Doing Waiting Work: Older Adults' Lived Experience of Waiting for Community Occupational Therapy

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ABSTRACT

This research occurred in response to the inability of a community occupational therapy service to meet the needs of community-dwelling older adults. High service demand for community occupational therapy has resulted in long-standing and lengthy waitlists. Services are not readily accessible in a timely manner. Older people, who make up an increasing proportion of the population, are referred to the community occupational therapy service to support their participation in daily occupations at home and in the community. However, rather than being provided with a service, many of these older people are placed onto a waitlist, where they wait for extended periods. It is not known how these people experience 'waiting'. The aim of this hermeneutic phenomenological study was to gain an in-depth understanding of the meaning of 'waiting for community occupational therapy' as experienced by community-dwelling older adults residing in Northland, New Zealand. Twelve older adults, eight men and four women, aged 68 – 88 years, who had waited three months or longer for community occupational therapy, were interviewed in their homes. The text (data) was comprised of participant stories, which were constructed from the transcribed interviews. These stories were interpreted using the philosophical notions of Heidegger and Gadamer, and van Manen's lifeworld existentials, whilst employing an iterative process of writing and re-writing. Three phenomenological themes illuminated the findings of this study. These interpretive findings describe the experience of: 'the uneasiness of waiting', which reveals the participants' struggle and uncertainty of being seen by the occupational therapist; 'waiting as being with', which shows how waiting occurs with and alongside others; and, 'the not at-homeness of waiting', which discloses how the participants were residing at home devoid of the comfort of being at-home in their home. Interwoven through the findings was the way occupations shaped, and were shaped by, waiting. Also revealed was the effect of physical, mental and emotional effort experienced and invested, as these older people determinedly carried on at home whilst waiting for community occupational therapy. This effort was a mode of work, which I term 'waiting work'. As the participants did waiting work, there was a diminishing doing and being. Waiting for community occupational therapy is the insidious depletion of the older person's meaningful life. Understanding the lived experience of waiting for community occupational therapy illuminates that the impact of waiting cannot be ignored or underestimated.

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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."

Signed:

Vicki Fryer

Date: 26 February 2023

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and curiosity; your thinking has made me think. I have been “getting there” for some time. I know you are waiting patiently for me to finish. I can now say that “I am there!”

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CHAPTER ONE: BACKGROUND

Waiting can be a tool of the powerful to maintain the status quo
by forcing people to invest their time in ways that inhibit their ability
to transform their situation.
(Jason Farman cited in Popova, 2018)

Introduction

The health system's inability to meet the needs of older people in the community means many are left waiting for services with little support. Excessive waitlists and waiting times for community occupational therapy results in exclusion from supposedly available public services; services that are not readily accessible in reality (Carrier, Levasseur, & Mullins, 2010). Older people, who make up an increasing proportion of the population, are referred to community occupational therapy to support their participation in daily occupations at home and in the community. However, many are blocked by waitlists, meaning they are unable to receive the help that they require in a timely manner. This thesis examines the experiences of community-dwelling older people who are waiting for community occupational therapy.

This chapter will lay the foundation to my study. I begin by providing some background about where the study was undertaken, why occupational therapy matters and why there is merit in embarking on this study. I then turn to why I considered the methodology of hermeneutic phenomenology, and in keeping with phenomenological tradition, share my forestructure of understanding. But first, let me introduce myself, who I am and why I am doing this study.

I qualified as an occupational therapist in 1999. For the past 23 years, I have lived and worked in the Far North of New Zealand, based at Kaitaia Hospital. The occupational therapy department in Kaitaia Hospital is small. I have the role of Charge Therapist, which sees me manage and work alongside two part-time therapists and more recently, two part-time allied health assistants. Together, we are responsible for providing intervention and rehabilitation to those patients or clients in the inpatient ward, outpatient service, and in the wider community.

In the early stages of my career, I worked in a variety of roles. I have worked in mental health, community rehabilitation, and the acute medical/surgical ward. For a short time,

I worked in the private health sector supporting injured people back to work. But my heart is in the community. I have worked as a community occupational therapist for over 20 years. It is here where I get to know the person within the context of their home and family, and where I get to know what matters to them. It is professionally satisfying to be able to provide 'the thing', whether it is something as simple as a shower stool or as complex as altering a person's bathroom environment, so that their needs are met and they can re-engage in, or continue, doing what they need to do.

With longevity of service and clinical experience comes seniority and responsibility. As Charge Therapist, my role also includes mentoring, supporting and supervising other occupational therapists and students. Within the Northland District Health Board (DHB)[1] I have been on several working groups representing occupational therapy. I also represent Northland DHB occupational therapists at meetings with occupational therapists from other DHBs. This provides me with the opportunity to hear what is happening within other community occupational therapy services in these regions.

Why am I doing this study? The demand for community occupational therapy services is relentless. I have worked hard to keep the waitlist in my service as short as possible but I find myself unable to keep up with the demand. Over time I have watched the waitlist grow. Compared to other community occupational therapy services within New Zealand, my waitlist of a few months could be considered short. The waitlists in two of the three other Northland DHB community occupational therapy services extend over 12 months, and across New Zealand the average waitlist time is 9.7 months (Fryer, Wright-St Clair, & Bright, 2019). It concerns me how long older adults have to wait for our service. But I am also concerned about my colleagues. I observe the constant burden and the effect of the waitlist on these therapists – frustration, stress, concern and diminished job satisfaction – similar to what has been identified in the literature (Bishop & Brott, 2019; Fryer et al., 2019; McGill, Crowe, & McLeod, 2020). With the constant demand and lengthening waitlist, there is a sense of never being able to get to the end of the list. As such, I feel an incessant pressure to deal with clients quickly and take on more work to limit people's time on the waitlist. This is similarly experienced by my colleagues and

[1] At the time of the study, DHBs were responsible for the provision of healthcare for their region's population. The structure and purpose of the DHB is explained further on p 10.

other therapists (Fryer et al., 2019). However, working this way makes me feel like I am compromising on my core values as an occupational therapist. Do I just get through the work by focusing on the individual's immediate needs, or, do I take my time and do a thorough job, practising in a holistic and client-centred manner? It does not seem possible to do both, and in this tension, care gets lost. Not only am I grappling with this tension, but having to tell someone they will have to wait, knowing they need help now, knowing that they may have to wait many, many months, and not being able to say how long the wait may actually be, is not easy. Knowing that some people will miss out, that I may be too late, and that the ability to meet the occupational needs of all clients will not be achieved, is disheartening. And my colleagues speak of this too. Given this, it is, perhaps, no surprise that the literature speaks to staff burnout and reduced job satisfaction as a result of waitlists (McGill et al., 2020).

The waitlists are so entrenched that the waiting is 'just how it is'. The numbers are there, and have been there for some time, but nothing seems to have come from gathering and reporting on the numbers. Clearly, the numbers alone have no meaning to those people who allocate resources. I felt that something more was needed, something that showed what it felt like to be waiting. I hoped that by capturing the experience of older adults waiting for community occupational therapy, I could illuminate the human experience and feelings behind the names on the list, prompting those people in a position of power to really attend to the waitlists. I also hoped that in doing this study, it would help to alleviate some of the pressure occupational therapists placed onto themselves. Maybe waitlists were not as bad for older people as we believed they were.

Why older adults? Although community occupational therapy services accept referrals for adults aged 16 years and older, I have chosen to focus on older adults in this study. Many of the referrals received into the service are for older adults and with an increasing ageing population, understanding the meaning of delayed services for this cohort is important. Older adults appear to be more vulnerable to delayed healthcare and prejudices within the sector. For example, when an older person presents to hospital, so often I hear the doctors recommending residential care placement, rather than supporting their discharge back home. Some of these patients have been on the occupational therapy waitlist. Could we have prevented their hospital admission?

On a personal level, I have always had an affinity for working with older adults. I have always enjoyed hearing about their history and their connection to the region and how they have contributed towards it. I am always struck by their resilience and ingenuity. As older adults quietly get on living their life, waiting for help, this study brings forth their voice.

The meaning of 'waiting'. According to the English Oxford Living Dictionaries (n.d.), 'waiting' is a mass noun defined as "the action of staying where one is or delaying action until a particular time or event". Waiting is "to *wait* (something) out" or "endure a period of waiting" (Online Etymology Dictionary, n.d.-b). 'Wait' as a noun can be defined as "a period of time when you must wait" or "an act or period of waiting"; and, as a verb, is defined as "to stay in place until an expected event happens, until someone arrives…"; "to remain in a state in which you expect or hope something will happen soon" (Merriam-Webster, n.d.-c).

When considering the language or meaning of 'waiting' at the outset of my study, I recognised there was both a physical and emotive element associated with waiting. To physically stay in place, and psychologically, to endure a state of anticipation for an unknown period of time; waiting for something to happen, being in limbo, hoping that something would happen soon, but not knowing. I wondered, is this how older adults experience waiting as they anticipate a phone call from the occupational therapist?

Language of the thesis

"Language is the universal medium in which understanding occurs. Understanding occurs in interpreting" (Gadamer, 1975/2004, p. 390). The text brings the phenomenon of waiting into language (Gadamer, 1975/2004). To provide some clarity for those reading my thesis, I would like to bring to light some of the ways in which I have grappled with, defined, and used language.

Defining the phenomenon. The phenomenon being explored is 'waiting for community occupational therapy', that is, the period of time from when the referral is received to the first assessment. 'Occupational therapy' is defined as a "client-centred health profession concerned with promoting health and well-being through occupation. The primary goal of occupational therapy [whakaora ngangahau] is to enable people to participate in the activities of everyday life" (Occupational Therapy New Zealand Whakaora Ngangahau

Aotearoa, n.d.). In order to receive the help they seek, people wait for a phone call to arrange the first home visit by the community occupational therapist. An occupational therapist is a healthcare professional who helps people "overcome occupational restrictions or limitations by identifying barriers to occupational engagement … to promote engagement; restore function; and enable important activities, tasks, and life roles" (Baum, Carey, & Polatajko, 2013, p. 1372). I use the terms 'waiting for community occupational therapy' or 'waiting for the community occupational therapist' interchangeably depending on the structure of the sentence. I shorten this to 'waiting for occupational therapy' or 'waiting for the occupational therapist' in the findings chapters due to the frequency of use. Similarly, occupational therapists are sometimes referred to as 'therapists'.

Client or Patient? I have a tendency to use these words interchangeably to describe people accessing occupational therapy services. I predominantly refer to occupational therapy service recipients as 'clients' when I talk of visiting them in their homes, whereas I often refer to the same persons as 'patients' when seen within the hospital setting.

Disabled person or person with a disability? According to the APA (American Psychological Association, 2010), researchers should avoid language that objectifies a person by their condition, and instead use people-first language, such as 'person with a disability'. Similarly, the term 'older adult' is preferable to 'elderly' or 'senior'. However, the New Zealand Disability Strategy uses the term 'disabled people' (Ministry of Social Development, 2016), and many disabled people prefer 'disabled person', as they are disabled by a world that does not enable them to participate and flourish (McColl, 2019). Using the term 'disabled people' reflects the context of my research; the lack of service, which is preventing participation in daily occupations in the home and community.

Wait-list, waitlist or waiting list? As these words are all very similar, I felt it necessary to differentiate and acknowledge how they are used within the thesis. 'Wait-list' is a verb meaning "to put (someone) on a waiting list" (Merriam-Webster, n.d.-d); 'waitlist' is a noun meaning "a waiting list" (Collins English Dictionary, n.d.); and, 'waiting list' is a noun meaning "a list of those waiting" (Merriam-Webster, n.d.-e).

Being or being? The capitalisation of Being is to identify the ontological difference, that is, the distinction between Being (the meaning of Being), and human beings (entities) (Wheeler, 2020).

Home. The usual place where one lives, a house, a private dwelling. Community occupational therapists visit older adults living in their home, and this also includes those individuals living in residential care, council flats, emergency accommodation, and retirement villages. In this study, the participants were all living in their homes, their private dwellings.

