm					
3.30pm-					
4.00pm					
4.00pm-					
4.30pm					
4.30pm-					
5.00pm					
5.00pm-	Took dog for walk	N	A	С	Е
5.30pm					
5.30pm-	Cooked and had dinner	N	A	Н	Е
6.00pm					
6.00pm-					
6.30pm					
6.30pm-					
7.00pm					
7.00pm-					
7.30pm					
7.30pm-					
8.00pm					
8.00pm-					
8.30pm					
8.30pm-					
9.00pm					
9.00pm-	Went to bed	N	A	Н	Е
9.30pm					
9.30pm-					
10.00pm					
10.00pm-					
10.30pm					
10.30pm					
-11.00pm					

## Figure 3.

Participant Pseudonym : Ivy Date: Second yesterday diary.

Information supplied by client

Record the main activities in each time period, along with pertinent information relating to where it was performed (home/community), if there was someone else there – noting if they were doing something different, and satisfaction with performance (difficult/easy).

## **Codes used**

Home= H Community = C Alone= A With Assistance= AS Company= Co Yes = Y No= N

Time	Activity	Was Activity new Y/N	Alone or with assistance/ or company	Where performed? H/C	Difficult or Easy or
6.30am- 7.00am					
7.00am- 7.30am					
7.30am- 8.00am	Got up showered fed self and the dog the birds and the fish	N	A	Н	Е
8.00am- 8.30am					
8.30am- 9.00am					
9.00am- 9.30am					
9.30am- 10.00am					
10.00am- 10.30am	Skyped nephew in uk	N	A	Н	Е
10.30am- 11.00am					
11.00am- 11.30am					
11.30am- 12.00pm	Took dog out for a walk	N	A	С	Е
12.00pm- 12.30pm 12.30pm-	Lunch boiled egg	N	A	Н	Е
1.00pm					
1.00pm- 1.30pm	Visitors	N	СО	Н	E

Time	Activity		Alone or with	Where	Difficult
			assistance?	performed?	or easy?
1.30pm-					
2.00pm					
2.00pm-	Mid afternoon nap	N	A	Н	Е
2.30pm	_				
2.30pm-					
3.00pm					
3.00pm-	Woke up and got up from bed	N	A	Н	Е
3.30pm					
3.30pm-	Listened to radio watched TV	N	A	Н	Е
4.00pm					
4.00pm-	Had a cup of tea and a biscuit	N	A	Н	Е
4.30pm					
4.30pm-					
5.00pm					
5.00pm-	Cooked pantry ready meal	N	A	H	E
5.30pm	made gravy				
5.30pm-	Had a sherry watched the	N	A	Н	Е
6.00pm	chase on TV				
6.00pm-					
6.30pm					
6.30pm-					
7.00pm					
7.00pm-					
7.30pm					
_					
7.30pm-					
8.00pm					
8.00pm-					
8.30pm					
8.30pm-					
9.00pm					
9.00pm-					
9.30pm					
9.30pm-	Went to bed	N	A	Н	Е
10.00pm					
10.00pm-					
10.30pm					
10.30pm					
-11.00pm					