I noticed that Heidegger (1927/1962) added the suffix 'ness' to certain words. I found myself employing this technique when describing certain ways of being. When you add '-ness' to a noun it becomes an adjective; it is used to say something about the quality (or property) of being that adjective (The Britannica Dictionary, n.d.). For example, I used the word *upsetness* when speaking of one participant's upset – the state of being upset.

I have used the pronoun 'we' or adjective 'our' when referring to people in general.

My interpretation of the participant stories is written in present tense. According to Heidegger, the Being of entities can only be truly understood in the present (Munday, 2009).

People who took part in this study are called participants. In phenomenology, the participant voices are included in the text. I have italicised the text spoken by the participants to differentiate their voice from mine.

Although the occupational therapy profession is female-dominated, I will be referring to occupational therapists as 'they' in this study rather than using gender-based pronouns. There are very few male occupational therapists working in Northland. Maintaining this neutral stance offers anonymity to any occupational therapists referred to by participants. In addition, I have removed the name of any therapist identified by the participants and replaced this with 'the therapist'.

I have used Māori[2] words within the thesis. I have provided their pronunciation and meaning in a footnote upon first use.

I have used New Zealand spelling, except in direct quotes. I have used Endnote X8, APA 6 for referencing.

MY CLINICAL PRACTICE CONTEXT

Background

This study was undertaken in Northland, also known as Te Tai Tokerau[3]. Northland is situated at the top end of New Zealand's North Island. Known for its beauty and isolation, the vast geographical landscape and cultural history have influenced how and where Northlanders live. Northland has a rich history. It is said that early Māori settlers arriving to New Zealand, landed first in the north. This was later followed by European traders, whalers and Christian missionaries who began to colonise the land (Orange, n.d.). In 1840, Te Tiriti O Waitangi[4], New Zealand's founding document, was drawn up and signed. Te Tiriti was an agreement made between the British Crown and representatives of Māori iwi[5] and hapū[6] (Berghan et al., 2017), to found a nation state and build a government (Ministry for Culture and Heritage, 2017). It was first signed at Waitangi, in Northland. Following this, many more immigrants arrived. Māori and Europeans had different understandings and expectations of te Tiriti, and breaches of te Tiriti caused conflict. Further, colonisation resulted in: laws that conflicted with the social structure of Māori; the confiscation or theft of Māori land; the erosion of traditional practices; and, the loss of cultural identity (Shine, n.d.). Illness and diseases were introduced into the Māori population. With many iwi deprived of their land, they were reduced to poverty and forced into living in overcrowded and unhygienic conditions (Pool, n.d.). Furthermore, lost land meant loss of access to traditional food sources resulting in poor diet. The combination of these factors allowed diseases to thrive (Pool, n.d.). The health,

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[2] Māori – pronounced mow-ri – meaning "an indigenous New Zealander" (Te Aka Māori Dictionary, n.d.-f).
[3] Te Tai Tokerau – pronounced teh tie tow-keh-row – meaning Northland.
[4] Te Tiriti O Waitangi – pronounced – teh tee-ree-tee O why-tongue-ee – is the Māori text of the Treaty of Waitangi (Berghan et al., 2017) and is often shortened to te Tiriti.
[5] Iwi – pronounced ee-wee – meaning "tribe; often refers to a large group of people descended from a common ancestor and associated with a distinct place" (Te Aka Māori Dictionary, n.d.-b).
[6] Hapū – pronounced ha-pooh – meaning "section of a large kinship group; several hapū form an iwi" (Te Aka Māori Dictionary, n.d.-a).

social and economic disparities experienced by Māori have been perpetuated through time. Northland remains one of the country's poorest regions, the population as a whole more socio-economically deprived than anywhere else (Orange, n.d.).

The population of Northland is predominantly European (64%) and Māori (34%) (Ministry of Health, 2019c) and the Northland population continues to be significantly older than the national average (Ministry of Health, 2016, 2019b). Older Māori often return to their birthplace as "connection to land is central to Māori society and identity" (Murton cited in Butcher & Breheny, 2016, p. 49). Many of these older Māori live in rural or remote areas. Health indicators for the Northland population, particularly for Māori, compare poorly with New Zealand norms (Northland District Health Board, 2012) and Northland has a "very high proportion of people in the most deprived section of the population … whilst the least deprived section is under-represented" (Ministry of Health, 2016, p. 1). This results in many people living in situations that contribute to ill-health and ill-being, such as overcrowding and/or living in homes that are cold and damp; circumstances beyond their control. Whilst services provided via the DHB incur no cost to individuals, those living in rural and remote areas may experience delays for community-based services due to their remoteness, difficulty arranging an appointment due to minimal or no phone service, or simply the challenges getting to their home (as seen in Figure 1).

The combination of these factors makes older adults more vulnerable to the waitlists. They may not have the financial means or social reserves to support themselves while waiting. Although older people in Northland are reported to use more health services compared to younger people, and spending on services for older people is increasing faster than other expenses (Ministry of Health, 2018), the waitlists for community-based occupational therapy services are growing, not shrinking.

Figure 1: Working in the community

On the left: a steep, washed-out driveway meant I needed to walk up to the house. On the right: a tidal stream blocked vehicle access to the home and meant I needed to carry equipment across the stream and up to the house. In this photo I was returning to my car.

Before I proceed to discussing the waitlist, the value of occupational therapy, and why this study matters, I will first describe the healthcare structure that I worked in, as it existed whilst my research was occurring.

Healthcare structure

Ministry of Health (MOH). The purpose of the MOH is "to lead and shape New Zealand's health and disability system to deliver a healthy and independent future for all New Zealanders" (Ministry of Health, 2017, p. 4). The MOH is the steward of, and has overall responsibility for, the management of the health and disability system. That is, it funds and regulates health and disability services (Ministry of Health, 2017).

The MOH has recognised the challenges of an ageing population and the benefit of supporting older people to remain living in their homes (Ministry of Health, 2015b). It reports to be working towards "accessible, effective disability support services" (Ministry of Health, 2017, p. 18).

Health and Disability System Review. Despite New Zealand having a publicly funded health system that is considered 'very good' by world standards, a Government-commissioned report highlighted the failings of the current system (Health and Disability System Review, 2020). The review identified that the "health and disability system [was]

under serious stress" (p. 3), and recommended implementing system-level changes that were equitable, sustainable, and which reflect te Tiriti commitments. This review began during the early stages of my research, and the recommendations were being rolled-out as I was nearing completion; this included disestablishing the DHBs. As this research occurred under the DHB structure, I will continue to refer to DHBs throughout the thesis.

The recommendations made in the Health and Disability System Review (2020) came into effect on 1 July 2022. A new crown entity, Te Whatu Ora - Health New Zealand, was established and would work in partnership with the newly formed Te Aka Whai Ora - Māori Health Authority to effect nationwide changes to the health and disability sectors.

District Health Board. Each of the 20 DHBs, of which Northland DHB[7] is one, are responsible for the healthcare of their region's population. Each DHB owns and funds public hospitals and public health services and has to prioritise services in order to meet government priorities, whilst simultaneously meeting the needs of their population.

Services provided by DHBs for older adults are broadly categorised into 'personal health services' and 'health of older people services'. The former includes a range of therapeutic interventions aimed to assist with ill health. The latter services address age-related disabilities. The latter service supports older adults to optimise their health, maximise their autonomy to live safely in their home, or facilitate the older person's progression into residential care (Duggal, 2014). Community occupational therapists provide community-based services for (older) people with personal health conditions and/or disabilities (Ministry of Health, 2015a). National service specifications are generated by the MOH and guide service provision within all the DHBs, including community occupational therapy services.

Northland District Health Board. Northland DHB has a base hospital located in the city of Whangārei, and three rural hospitals based in the surrounding areas of Kaitaia, Kawakawa and Dargaville. Each hospital covers a defined geographical area, has varying staffing levels, and may offer slightly different services dependant on its relative distance from the base hospital, where specialist services are located. The population served by Northland DHB is just under 180,000 people (Ministry of Health, 2019b). Of this number,

[7] I refer to DHBs in the present tense because that was the situation at the time I undertook the research.

half live in the Whangārei district, and the remainder of the population are spread throughout the region.

Community occupational therapy services in Northland. Each of the four hospitals in Northland manages and delivers community occupational therapy services. A person referred to community occupational therapy may have a short or lengthy wait depending on where they live, as wait times for assessment vary considerably across the four community occupational therapy services.

Referrals are triaged using the Risk Assessment framework (Ministry of Health, 2015a), which guides entry and priority of service. This is presented as a continuum of risk, from high risk (for example, experiencing irreversible and fast deterioration of health or functional status) through to medium risk (for example, the loss of functional skills that would lead to more extensive problems) and low risk (for example, living with compromised health status or function which is not life threatening). There are also guidelines for service response timeframes following receipt of referral (refer to Appendix A: Ministry of Health Framework).

Service provision includes both direct contact with the person and indirect tasks such as administration, documentation and liaison with other people and agencies. The complexity of the occupational performance issues identified during assessment will determine if these issues can be addressed immediately, or whether ongoing intervention is required. The complexity of need influences how long people remain on the caseload. Underlying this complexity, and affecting service provision, are the varying patterns of growth in the ageing population across the region, regional differences in socioeconomic and cultural composition, and the geographical distances to access people living in the community. The combination of all these factors influences the demand for, and provision of occupational therapy services. Because demand exceeds supply, the waitlists grow.

The waitlist

As I embarked on this study, the waitlists across the four community occupational therapy services in Northland ranged from several weeks to over 20 months. The two services carrying the longest waitlists had been in this state for several years. Over the course of this study, during regular regional meetings, therapists reported on their waitlists, which

never seemed to shrink despite their best efforts. This included my own service where the waitlist was now hovering between six and seven months.

The Covid-19 pandemic affected the waitlists. In early 2020, Covid-19 reached the shores of New Zealand. The New Zealand Government implemented a series of lockdowns with varying restrictions. Public interaction was limited intermittently between March 2020 to April/May 2022 to protect the health and well-being of all New Zealanders. During the lockdowns, community occupational therapists were prevented from completing home visits, except under urgent circumstances. Services gradually resumed as the restrictions tapered off. These lockdowns further exacerbated the existing waitlists as referrals were still being received into the service.

The role and value of occupational therapy

The primary focus of occupational therapy is to enable people to participate in their everyday life occupations, that is, all the things that people need to, want to, or have to do across the sleep-wake continuum (Wilcock & Hocking, 2015). Occupational therapists become involved when a person cannot engage in their everyday activities as a result of an impairment or disability, and their everyday living is jeopardised (Baum et al., 2013). Occupational therapists focus on assisting people to find fulfilment through engagement in occupations (Curtin, 2010) by identifying barriers to occupational engagement and implementing interventions that restore function and enable participation in valued activities and life roles (Baum et al., 2013). A fundamental concept of occupational therapy is ‘occupational balance’, the balanced rhythm between self-care, work, play and rest occupations (Matuska & Barrett, 2019; Polatajko, Backman, et al., 2013). Having the right amount and range of meaningful occupations is essential for a person’s health, well-being and quality of life (Matuska & Barrett, 2019). Enabling occupation through empowering people to choose and perform those occupations they find useful and meaningful in their environment (Townsend & Polatajko, 2013) is a cornerstone of occupational therapy practice.

Occupational science is “the systematic study of the things that people do” and was instituted to support occupational therapy practice (Hocking, 2013, p. 1365). The core values and assumptions of occupational science and therapy are that: people are occupational beings (Hocking, 2013; Townsend & Polatajko, 2013); each person is

unique and using a client-centred approach when providing occupational therapy ensures that the needs of the individual are addressed (Baum et al., 2013); there is a recognised relationship between engagement in meaningful occupation, health and well-being (Hocking, 2013; Molineux, 2010); all people have the need for, and right to engage in meaningful occupations of their choice (Townsend & Polatajko, 2013); and, occupation has therapeutic potential (Polatajko, Davis, et al., 2013).

Occupational therapy practice in New Zealand is guided by well-established theories and models, such as: the Model of Human Occupation (Kielhofner, 1985), the Canadian Model of Occupational Performance and Engagement (Townsend & Polatajko, 2013), and the Person-Environment-Occupational-Performance model (Baum, Christiansen, & Bass, 2015). These models examine the dynamic relationship between the person, their occupations, and their environment, and how these interactions influence occupational performance. These models arise from a Western worldview, perpetuating Western values and assumptions such as individualism and independence (Whalley Hammell, 2013). Western ethnocentrism dominates these models, thus failing to recognise the worldview of other cultures (Whalley Hammell, 2013), such as Māori, who, for example, value wholism, connectedness, and interdependence (Cunningham, 2000), and other non-Western cultures who similarly value being part of a family and community (Whalley Hammell, 2013). Recognising and acknowledging these differing worldviews, and how this may influence a person's decision-making may enhance occupational therapy practice. Likewise, understanding that occupational performance can change over the course of an individual's lifespan is also integral to occupational therapy practice. Further, these changes can occur gradually, predictably, or suddenly, impacting on the person's ability to engage in, or perform once taken-for-granted occupations (Polatajko, Backman, et al., 2013). Hence, a referral being made to community occupational therapy.

Community Occupational Therapy. Community occupational therapists deliver services within the context of a person's life roles and responsibilities, which, for older people, mostly occurs within their home. Community occupational therapists aim to restore a person's function and enable them to participate in their activities of daily life and their life roles (Occupational Therapy New Zealand Whakaora Ngangahau Aotearoa, n.d.) by helping people overcome occupational limitations (Baum et al., 2013). Occupational therapists may draw on a range of skills and strategies when working with

people to help them to achieve what matters to them (Curtin, 2010). This may include teaching adaptive or coping strategies, teaching new skills, providing assistive devices (such as shower seats, toilet raisers and wheelchairs), and/or prescribing housing modifications, such as rails, modifying bathrooms and installing ramps. The focus of community occupational therapy is to support people to remain in their home (Ministry of Health, 2015a) for as long as they choose to be there.

Occupational therapists are always trying to balance supports against service capacity and funding resources to enable best practice and achieve best possible outcomes for their clients. Community occupational therapy intervention provided through DHB funded services is predominately focused on self-care tasks, falls prevention and being independent within the home environment. This is influenced by current legislation and national health contracts, which direct what outcomes and services can be provided (Occupational Therapy New Zealand Whakaora Ngangahau Aotearoa, 2002). The ability to direct resources that enable engagement in occupations within a person's wider community is restricted. Therefore, occupations identified as meaningful by the client may not be meaningful to the health care system, resulting in the inability to fully meet the client's identified needs. This begets a clash between core professional values, organisational needs, and the existing systemic constraints (Raymond, Feldman, & Demers, 2020).

Why this study matters

When a person is unable to engage in occupations that are important to them, occupational loss occurs. Occupational loss can be short-term or long-term and may have an immediate or delayed impact on a person's routines and daily life. Limited or inadequate resources, or delays in service provision, such as those posed by waitlists, can result in 'missed' or 'minimal' opportunity for an occupational therapist to support occupational enablement because the moment to intervene at the right time is passed by or because the intervention that is provided is insufficient (Townsend et al., 2013). Losing occupations can have an effect on a person's sense of identity and self-efficacy, and may narrow or change the occupations that a person can engage in (Polatajko, Backman, et al., 2013). Consequently, the inability to engage in valued occupations can impact on an individual's health or well-being.

This research occurred in response to the current inability of the community occupational therapy services in Northland to meet the needs of community-dwelling older adults. As clinicians, we are concerned about those that wait, but little is known about the experience of older adults waiting for community occupational therapy and how waiting influences their ability to be at home. There is a need to establish if waiting is a concern or issue for older adults, or if this is simply the perception of therapists. We need to understand how waiting affects older adults, as anecdotally, there are not many complaints made by older adults who are waiting for the community occupational therapist. We cannot assume that the silence means they are okay. Understanding the lived experiences of older adults waiting for community occupational therapy services will advance knowledge and inform practice. Furthermore, capturing the lived experience and bringing to light the meaning of waiting may support resource allocation decisions.

METHODOLOGICAL GRAPPLING

Occupations are interwoven within the fabric of our daily lives and fill our days. "Many occupations are ordinary and become part of the context of daily living" (Dickie, 2009, p. 15) and can only be understood when a person tells you about its meaning (Polatajko, Backman, et al., 2013). Similarly, waiting is a common phenomenon; it is often embedded within the normalness of daily living and thus is easily overlooked. When reflecting on my topic of 'waiting for community occupational therapy' I considered the methodologies that could help me to explore this phenomenon, such as interpretive descriptive (Thorne, 2016) and qualitative descriptive methodology (Sandelowski, 2000). However, I wanted to gain an in-depth understanding of the phenomenon and I needed a methodology that could help me achieve this. Phenomenology is concerned with understanding lived experience and aims to "transform lived experience into a textual expression of its essence" (van Manen, 2016, p. 36), to put words to something otherwise difficult to describe. Hermeneutic phenomenology lends itself to exploring the phenomenon of waiting. It also provides an opportunity for older people to be heard and their voices elevated.

I was made aware of Martin Heidegger and Hans-Georg Gadamer, the forefathers of hermeneutic phenomenology. Although my initial understandings of hermeneutic phenomenology were limited, there was something about it that felt a good fit with being an occupational therapist. The philosophies of phenomenology and occupational science

and therapy aligned. People are occupational beings, and the aim of occupational science is to understand the occupational essence of 'being' human (Wright-St Clair, 2015). Further, the ontological nature of hermeneutic phenomenology is understanding Being, which is grounded in the idea that in existing, "we are constantly up to something" (Inwood, 2019, p. 45). Doing is being and Being is doing. The core tenets of the methodology will be discussed in more detail in Chapter Three.

Laying bare my forestructure of understanding

It is assumed when doing hermeneutic phenomenology that the researcher brings their horizon of understanding and prejudices to a study. Heidegger (1927/1962) referred to this as the 'forestructure of understanding'. Before I go further, it is necessary for me to make my own biases, experiences, values, prejudices[8] and expectations explicit. By bringing these to the fore, I can check them and keep a check on them, and thus acquire an understanding from the things themselves (Gadamer, 1975/2004).

Personal experience of waiting. I have known people on waiting lists and have observed the effect on their lives. I have seen their inability to do what is meaningful and important. I have heard how their world slowly changed and narrowed, as they were able to do less and less. A family friend in his 70s who had been waiting many months for surgery, said to me "there are others who are worse off than me… and so I will wait". The delay affected many aspects of his life. He stopped cycling, an occupation that he loved. I watched him slowly deteriorate and before he received the help he needed, he fell. He could not stay at home and went into care. He died soon after.

I have been on a waiting list for surgical intervention. Waiting insidiously affected my work, social and personal life. At first, I thought I could cope and that I could wait. But as time went on I noticed that I could not work as efficiently and could not participate in activities that I enjoyed. Slowly my thinking changed about how I organised my life. I also started to consider what other options I had. Could I continue to wait or could I afford private healthcare? Why should I have to wait? How sick do you have to be?

[8] Prejudice – the concept of prejudice often has a negative connotation, which Gadamer rejects. Prejudice can have either a positive or negative value (Gadamer, 1975/2004).

As a person working in the health system, managing the waitlist in my own service, and having my own personal experience of waiting gave me a new insight into this experience. I do not want people to have to wait.

Professional experience of waiting. I hate looking at the folder of referrals in my office. My eyes are constantly drawn to it. It raises my anxiety, and I am constantly trying to find ways to reduce it. The topic of waiting lists is raised regularly, whether it is departmental, within our regional community occupational therapy meetings or in meetings with occupational therapists from other DHBs. I hear how waitlists affect occupational therapists; their stress and dissatisfaction, and of their never feeling that they are making progress. They speak of their concern about the impact of the long wait on those people waiting.

Longevity in my role has offered me a longitudinal perspective. There have been periods where I have had a very short waitlist and could attend to the needs of people quickly and efficiently when they were referred. I have had the opportunity of observing the positive impact of timely intervention and how this benefits older people; that is, they are able to continue to actively participate in their valued occupations and maintain their safety and independence within their home and community, and with less reliance on other people or services. Practising with a short waitlist allowed me the opportunity to be more holistic. I was able to give adequate time for each assessment and intervention to ensure the best outcome for the person. However, this no longer seems 'the norm'. Lengthy waitlists have become embedded within my service. As the waitlist lengthens, so has the pressure to keep it contained. I have caught myself adapting my practice by focusing on the immediate issues identified rather than practising in my usual holistic manner. Where once I felt as if I could respond to older people's needs promptly and do a good job, now I feel as if I am losing the battle.

I have seen how waiting can alter an older person's life. Difficulty doing a once simple, taken-for-granted activity can have a detrimental impact on their ability to function in their home or continue participating in valued occupations. While a younger person may have the benefit of time to re-engage in valued occupations, an older person may not have this luxury. The elderly spouse of a client who experienced a life-changing medical event thanked me for the work I had done for them. Altering the bathroom meant my client could be showered. Installing a lift meant that my client could be taken out of the house,

and go out with their spouse, as they used to. They reflected on their lives and the difficulties experienced while they were waiting, and they stated, "we would have done whatever it takes to stay at home, whatever was needed …" (personal communication, January 2020). I knew how challenging it was for them without the right tools.

My values and beliefs about health, ageing and health service provision. I have always had positive role models in my life who have encouraged me to value my health. As such, I have always played sports, tried to eat well, and maintain a work-life balance. I am inspired by my granny, who is 92 years young. Although she lives in a rest-home in Johannesburg, far from family, she is fit, healthy and actively engaged in daily activities; she does not need help with showering or dressing and uses no walking aid. Each morning, she gets up at 5:30am and goes for a 4km walk with a friend. She enjoys scrabble, kaluki, crocheting, and going shopping with the other residents. My gran always says she feels safe, secure and happy. She says that life doesn't stand still and that we should always look forward.

In my work, I come to meet many older adults. Some who are chronologically "old" yet appear young, and others who are chronologically "young", yet seem so old. People make many choices throughout their life, which can affect their health and well-being in their later life. With all that we now know, it can be difficult not to judge people. That said, my job is not to scrutinise peoples' life choices, but rather, to understand peoples differences and support people to do what they need or want to do, to stay at home. Several years ago, a retiring doctor at work said that we should treat every person as if they were 'the Queen'; that is, every person should get the best service irrespective of who they are or where they live. This has always stuck with me. I try to do my best for each person I meet. Some people I meet have not been treated well within the health system, pushed aside or labelled 'non-compliant'. It is easy to turn away, but with what I have come to learn over time is that these people need more help, not less. I believe that if people have what they need, when they need it (or even before they need it), they are able to keep doing what they need or want to, and feel safe and secure doing it. If we get it right, people can live well. Despite working hard to provide good health services, it no longer feels like I am able to meet the needs of those people in our community. Rather than being proactive, the demands on our service means we are always reactive; always dealing with a crisis.

Laying bare my forestructures helped me to understand myself as I entered into the study. As Heidegger (1927/1962) said, it is about entering the hermeneutic circle "in the right way" (p. 195). Given my personal and professional experiences of waiting and waitlists, and my own values and beliefs about health, ageing and health service provision, I needed to ensure that I remained open to the possibilities when starting my study.

Summary

Lengthy waitlists for community occupational therapy services have been entrenched within the DHBs. These waitlists block access to timely care. In Northland, community occupational therapy services have remained largely unchanged in relation to the increasing ageing population. As the population in Northland is ageing more quickly, and is already experiencing marked inequities, there is potential for greater inequalities (Office for Senior Citizens, 2015) as demand outstrips service availability.

The complex and diverse needs of an ageing population are placing an increased strain on already under-resourced services. Older adults in Northland, a large, spread out and rural region are experiencing long waiting times to be seen by a community occupational therapist. It is unknown how waiting is experienced by older adults. This study asks, what is the lived experience of community-dwelling older adults waiting for community occupational therapy?

OVERVIEW OF THE THESIS

This study aims to uncover the meaning of 'waiting for community occupational therapy', as experienced by community-dwelling older adults. This thesis is a progression of my study presented in nine chapters. Each chapter is a part of the whole (thesis), which together led me, and leads the reader, towards an understanding of what it means for older adults waiting for community occupational therapy.

Chapter One: Background

This chapter provided the background to this thesis – who I am, why I embarked on this journey, the value of community occupational therapy, and why this research matters. I also discussed why I chose hermeneutic phenomenology and explored my forestructure of understanding.

Chapter Two: Ageing in Place

This chapter draws together the health and socio-political context of ageing in place and the literature, to understand how staying at home is relevant to the experience of community-dwelling older adults waiting for community occupational therapy.

Chapter Three: Literature review

In this chapter, I present the results of the literature review I undertook to determine if my research question had been asked and answered. Through this process, I was unable to find literature that answered my research question. The lived experience of community-dwelling older adults waiting for community occupational therapy had not yet been explored.

Chapter Four: Methodology

In this chapter, I discuss the philosophy underpinning the methodology of hermeneutic phenomenology and how it relates to my study.

Chapter Five: Method

This chapter explains how I engaged with the research process and carried out the research. I describe the initial consultation process, engaging in a pre-understandings interview, and obtaining ethics, through to recruitment, collecting the data, and interpreting the participant stories. This chapter also provides an in-depth description and justification of decisions made and the study's trustworthiness.

Chapter Six, Seven, and Eight: Findings

These are the three findings chapters. Each chapter has an overarching phenomenological theme with several sub-themes describing an aspect of the experience of waiting.

- Chapter Six: drawing on Heidegger's notions of mood, thrownness, and temporality helped explore the ways in which the participants experienced 'the uneasiness of waiting'.
- Chapter Seven: the Heideggerian notion of being-with helped to uncover the relationships the participants have with others, hidden in the ordinariness of waiting.
- Chapter Eight: Heidegger's notion of being-at-home was key to understanding 'the not at-homeness of waiting'.

Chapter Nine: Discussion

In this chapter, I draw together the findings in relation to the literature and bring to light my interpretation of the experience of waiting for community occupational therapy. I also discuss the implications of this research on practice and offer suggestions for further research.

CHAPTER TWO: AGEING IN PLACE

There is nothing like staying at home
for real comfort.
(Jane Austen quote, n.d.)

Introduction

In the previous chapter, I provided the background to what brought me to this study. In this chapter, I situate the study within its health and socio-political context and reflect on the disconnect that exists between policy and practice. I then draw together the literature that explores the different aspects of ageing in place to understand how staying at home is relevant to the experience of waiting for community occupational therapy. I conclude with why the current situation matters.

THE HEALTH AND SOCIO-POLITICAL CONTEXT OF AGEING IN PLACE

Worldwide, most people are likely to live into their 60s and beyond, with one in five people expected to be within this age range by 2050 (World Health Organization [WHO], 2016). In New Zealand, those aged 65 years and older made up 11.5% of the population in 2002. This increased to 15% in 2016, and is expected to continue to increase (Associate Minister of Health, 2016). As the New Zealand population ages, an increasing proportion will experience disabilities. In 2013, 59% of New Zealand adults aged 65 years and older were identified as having a disability (Ministry of Social Development, 2016). Similarly, people with disabilities are also living longer, thus also experiencing and living with age-related impairments (Ministry of Social Development, 2016). Disability, age-related impairments and chronic illness lead to functional decline and activity limitations, which contribute to increased healthcare costs and reduced quality of life (Gitlin, Hauck, Winter, Dennis, & Schulz, 2006).

The health and social needs of the ageing population are an important issue because as this cohort continues to get bigger, greater demands will be placed on existing health and social services. The occurrence of chronic diseases such as heart disease, stroke and cancer (Turcotte et al., 2015), and arthritis and musculoskeletal disorders (Passalent, Landry, & Cott, 2009) are associated with ageing and disability, and have an effect on performance of daily activities, quality of life (Turcotte et al., 2015), home safety and increased risk of falls (Sheffield, Smith, & Becker, 2013). People with these conditions

are more likely to need intervention from allied health therapists, such as occupational therapists, to optimise mobility, function and independence in the community (Passalent et al., 2009). Of concern, those people with the greatest needs may be those who have the least resources and capacity to address their needs (Associate Minister of Health, 2016).

Compared to other age groups, older people are high users of health services (Schofield, Davey, Keeling, & Parsons, 2006), and this usage increases with age (Office for Senior Citizens, 2015). In New Zealand, to be eligible for age-related health services, an 'older adult' is defined as a person aged 65 years and older, or aged 50 to 65 years for those who meet the definition of a 'person with disability' consistent with the 'like in age and interest' policy (HOP Management Team, 2016)[9]. One in six older people in New Zealand are living with three or more long-term conditions (Associate Minister of Health, 2016). Living with multiple long-term conditions is often complex due to the need to engage with numerous services, coordinate appointments, manage medications and cope with any resultant physical or sensory impairments. Managing this complexity, at a time of reducing capabilities, increases the demand for home and community services (Associate Minister of Health, 2016). In 2015/2016, approximately 42% of health expenditure within DHBs in New Zealand was spent on the care of older people and this is expected to increase to 50% by 2025/2026 if services continue to be funded in the same way (Associate Minister of Health, 2016). As this cohort increases, so too does the demand for health services.

Occupational therapists have skills to support rehabilitation and assist older people to remain living in their homes. Systematic reviews have convincingly demonstrated that occupational therapy intervention for older people living at home aided in falls prevention and improved functional ability (Steultjens et al., 2004), moderately improved the function of physically frail community-dwelling older people (De Coninck et al., 2017), and, improved function for frail older adults through the use of home modification interventions (Stark, Keglovits, Arbesman, & Lieberman, 2017). However, to the detriment of older adults' health and well-being, high service demand for community occupational therapy services has resulted in lengthy (and growing) waitlists in New

[9] HOP – Health of Older People

Zealand and internationally (Bishop & Brott, 2019; Harding, Robertson, et al., 2018; Passalent et al., 2009), which limits access to services.

Healthcare in New Zealand

The right to health, a fundamental human right, states that "everyone has the right to enjoy the highest attainable standard of physical and mental health" (Human Rights Commission, 2010, p. 41). The right to health also includes access to timely and appropriate healthcare (Human Rights Commission). Whilst New Zealand has a well-established, publicly funded health system, with various statutory provisions that address a right to health (Gledhill, 2014) and numerous strategies to guide the provision of healthcare, it can be argued that for (older) people waiting for community occupational therapy, their right to health is blocked by the waitlist. The Health Act 1956 compels the Ministry of Health (MOH) to improve, promote and protect public health. It interacts with the New Zealand Public Health and Disability Act (NZPHDA) 2000 "to secure better health outcomes and reduce disparities by improving the health outcomes of disadvantaged population groups" (Gledhill, 2014, p. 162). In spite of this, extended waitlists for community occupational therapy continue to exist across New Zealand (Fryer et al., 2019) contributing to inequity and inequality. The opportunity to enhance the physical, mental, and social health and well-being of disadvantaged population groups, such as disabled older adults, is missed.

There are multiple government strategies that influence healthcare for all New Zealanders, including specific strategies that discuss the needs of, and service requirements for, older people in New Zealand. The Healthy Ageing Strategy (Associate Minister of Health, 2016) sits within the New Zealand Health Strategy (Minister of Health, 2016) to ensure that the needs of older people are recognised and that healthy ageing initiatives and outcomes are achieved. The New Zealand Disability Strategy (Ministry of Social Development, 2016), Positive Ageing Strategy (Office for Senior Citizens, 2015) and Better Later Life Strategy 2019 – 2034 (Office for Seniors, 2019) inform the Healthy Ageing Strategy to ensure government agencies, at all levels, are working towards a vision of society where all people can age positively and older people are valued and recognised within families and communities (Associate Minister of Health, 2016). While all these strategies have some influence on the health of older New

Zealanders, I will summarise the key strategies that support older adults to age well in place.

Ageing in Place. Ageing in place refers to an older person's ability to remain dwelling in their community with the support they need to do so (Schofield et al., 2006). The ability to age in place is supported through the Healthy Ageing and Positive Ageing strategies (Associate Minister of Health, 2016; Office for Senior Citizens, 2015). Ageing in place is a concept that is both politically and fiscally driven. In the first instance, it supports older peoples' preference to remain living in their own homes and communities for as long as possible (Hillcoat-Nalletamby, 2014; Stones & Gullifer, 2016). In addition, the financial advantages for the government to support ageing in place are well recognised (Sixsmith & Sixsmith, 2008). For ageing in place to succeed, M. Parsons, Parsons, and Jacobs (2014) argued that funding for community-based services needs to be prioritised above aged residential care. To support people to age well in place there is a need to: (a) ensure equity in health across population groups, (b) have a health system that supports healthy ageing closer to home, (c) support people to plan for future health and health-related needs, and (d) support the development of age-friendly environments (Associate Minister of Health, 2016). As people age and their needs become more complex, "equitable, timely, affordable and accessible health services" (Office for Senior Citizens, 2015, p. 17) are required. Ageing in place and being able to remain in the community helps to build resilience and facilitate successful ageing (Butcher & Breheny, 2016). Multiple factors help to develop resilience and influence ageing in place. These include physical activity, mental well-being, partaking in healthy behaviours, remaining socially connected (Associate Minister of Health, 2016), adequate income, safety and security, and access to community based support (Schofield et al., 2006). Further, familiar surroundings enable older people to maintain links to social networks and provide a source of stability through times of uncertainty (Butcher & Breheny, 2016). The most common problems identified in being able to support older people to age in place are: the lack of occupational therapy or physiotherapy involvement in service delivery; poor pain control; and, a failure to action rehabilitation to enhance an older person's potential with their daily activities (M. Parsons et al., 2014). Therefore, ensuring older people remain engaged in meaningful occupations, are active, physically healthy, mentally stimulated, and connected in a safe and suitable environment, and have access to the necessary community-based services is imperative in promoting older people's health.

Healthy Ageing Strategy. The Healthy Ageing Strategy (Associate Minister of Health, 2016) sets the strategic direction for the health and well-being of older adults using a life-course approach. The aim of this strategy is to facilitate healthy ageing and independence through coordinated, person-centred services. The strategy identifies that better support is required for those with high and complex needs through to end of life care, and that the right services are provided at the right time and place. To achieve the vision of this strategy, it is understood that both the social and health needs of older people have to be adequately addressed in order for them to remain living well in their homes and communities.

Better Later Life Strategy 2019-2034. The Better Later Life Strategy supersedes the Positive Ageing strategy (Office for Senior Citizens, 2015) and has a vision of a society where "older New Zealanders lead valued, connected and fulfilling lives" (Office for Seniors, 2019, p. 20). This strategy identifies the need to improve access to services, and that services are flexible and available when required.

Together, the Health Ageing and Better Later Life strategies point to the need for timely, coordinated, accessible, effective and equitable services to support older adults to age in place. Responding to older adults' health and disability-related needs is a fundamental aspect of these strategies. Hence, the ability to access community occupational therapy services when needed is integral to realising the vision of these strategies.

Ageing in place: The rhetoric

In a bid to support older people, the New Zealand government adopted and endorsed the 'Ageing in Place' policy to advocate for older people to remain living in their homes and communities. The Government has recognised the social and financial benefits of ageing in place in the context of a rising ageing population. The Healthy Ageing Strategy and Better Later Life 2019-2034 Strategy (Associate Minister of Health, 2016; Office for Seniors, 2019) were developed to ensure that "older people live well, age well and have a respectful end of life in age-friendly communities" (Associate Minister of Health, 2016, p. 16). Further, it has been recognised that a 'one size fits all' approach cannot be assumed, as older people are a diverse group of individuals with varying needs, abilities and socioeconomic backgrounds. With ageing, health issues become more acute and complex, and a high percentage of the older population are classed as disabled (Office for

Senior Citizens, 2015). These strategies have identified the need to improve access to health services, to ensure that access to these services is equitable, and importantly, that services can be accessed when needed (Office for Seniors, 2019). Services that provide healthcare for older adults need to work for their users and be responsive to their needs.

Ageing in place: The reality

While these high-level strategies are implemented and endorsed at government level, in reality, there has been little change in Northland community occupational therapy services over the 20 years I have been employed by the DHB. What is noticeable and palpable are the rising waitlists to access community occupational therapy services, which sit alongside the increasing, ageing population who are ageing in place. My observations are consistent with a commissioned DHB occupational therapy workforce assessment report (Valentine, McLean, & Rahiman, 2017), which similarly identified that: demand for occupational therapy services was being driven by an ageing population presenting with complex conditions and chronic illnesses; new models of care had contributed to increasing service demand, particularly for services in the community; and, the employed workforce had not kept up with increasing service demands. This pressure on community occupational therapy services is occurring nationally.

The Healthy Ageing and Disability Strategies (Minister of Health, 2016; Ministry of Social Development, 2016) have a strong focus on providing better support for older people with high and complex needs and for people with disabilities so that they may live independent and productive lives. Community occupational therapy practice is congruent with these strategies, but the constant demand for community occupational therapy services and subsequent waitlists inhibits responsiveness to the needs of these people. Further, community occupational therapy practice has become narrowed by the pressure to see as many clients as possible (Carrier et al., 2010; Fryer et al., 2019). In practice, intervention is limited to essential activities of daily living within the home environment, with little to no opportunity to explore or enable occupations outside of the home.

Community occupational therapy services are not working for service users due to the inability to respond to their needs in a timely manner. The MOH service specifications, which specify a referral response time (Appendix A: Ministry of Health Framework) do not reflect what is occurring in real time. Lengthy waitlists to access the service have not

been adequately addressed, meaning service users can be waiting many months (or years) for the support that they need. Whilst urgent or high priority referrals should not get placed onto the waitlist, given that therapists carry constant large caseloads and cover wide geographical areas, it is not always possible to respond to referrals identified as 'urgent' or 'high' within the specified timeframes. These individuals may still have to wait. With a rising ageing population and increasing referrals into the services, clients prioritised as 'medium' or 'low' could be waiting too long, or indefinitely, as higher priority referrals are continuously placed ahead (Harding, Lewis, Snowdon, Taylor, & STAT Research Group, 2018; Raymond, Demers, & Feldman, 2018). The MOH has recognised the need for accessible and effective disability support services, yet existing service structures have not changed to meet the needs of older adults ageing in place, and are not prepared for the increasing ageing population.

The waitlists to access community occupational therapy sit side-by-side with Government strategies, yet remain hidden, invisible to those people who can make change. On one hand, the Government wants older people to remain at home, to age in place and receive the services that they need to achieve this. On the other hand, there have been few changes made to the services that can provide this help. Occupational therapists can make a difference to the lives of older people in the community (De Coninck et al., 2017; Gitlin et al., 2006; Sheffield et al., 2013; Stark et al., 2017; Steultjens et al., 2004). Waitlists exclude individuals from accessing this service.

STAYING AT HOME MATTERS

The ability to stay in one's home, to age in place, is preferable to many older adults. In many societies, particularly in Western societies, individual autonomy and independence is highly valued (Lloyd, Calnan, Cameron, Seymour, & Smith, 2014), and 'home' is seen to be the place that fosters one's independence, freedom, choice, and self-determination. Admission into residential care is not something that people look forward to (Rodgers & Neville, 2007). Rather, for many older adults, the progression to residential care is feared (Stones & Gullifer, 2016). Older adults perceive that moving into residential care will result in the loss of their independence, choice (Hillcoat-Nalletamby, 2014), control and privacy (Stones & Gullifer, 2016). What is more, going into residential care can be seen as 'the last stop', pointing to one's "imminent, literal and metaphorical death" (Stones & Gullifer, 2016, p. 462).

‘Home’ provides a refuge from the outside world, a place of privacy, safety and security. ‘Home’ fosters a sense of self and well-being (Board & McCormack, 2018), is a space to restore oneself out of sight and away from the world outside (Green, Sixsmith, Ivanoff, & Sixsmith, 2005), and is a place to let go and be yourself, a place of comfort and centering (Rowles, 2009). ‘Home’ provides the older person with things, and traditional or habitual ways of doing things. This gives order and purpose to life (Wrathall, 2005).

The premise of ageing in place is that older people benefit from living in their homes. Not only does this positively contribute towards increased well-being, social participation and healthy ageing, but it is economically less expensive than placing older people into residential care (Sixsmith & Sixsmith, 2008). Thus, preserving older adults’ functional independence is, or should be, a public health priority (W.-J. Lee, Chen, Peng, & Chiou, 2016). Ageing in place “is not a one-size-fits-all concept” (Pani-Harreman, Bours, Zander, Kempen, & van Duren, 2021, p. 2050), rather, it is determined by the uniqueness of each older adult’s values, preferences, socio-economic status, and cultural background.

To stay at home

An extensive body of literature explores various aspects of ageing in place and considers why older people choose to stay at home. Even when challenged by their physical decline, older adults prefer to, and attach great importance to, living at home in their community for as long as possible (Fjordside & Morville, 2016; Hillcoat-Nalletamby, 2014; Lambotte et al., 2019; Stones & Gullifer, 2016). The values most strongly associated with staying at home are autonomy, choice and independence (Gabriel & Bowling, 2004; Schofield et al., 2006). Being at home means being able to do the things that matter in a way that matters.

Maintaining functional independence in older age is seen to be integral to preserving a sense of independence and staying in one’s home (Hillcoat-Nalletamby, 2014). In other words, older adults maintain a strong focus on being able to contend with, and do, the everyday activities required to live at home. However, many older adults are synchronously contending with chronic disease and disability, which can affect managing daily activities (Sheffield et al., 2013; Turcotte et al., 2015). Frailty, loss of energy and reduced function have the potential to transform ‘home’ into a place of isolation, fear and vulnerability (Sixsmith & Sixsmith, 2008), which can undermine an older person’s

confidence to stay at home. As people are interconnected with their environment (Hooper & Wood, 2019) the suitability of the home environment becomes important. As people age, the environment can either facilitate their independence, quality of life, health, and ability to stay at home, or become an insurmountable barrier that constrains healthy ageing and ageing in place (Sixsmith & Sixsmith, 2008).

To stay at home can bring a sense of mastery and control over one's life, which older adults highly value (W.-J. Lee et al., 2016). Equally, maintaining mastery and control supports successful ageing in place (Stones & Gullifer, 2016). Being able to act or do things enhances one's sense of control and self-reliance (Green et al., 2005). Being in one's own home enables older adults to make their own decisions, thus conferring a feeling of 'being in charge' and leading a life based on their own personal values (Fjordside & Morville, 2016), even when the ability to live at home is severely restricted (Sixsmith & Sixsmith, 2008). Because of the culturally embedded emphasis on being autonomous, many older adults assign meaning and importance to staying in their own homes.

The ability to cope and adapt to changing circumstances is seen to be an important determinant in the ability to stay at home. Older adults may manipulate their home setting (Rowles, 2009) in order to be as independent of help for as long as possible (Fjordside & Morville, 2016). Nonetheless, declining functional ability and ill health is an ongoing threat to the older adult's autonomy, choice and their ability to stay at home. While older adults may dread becoming dependent on family members or having strangers in their home (Lloyd et al., 2014), they must decide whether or not to accept help from others in order to continue to stay at home. The literature exploring older adults' willingness to accept help is broad, and preparedness to accept assistance depends on the person's perception of independence (Canvin, MacLeod, Windle, & Sacker, 2018). For example, on one hand, recognising and accepting help as a means to stay at home, and on the other hand, rejecting support to preserve a sense of self-sufficiency (Canvin et al., 2018; Fjordside & Morville, 2016; Hillcoat-Nalletamby, 2014; Lloyd et al., 2014). The individuality of older adults is illuminated as decisions made about whether or not to accept help, and from whom, reflects their personal preference in the effort to stay at home. Typically, in New Zealand European cohorts, similar to other Western societies, autonomy and independence is highly prioritised (Schofield et al., 2006). Conversely,

dependency has been seen as a weakness and something to be avoided (Sixsmith & Sixsmith, 2008). However, for many Māori this is different. Butcher and Breheny (2016) explain that Māori embrace interdependency to achieve autonomy; rather than avoiding relying on others, through the values encapsulated by whakawhanaungatanga[10], older Māori think about who they can depend upon to successfully age in place.

To be at home

To age in place in the familiarity of one's home shapes people's identity and well-being (Rowles, 1991). Being in place is being 'at home' (Rowles, 2009), which provides a sense of safety and security. 'Home' is a familiar place. It is a "special space experience which has something to do with the fundamental sense of our being…" (van Manen, 2016, p. 102). It is where one dwells, a place where one may define or express oneself through the space in which one lives, with familiar furniture or objects within. Likewise, the familiarity of the space and how it is used becomes taken-for-granted and subconscious as the body unassumingly adapts to the space. There is a comfort in the familiarity of habit (Rowles, 2000) and being at home.

Older adults have a strong attachment to place. This attachment is not just to the physical things at home, but also the associated memories, experiences, security, familiarity, sense of belonging and the connection between their past and present self (Pani-Harreman et al., 2021; Sixsmith & Sixsmith, 2008; Stones & Gullifer, 2016). For Māori, their connection to their birthplace is significant and central to their identity (Butcher & Breheny, 2016). Being in place is being-at-home. According to Seamon (2002), people become bodily and emotionally attached to their geographical world. This attachment is experienced as at-homeness; at-homeness is the familiar pattern of continuity and order. The real sense and significance of home with its accumulated layers of meaning over time contributes to the feeling of being-at-home, and the continued desire to stay at home. The things or stuff in one's home, as well as the everyday sounds, smells and textures of home represent the meaning of home and creates an at-homeness (Board & McCormack, 2018). In this way, ageing in place in their home enables the older person to retain a sense of who they are and provides continuity in times of change.

[10] Whakawhanaungatanga – pronounced fah-ka-far-no-nah-tongue-ah – meaning "process of establishing relationships, relating well to others" (Te Aka Māori Dictionary, n.d.-i).

Being at home supports an older person's daily activities. Habitual behaviours or pattern of doing things within time and space are developed over time and understood against the backdrop of the person's life history. These habits underpin the older person's sense of being in place (Rowles, 2000; Seamon, 2002), and enable them to do things automatically. Furthermore, the intrinsic knowledge of their home in its layout and where things are strategically placed supports older people to continue to function effectively. This innate comfort may be a factor in the strong attachment to home and the reluctance to leave (Rowles, 1991). However, ageing, illness and disability can alter the rhythm and routine of daily life. Previously taken-for-granted ways of being at home are disturbed, and the embedded habitual and social patterns of using one's space start to unravel over time. Where home was once a space that enabled freedom of movement and the ability to act, it becomes constraining, and people's relationship with their home slowly alters (Rowles, 2000).

WHY THE CURRENT SITUATION MATTERS

The literature speaks to older adults' strong attachment to home. The familiarity and comfort of home (Rowles, 1991, 2009), in combination with the perceived ability to maintain their autonomy and choice that comes from being at home, buoys older adults' determination to stay there. However, older adults are contending with bodily changes arising from ageing, illness, and disability, which can disrupt everyday routines and the ability to engage in valued occupations. The literature illuminates how these bodily changes can threaten an older person's ability to manage in their home (Sheffield et al., 2013; Turcotte et al., 2015), and consequently undermine their confidence to stay at home (Sixsmith & Sixsmith, 2008).

Community occupational therapists have unique skills and knowledge to assist older adults to be in their home and enable them to do what they need or want to do, and this is supported by research that demonstrates the effectiveness of occupational therapy intervention for improving the function of community-dwelling older adults (De Coninck et al., 2017; Stark et al., 2017; Steultjens et al., 2004). In addition, occupational therapists understand the interconnectedness of the person and their environment (Hooper & Wood, 2019) and the value of 'place' or 'home'. Correspondingly, community occupational therapy contributes to older adults ageing well and ageing in place. The occupational therapy emphasis on maintaining health and well-being through engaging in occupation

(Hocking, 2013; Molineux, 2010) and maintaining functional independence aligns with key Government strategies (Associate Minister of Health, 2016; Office for Senior Citizens, 2015) that support older adults' preference to stay at home. These strategies identify the need for responsive, efficient and effective services that enable older adults to age well in place. This is underpinned by research that emphasises the benefit of supporting older adults to age in place and the corresponding need to maximise an older person's physical and mental health and well-being, and social connectedness to achieve this (Associate Minister of Health, 2016; Hillcoat-Nalletamby, 2014; Schofield et al., 2006). Accordingly, the current situation of prolonged waiting times to be seen by a community occupational therapist matters.

Summary

This chapter has considered the health and socio-political context of ageing in place and the disconnectedness between policy and practice reality. Through the literature review, we come to see why staying at home matters to older people, and how this is relevant to the experience of waiting for community occupational therapy. Being at home not only provides a sense of autonomy, control, and of belonging, but it also enables an older person to retain a sense of self, and provides a feeling of at-homeness amid times of change. In spite of older adults' strong attachment to home and the comfort and familiarity that being at home provides, ageing, illness and disability, are a continual threat to their ability to age in place. Community occupational therapists have the skills to support older people to age well in place, enacting Government strategies that promote healthy ageing and ageing in place. However, people are prevented from receiving the community occupational therapy intervention they need because of the waitlist. In the following chapter, I turn to the literature to establish what is known about older adults' lived experience of waiting for community occupational therapy services.

CHAPTER THREE: LITERATURE REVIEW

New understandings do not arise in a vacuum
but are always built on the foundation of that
which has come before.

(Sutton, 2008)

Introduction

In the previous chapter, I considered the health and socio-political context of ageing in place, and reviewed the literature to understand how staying at home is relevant to the experience of waiting for community occupational therapy. In this chapter, I present my literature review, which I undertook at the start of my doctoral research. A literature review seeks to identify what is already known, which allows researchers to build on previous work, avoid duplication, and identify omissions or gaps (Grant & Booth, 2009). I chose this type of review because my intention was to establish if my research question, *what is the lived experience of community-dwelling older adults waiting for community occupational therapy?* had already been researched, and if so, what was already known about this topic, and whether there were gaps in the literature. It is advised that researchers using a phenomenological approach read very little literature about their research topic at the early stages of their study (Todres & Holloway, 2010) to lessen bias and pre-judgement when entering the hermeneutic circle. Therefore, I completed the literature review and then set the literature aside. I conclude this chapter by drawing together the knowledge gained, and show the gap in the literature, which subsequently became my research focus.

LITERATURE REVIEW

Literature reviews are used to explore published material (Grant & Booth, 2009) in order to identify what literature already exists and whether there are gaps. The articles surveyed can cover a wide range of subject material of various levels of comprehensiveness (Grant & Booth, 2009), and together, provide an overview of the data. However, there are recognised weaknesses of literature reviews, and this includes: a lack of critical appraisal of the evidence (McKinstry, Brown, & Gustafsson, 2014); these reviews typically report on the conclusions of a study rather than providing a description of the research design and results (McKinstry et al., 2014); and, there is potential for bias related to what material is included and excluded (Grant & Booth, 2009), as researchers may select

literature that supports their argument. Considering this 'bias' from a phenomenological approach, a researcher's forestructure of understanding may consciously or unconsciously influence what literature is selected, and how it is interpreted and presented in relation to the research topic.

Searching the literature

The main aim of this literature review was to establish if my research question had been asked, and what was known about the lived experience of community-dwelling older adults waiting for community occupational therapy. I started with a broad exploration of the literature to generate breadth and depth of coverage. I was searching for information about the demand for healthcare, waiting for healthcare, waiting for allied health, waiting for occupational therapy, and the (lived) experience of waiting for healthcare. I then narrowed my search, exploring literature that included older adults in healthcare, older adults waiting for occupational therapy, and, older adults' experience of waiting for healthcare.

Search strategy. My primary search was conducted between February and May 2018. The main concepts and search terms (in square brackets) I used were:

- **healthcare** [healthcare OR health care OR health services OR health access]
- **wait***[11]
- **experience** [lived experience OR phenomenology OR life experience]
- **occupational therap***
- **community** [community OR home setting OR community dwelling]
- **older people** [older adults OR elderly OR seniors OR aging OR age related]

I used various combinations of these search terms using the Boolean AND. I also used phrases such as 'waiting for allied health'. I searched several databases, which included EBSCOhost, Google Scholar, CINAHL, Scopus and OTSeeker.

[11] The asterisks indicate truncation – search strategy to ensure the search included variations of the base word.

Examples of searches undertaken:

- healthcare AND waiting AND experience
- occupational therap* AND community AND older people
- community AND occupational therap* AND wait* list AND older people
- "waiting for allied health"
- experiences AND wait* AND community
- healthcare AND waiting AND experience AND occupational therap* AND community AND older people

I read the abstracts of articles that appeared pertinent to my research topic to determine their value and relevance. I scanned the reference lists within the articles for further literature that appeared to be relevant to the research topic. There were also instances when other people, such as colleagues or my supervisors, pointed me towards literature they had seen or read, for example, an article by Harding, Lewis, et al. (2018). Determining which literature to include was guided by the research question and the inclusion criteria listed below.

Articles were included if they:

- focused on waiting for healthcare services
- explored the experience of waiting for healthcare
- included older people who required support to live in their home
- involved older people accessing or waiting for healthcare in the community
- investigated the effect or experience of occupational therapy intervention for community-based older people
- full texts were available in English

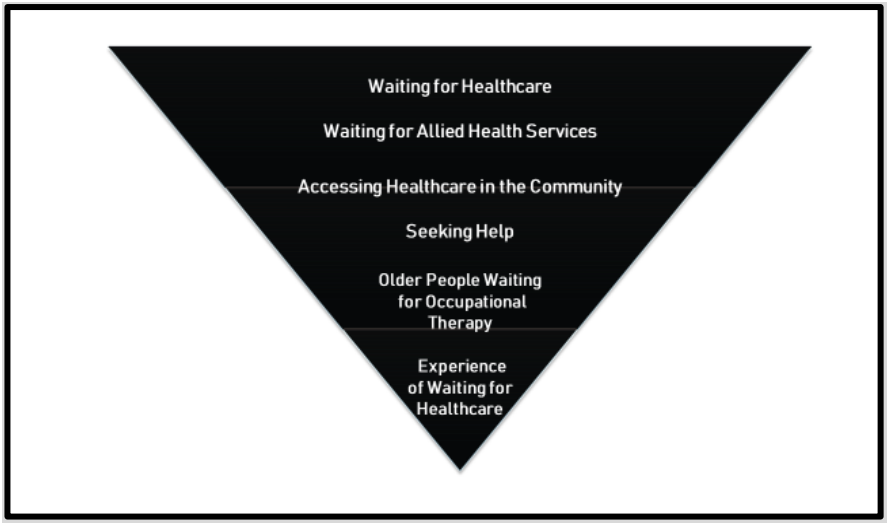
Towards the end of 2021, as I completed my findings chapters, I went back to the literature to see if any research had been published that addressed my research question. My research question had still not been answered but I located four new studies (Bishop & Brott, 2019; Carr, Teucher, & Casson, 2017; McGill et al., 2020; Raymond et al., 2020), which were pertinent and have been incorporated into the review.

Outcome. A wide range of literature was uncovered about the topic of 'waiting' in relation to healthcare. I selected, printed out and read each study that appeared relevant to my research topic. There were approximately forty papers ranging from systematic reviews through to randomised control trials, case studies, phenomenological research, grounded theory, short reports, discussion papers, and an editorial. As I read these articles, it became clear that not all of them were relevant to my research question. Thirty-three articles were included in my final review. Further details of these articles can be found in Appendix B: Details of Articles.

Collating the literature

I collated the literature into six themes to provide an overview of the information collected. Some papers crossed over themes. Figure 2 illustrates how I moved from a broad discussion of the literature related to 'waiting for healthcare', to concentrating on literature more closely aligned to my research question; that is, literature that focused on 'older people waiting for occupational therapy', and 'the experience of waiting for healthcare'.

Figure 2: Collating the literature



The first two themes encapsulate the literature that I located relating to the high demand and consequent wait for healthcare, which underlies my research question. The first theme, *waiting for healthcare*, draws attention to the demand for acute health services, and simultaneously highlights the lack of data for community-based services, pointing to a gap in the literature. The second theme, *waiting for allied health services*, captures the

pressure on allied health services and the resultant wait times for therapy, connecting with the research topic of being on a waitlist for occupational therapy.

Waiting for healthcare. Waiting for healthcare is common in many Western public health care systems (Biringer, Sundfor, Davidson, Hartveit, & Borg, 2015; Fogarty & Cronin, 2008; McGill et al., 2020). Waiting times arise because demand exceeds supply, and a queue for treatment forms (Passalent et al., 2009; Viberg, Forsberg, Borowitz, & Molin, 2013). Time spent waiting for healthcare is often used as a measure of patient satisfaction with services. Long waiting times lead to patient dissatisfaction with organisations and service providers (Kolehmainen, MacLennan, Francis, & Duncan, 2010; Rittenmeyer, Huffman, & Godfrey, 2012). Conversely, timely services are highly valued by patients and clinicians alike (Kolehmainen et al., 2010), and when waiting times are less than expected, patients perceive staff as being kinder and more compassionate, and their satisfaction with medical care increases (Fogarty & Cronin, 2008). Beyond this, waiting can contribute to reduced health outcomes and ongoing deterioration of an individual's condition (Harding, Robertson, et al., 2018), which can be associated with poorer physical functioning, quality of life and health status (Biringer et al., 2015).

Waiting for healthcare concerns patients, health workers and policy makers. Long waitlists for healthcare have been, and continue to be, an important health policy issue. Subsequently, the topic of waitlists and wait time statistics means that they can be used for political advantage (Fogarty & Cronin, 2008; Young & Turnock, 2001) because lengthy waiting times can be linked to prolonged patient suffering, dissatisfaction in the public sector (Viberg et al., 2013), and contribute to negative perceptions of the quality of care received (McGill et al., 2020). Young and Turnock (2001) argued that "community care has low public visibility" (p. 254), and as a result, waitlists for community-based services are less visible, and not well represented in the data. In contrast, waitlists for surgical procedures, such as elective surgery for hip replacements, and cardiac and cancer care treatment are visible to the public and are commonly indicated as performance targets for health services, reflecting political agendas (Fogarty & Cronin, 2008; Passalent et al., 2009; Viberg et al., 2013; Young & Turnock, 2001). Public reporting of the quality and performance of healthcare and healthcare providers is

said to help improve accountability, empower people to make informed choices and provide policy-makers with knowledge about service performance (Rechel et al., 2016).

International studies, such as those undertaken by Viberg et al. (2013) and Rechel et al. (2016) aimed to compare data regarding waiting times for healthcare across countries. These studies included 23 Organisation for Economic Co-Operation and Development (OECD) countries and 11 high-income countries respectively. Both studies included New Zealand, Australia, England, USA and several European countries where waiting time statistics are routinely collected. However, significant differences in how countries collected and measured waiting times meant that comparisons were not possible. Nonetheless, the most common measured waiting time was for elective surgery (Viberg et al., 2013), and the most common data made available to the public were for waiting times for hospital treatment and hospital-based patient experience (Rechel et al., 2016). This data is collected to gauge effectiveness of policy and resources (Young & Turnock, 2001). However, by simply focusing on the statistics of time spent waiting for hospital-based services, only particular aspects of waiting have been captured. Carr et al. (2017) argued that existing research has often focused on how long patients can tolerate waiting and the effect this has on symptom severity and quality of life, with little emphasis on the subjective nature of waiting. Accordingly, qualitative data related to the experience of waiting for healthcare have not been adequately captured, and consequently, are unable to be reported on.

The data produced from these quantitative studies confirm the existence of waitlists across healthcare services, but these studies primarily focus on acute services; waitlists for community-based services remain hidden. While studies have shown the association between lengthy wait times and dissatisfaction of care in the public health sector, these quantitative studies do not consider the impact and experience of waiting, and what this may mean for (older) people. This subsequently also reveals a gap in understanding the subjective experience of waiting.

Waiting for allied health services. In the process of conducting the literature review, I identified several studies that highlighted the high demand for allied health services, such as occupational therapy. The studies presented below do not solely focus on older adults, but look across the wider population who are accessing and waiting for allied health intervention. Such studies provide information about the context in which waiting

is experienced, and a general description about its impact on those waiting. One such study demonstrated how allied health services for young adults with a disability, living in rural areas of Australia, were difficult to access due to high service demand and subsequent lengthy waitlists. This was further complicated by geographical location and long distances from services (Gallego et al., 2017). This study highlighted how delayed access to therapy not only affected the young adult, but also their family and carers. In other studies, Kolehmainen et al. (2010) explored access to paediatric community occupational therapy services and Birch and Adams (2008) explored the experience of informal carers whose family member had previously accessed occupational therapy services. These studies, undertaken in the United Kingdom, both illustrated high service demand, which consequently gave rise to lengthy waitlists and long waiting times for therapy (Birch & Adams, 2008; Kolehmainen et al., 2010). Although it was reported that occupational therapy intervention was valued, once it had been received, one of the concerns identified by informal carers was that the service was not available when it was needed (Birch & Adams, 2008).

An Australian based study drew attention to the high demand for speech-language therapy services for children and adults (McGill et al., 2020), and also identified a similar trend in Canada, Scotland and Ireland. Delayed speech-language therapy exacerbated, or prolonged, communication or swallowing difficulties. Living with these types of difficulties had negative implications that extended into many aspects of people's lives, particularly for children, as these difficulties persisted into adolescence and adulthood. In a different study, Bishop and Brott (2019) examined the growing pressure on a regional community occupational therapy service in New Zealand. The researchers observed that the waitlist had "dramatically increase[d] year on year since 2014" (p. 19), and that the escalating demand was due to a combination of factors, which included: the increasing complexity of client needs; inadequate resources to cover staff on leave; and, service delivery inefficiencies such as processes that did not maximise time for completing home visits.

Together, these five studies bring to light the high demand for allied health services and subsequent delayed therapy because of the waitlists. What is more, is that these studies reveal how delayed therapy can negatively impact on the individual's condition and their

well-being (Gallego et al., 2017; McGill et al., 2020), thus pointing to older adults' experience of waiting for community occupational therapy.

In the next two themes, *accessing healthcare in the community* and *seeking help*, I continue to maintain a broad view of the literature. However, as my study seeks to understand the experience of older adults waiting for community occupational therapy, in the first of these themes, I draw on studies that focus on older people accessing care in the community. These studies provide a context to how older adults may experience accessing care in the community, however, there is no specific data related to accessing community occupational therapy services. In the second, I discuss the literature that provides some insight into how older adults experience and respond to a decline in their function, and when they subsequently seek help from healthcare services. Lost function is typically associated with the need for occupational therapy, and correspondingly relates to the experience of being on a waitlist.

Accessing healthcare in the community. Older people want to remain independent, maintain their quality of life, and live at home for as long as possible. To achieve this, older adults need to be able to access supportive services in the community (Bien et al., 2013). Therein lies the connection to the research topic. This growing, ageing population is placing an increasing demand on existing health services across the continuum of care (Passalent et al., 2009), resulting in lengthy waitlists and wait times for services, such as community occupational therapy. One study, which explored older people's reasoning about prioritisation in healthcare, found that many older people would be willing to pay for healthcare to avoid waiting if in a financial position to do so (Werntoft, Hallberg, & Edberg, 2007). However, it was also identified that those aged over 85 years were more likely to choose to stay on a waitlist irrespective of their financial situation. Within this study, the researchers recognised the diversity inherent within their cohort and how the range of personal attributes of the participants influenced their decision-making regarding prioritisation. This was evident as several polarised perspectives were revealed. For example, some older people felt that people should be treated in order of succession while conversely, another group felt that there is a need to prioritise those who were most severely unwell. There was also a belief that while everyone should receive treatment, younger people who were working and were contributing to the economy should be prioritised above older people. On the other hand, some participants felt that older people

have less time left and should not have to spend their remaining time waiting. This type of study illuminates the complexity inherent within qualitative research exploring waiting for healthcare. People have differing values and expectations, which similarly occurs in clinical settings. Accordingly, the study by Werntoft et al. (2007) helps to enrich our understandings about subjective experiences within healthcare, and provides an insight into how older people rationalise waiting for healthcare.

Many disabled older people depend upon health and social services to remain living in their homes. Accordingly, they require easy access to engage with community services that address their needs. Failure to meet the needs of older people through poor service provision has been found to have serious consequences for older people (Bien et al., 2013). The findings from a comparative cross-sectional study across six European countries, comparing older adults' service use, identified the need for integrated services (Bien et al., 2013). The study showed that in countries with less developed social services there was a greater unmet need, which resulted in poorer quality of life for the older person and their family carer. Although it was recognised that poor service provision affected older adults' quality of life and their ability to remain at home, this study did not identify the impact of delayed service provision. Despite this absence, this study connects to the research topic as it draws attention to the complex needs of older people living in the community, and the consequence of poor service provision. This study also highlights the need for integrated services, which includes occupational therapy, to support older people and their carers, to live at home.

Given the prevalence of chronic disease and complex conditions in older people, and the projected population increase, Ho, Kuluski, and Im (2017) determined that the needs and experiences of people with multi-morbidity accessing care in the community needed to be better understood. Subsequently, they undertook a study, which focused on accessing care in the community. It became clear that this study was not purely about provision of care in the home; this study primarily explored the ability of individuals to access care in the community. Relevant to my research, Ho and her colleagues' study found that for many people with multi-morbidity, accessing community care was a difficult experience that involved trying to navigate through multiple services, each with their own entry criteria and waitlists. This issue was also recognised by Young and Turnock (2001), and discussed by Birch and Adams (2008) who similarly identified the difficulty carers

experienced navigating the system when supporting family members in the community. Together, these studies suggest that healthcare systems have not adapted to support older people in the community to access and engage with healthcare services.

Seeking help. Literature sheds some light on how older adults may respond to lost function and when they may seek help. People who acquire disability in later life may experience a gradual process of disablement and will spend energy and attention to restore their capabilities (Verbrugge & Jette, 1994), and reduce the gap between personal capability and environmental demand (Stark et al., 2017; Verbrugge & Jette, 1994). Older people utilise coping strategies to adapt to ageing (Canvin et al., 2018; Golant, 2015; Raymond et al., 2020), maintain their ability to participate in valued occupations and preserve their quality of life (Levasseur & Couture, 2015). Coping strategies employed by older people have been broadly described as problem-focused, emotion-focused (Levasseur & Couture, 2015), assimilative (action) and accommodative (mind) (Golant, 2015). Of relevance to the research topic, is that the use of assistive devices or technology, largely provided by occupational therapists, is identified as the most relied upon coping strategy employed by older people living in their home (Stafford, 2017). Research has shown that older people living at home benefit from assistive devices and technology introduced by occupational therapists, as it enhances their control over daily life, which in turn, maximises their participation and quality of life, improves function and reduces mortality risk (Gitlin et al., 2006). However, the literature also shows that when older people are unable to implement strategies to exert control over their environment, they may experience a threat to their self-esteem, perceived self-efficacy and mastery (Heckhausen & Schulz, 1995). In another study, it was found that older people who employed escape-avoidance strategies, a type of emotion-focused coping strategy, experienced lower participation and quality of life compared to participants who utilised alternate strategies, such as seeking social support (Levasseur & Couture, 2015). Over and above this, Golant (2015) argued that "even the most successful adaptations may not result in older persons bouncing back or returning to their original equilibrium position" (p. 79). Consequently, a 'new normal' is experienced; lost activities may not be replaced, or the continuity of their past life is not able to be maintained. This infers that timely occupational therapy intervention is necessary for older adults to prevent or minimise irreversible functional decline, connecting this literature with the research question.

Older people are recognised as high users of health services. However, I found two studies that offer a different perspective to older adults' health-seeking behaviours. These studies illustrated how older adults may delay seeking help, which subsequently points to the need for responsive services when they do eventually ask for help. One of these studies found that older adults may keep away from using available services due to access barriers, or avoid assistance to preserve their independence and maintain an image of self-reliance (Canvin et al., 2018). Further, this study found that older adults tended to "avoid assistance and treat public services as a last resort even in urgent circumstances" (Canvin et al., 2018, p. 472). This hesitation to seek help is corroborated by Gramstad, Storli, and Hamran (2013) who identified that the older adults in their phenomenological study did not see themselves as needing help, or were in denial of the ageing process and the consequent change in need, or, they were embarrassed to discuss difficulties with performing everyday activities. As such, they delayed seeking help, with some people in the study waiting up to nine years.

Canvin et al. (2018) established that older people did not present to services for minor issues, instead, adapting to changes in their function and circumstances through implementing coping strategies. They would modify their behaviour, environment and expectations, and ask for help from family or pay privately for assistance. This study uncovered that for older people, recognising and then acting on the need for help was a gradual process. Similarly, Gramstad and colleagues (2013) revealed how older adults endured through their difficulties to maintain their everyday life. The participants "were creative and assertive in managing their problems… [they] changed and adjusted their habits" (p. 290). Asking for help was a last option when all other options were exhausted. This study exposed that the process of recognising and initiating the decision to request help can be prolonged and subtle because older people do not always recognise their difficulties. Importantly, these two studies highlight that when older people acknowledge the need for, or the potential of, assistive devices to improve their situation, it is important that intervention is then promptly provided.

Supporting older people to maintain their abilities and restore control is important to facilitate their decision, and subsequently their ability, to stay at home. Older people may have tolerated, endured or managed with their limitations for months or years before recognising the need to ask for help. The value of introducing environmental changes and

control-oriented strategies as soon as possible after the request for help has been made is recognised in the literature (Gitlin et al., 2006; Gramstad et al., 2013). Self-care activities such as bathing and toileting can be complex to perform, and for those who are only just managing, a small environmental change, such as a rail, can have a significant impact in supporting functional abilities (Gitlin et al., 2006). In the current healthcare environment of high service demand and lengthy wait times for support, the older person will likely have to wait for community occupational therapy, meaning that they may not receive the right help at the right time.

In the final two themes of this review, I analyse the literature to understand the phenomenon closest to my research question. The theme *older people waiting for occupational therapy* captures the embeddedness of waiting for occupational therapy. However, the research on this topic does not capture the subjective nature of waiting for occupational therapy, nor does it provide an understanding of how older adults experience being on a community occupational therapy waitlist. The final theme, *the experience of waiting for healthcare,* brings to light the lack of research exploring older adults' experience of waiting for healthcare.

Older people waiting for occupational therapy. There is limited research examining wait times for allied health services, particularly occupational therapy (Passalent et al., 2009), highlighting a gap in the literature. A study exploring wait times across publicly funded outpatient and community occupational therapy and physiotherapy services in Ontario discovered that of the total number of people waiting, just 16% were waiting for occupational therapy services. However, of those people waiting for occupational therapy, 49% were waiting for *community* occupational therapy. In comparison, only 6% of people were waiting for community *physiotherapy* (Passalent et al., 2009). This study exposed the imbalance of publicly funded allied health services in Ontario, but did not identify why these imbalances existed. Related to the research topic, the authors recognised that there were no guidelines to benchmark acceptable wait times for community rehabilitation services and they highlighted the need for further research to explore the adverse consequences of delayed services.

More recent research shows that a delay in occupational therapy can potentially compromise an older person's safety, health and community participation, leading to hospitalisation or premature entry into residential care (Raymond, Feldman, Prud'homme,

& Demers, 2013), and reducing the person's ability to benefit from services when they are eventually received (Raymond et al., 2020). Given that older people are being encouraged to age in place, the rising prevalence of age-related disability and chronic disease is increasing the demand for rehabilitation and community occupational therapy, resulting in waiting lists for assessment and intervention (Harding, Robertson, et al., 2018; Passalent et al., 2009; Raymond et al., 2013). Despite a body of evidence establishing the effectiveness of occupational therapy intervention (De Coninck et al., 2017; Gitlin et al., 2006; Sheffield et al., 2013; Stark et al., 2017), waitlists have been present for decades (as shown in the article published by Grime in 1990). Adding to a changing healthcare milieu is the increasing pressure to shift care from hospitals into the community. Inevitably, the demand for community health services such as occupational therapy is going to continue to rise (Harding, Robertson, et al., 2018; Passalent et al., 2009). Under the circumstances of an increasing ageing population who want to stay at home, De Coninck et al. (2017) argues that there is a need to invest in community-based occupational therapy services, which is similarly supported by Canvin et al. (2018) who recommends improving the availability and accessibility of assistance.

Due to high service demands, prioritising referrals for community occupational therapy service is common practice in New Zealand and internationally (Bishop & Brott, 2019; Grime, 1990; Raymond, Demers, & Feldman, 2016; Raymond et al., 2013). Prioritisation ensures that those people with the greatest risk, urgency and/or needs are seen first. Prioritising patients correctly is important, as patients deemed low priority may wait many months or years (Raymond et al., 2013), or may never get access to care (Harding, Robertson, et al., 2018). Understanding what is important to older people may help with prioritising referrals. In a small exploratory-type study Raymond et al. (2020) uncovered that older adults strove to maintain their independence and prioritised their personal hygiene and ability to get out of their home in order to engage in social activities, over the risk of falls. Although a small study, it highlighted the importance of understanding the preferences of older people waiting for occupational therapy services as this could influence service priorities, which are typically focused on safety and falls prevention.

The experience of waiting for healthcare. There is a paucity of research related to understanding the complexities of the experience of waiting for healthcare (Carr et al., 2017), and what research has been undertaken has primarily concentrated on waiting for

medical or surgical services. Fogarty and Cronin (2008) conducted an analysis of the concept of waiting for healthcare from the client perspective drawing on published research. The literature they included was predominantly focused on medical and surgical services and did not include allied health service provision. Their analysis identified strong adverse emotions and consequences associated with 'waiting for healthcare', which included: loss of control; disappointment with treatment; stress, anxiety, anger and frustration; reduced physical activity; low morale; changes in family and social relationships; and, feelings of powerlessness and uncertainty.

A systematic review, which aimed to identify and evaluate existing research related to the experience of waiting in healthcare, resulted in two synthesised findings following the analysis of 39 studies (Rittenmeyer et al., 2012). Although a small number of studies in the review included older adults, the review focused on waiting for lab test results, diagnostic procedures, and medical or surgical interventions, hence, studies that focused on occupational therapy or allied health services were excluded. The findings from this review established that waiting for healthcare was a fearful, turbulent and sometimes torturous experience that produced feelings of anxiety and frustration, and a loss of autonomy due to lack of choice. The authors also illuminated how waiting is deeply entrenched within healthcare culture, exposing the disconnect that exists between the patients' and providers' perception of waiting, because those who work within healthcare considered 'waiting' normal – that is how it is.

Using phenomenology, Walker (2009) explored the lived experience of adults waiting for public healthcare in Canada. Her results suggested that patients waiting for medical and surgical care endured significant pain, anxiety and suffering. Almost all the participants had decided to find their own solution via the private health sector stating that they 'could not wait'. Likewise, Biringer et al. (2015) used phenomenology to explore the lived experience of adults waiting to access mental health services. Several themes evolved from their research, of which, coping with symptoms and challenges by being active and taking control was one. Despite the theme of 'coping' emerging, the researchers revealed the dominance of waiting as being problematic and challenging, which outweighed the "desperate creativity" (p. 4) participants employed to find ways to cope in the wait. Similarly, Carr et al. (2017) drew on interpretive phenomenological analysis to explore patients' experience of waiting for either cardiac, hip, knee or shoulder surgery. The

participants, aged between their early 40s and late 80s, described a range of waiting experiences. This study highlighted the complexity and individuality of the experience of waiting. In common with other studies, the undesirable emotions of anger, frustration and depression emerged. Further, the researchers identified waiting as a barrier to the restoration of daily function. Although participant details were not made clear, it was intimated that some of the older participants experienced waiting as an opportunity, 'a gift of time', in comparison to those participants who were working and assumed to be younger, who did not experience this. Phenomenological studies aim to illuminate the uniqueness and diversity of experiences to enhance one's understanding of the phenomenon. Accordingly, the reader needs to consider the findings and their transferability to other situations. As I read across these studies, there was congruence between the findings from these three phenomenological studies with the larger reviews undertaken by Fogarty and Cronin (2008) and Rittenmeyer et al. (2012), specifically, the strong adverse emotions experienced by people waiting. However, none of these studies have exclusively focused on older people's experience of waiting for healthcare services nor waiting for allied health services, nor community allied health services.

What is the knowledge gap?

What we know. In Chapter Two, the literature showed that older adults have a strong attachment to their home, and the importance they place on being at home and ageing in place. However, the literature also showed that ageing, illness and disability can threaten their ability to stay at home. Self-care activities such as bathing and toileting can be difficult to perform. For those just managing, a small environmental change can have a significant impact in supporting functional abilities (Gitlin et al., 2006). Occupational therapists are able to address these everyday difficulties faced by older people living in the community, by reducing environmental barriers, selecting and prescribing assistive devices and teaching adaptive strategies (Gitlin et al., 2006; Stark et al., 2017). However, lengthy waitlists are well established, and the rising number of older adults is generating an increasing demand on services. Simultaneously, the pressure to shift care from hospitals into the community is intensifying the demand on community health services (Harding, Robertson, et al., 2018). Consequently, community occupational therapy waitlists are likely to continue to lengthen.

‘Waiting’ for medical, surgical or diagnostic services has been researched using both quantitative and qualitative methods. The waiting has been described as stressful, fearful, frustrating and torturous, and the endless waiting can negatively affect the patient’s physical activity, and family and social relationships (Fogarty & Cronin, 2008; Rittenmeyer et al., 2012). That said, there is limited literature exploring wait times for community occupational therapy services (Passalent et al., 2009). However, since 2009, there have been studies published that examine how referrals are prioritised and improving access to community occupational therapy services (Bishop & Brott, 2019; Harding, Lewis, et al., 2018; Raymond et al., 2016; Raymond et al., 2013), suggesting that waitlists for community occupational therapy services continue to exist and are well-embedded within services.

Older people may delay asking for help. Literature has shown that older people do not present to services with minor issues and asking for help is often a last resort (Canvin et al., 2018), usually when coping strategies are no longer effective. Consequently, providing intervention at the right time is important (Gramstad et al., 2013). Poor service provision can have serious consequences for older people (Bien et al., 2013). A delay in occupational therapy has been shown to compromise older people’s safety and health, and can lead to hospitalisation or premature entry into residential care (Raymond et al., 2013), and increased mortality risk (Gitlin et al., 2006).

What we do not know. Due to the paucity of qualitative research investigating: (a) the phenomenon of waiting for healthcare, (b) older adults waiting for allied health services, and (c) older adults’ experiences of waiting, it is not known how community-dwelling older adults experience waiting for community occupational therapy. Whilst Gramstad and colleagues (2013) focused on the experience of unmet assistive technology needs, understanding the experience of older adults waiting for community occupational therapy services remains unknown. Gaining an understanding of older adults’ experience of waiting for community occupational therapy may help to improve services.

I was unable to find literature that explored the lived experience of community-dwelling older adults waiting for community occupational therapy, that is, the time from referral to first assessment.

Summary

This literature review provided an opportunity to explore the literature related to the experience of older adults waiting for community occupational therapy. The existing quantitative and qualitative studies uncovered in the review reveal that 'waiting for healthcare' has been researched within various health sectors, including allied health services. Furthermore, it shows that waiting for healthcare exists across services and countries, and that waitlists can be politicised. In addition, the literature identifies that the demand for community occupational therapy will continue to rise proportional to the growing ageing population who are ageing in place.

Existing studies exploring the experience of waiting have predominantly focused on medical and surgical services, and young or middle-aged adults. As increasing demand and pressure is placed onto community occupational therapy services and allied health teams, there is a need to understand the experience of older adults waiting for such services. We currently do not have an understanding of the lived experience of older adults waiting for community occupational therapy services, thus revealing the gap in the literature.

In the next chapter, I turn to the methodology of hermeneutic phenomenology as I used it to search out the meaning of 'waiting for community occupational therapy'.

CHAPTER FOUR: METHODOLOGY

To let that which shows itself be seen from itself
in the very way in which it shows itself from itself
(Heidegger, 1927/1962, p. 58)

Introduction

In Chapter One, I introduced my own view of the world as an occupational therapist and how I came to hermeneutic phenomenology, a methodology congruent with these views. This chapter explores the underpinning philosophies of Heidegger and Gadamer, which are often used simultaneously in phenomenological research, and outlines how I applied a hermeneutic phenomenological approach (methodology) to answer my research question. I describe the origin of modern phenomenology and how phenomenology evolved from descriptive to hermeneutic phenomenology. I then discuss Heidegger and Gadamer's philosophies and van Manen's work on lifeworld existentials, which helped me to interpret the lived experience of waiting for community occupational therapy. I conclude this chapter by summarising the philosophical notions central to this hermeneutic phenomenological study.

PHENOMENOLOGY

Phenomenology is, in its essence, a philosophy (van Manen, 2014). As a methodology, it is used to study phenomena. Phenomenology is an attempt to uncover and describe the essence or nature of an experience, or the way we experience things, from the first-person point of view (D. Smith, 2018). It does not produce facts, absolute truths or empirical generalisations as in positivist research inquiry. Rather, it is about throwing a light on something that is already there, concealed or hidden in our everyday existence, so that one may be able to act more thoughtfully about a given situation.

The phenomenological movement is built upon the early philosophies of Plato and Aristotle, while modern phenomenology, as we know it, was launched by Edmund Husserl at the turn of the 20th century (D. Smith, 2018). Husserl's philosophy gave rise to descriptive phenomenology (Lopez & Willis, 2004; Nelms, 2014), which aims to describe the characteristics of how phenomena are experienced (Tuohy, Cooney, Dowling, Murphy, & Sixsmith, 2013) or appear to the consciousness (Nelms, 2014). Descriptive phenomenology is about the experience itself, not the context of the experience (Tuohy

et al., 2013), which is bracketed and kept aside. Husserl introduced the idea of bracketing; a mathematical tool to keep whatever is in the brackets separate and dealt with separately. In other words, through 'bracketing', the researcher's existing knowledge and preconceived ideas are kept separate from the phenomenon being studied so that the researcher does not influence the outcome, thus interpreting the phenomenon with a neutral mind-set. In contrast to Husserl, Heidegger's position was that as human beings we are always 'in the world' and situated in a context of equipment and other people (D. Smith, 2018). Heidegger's stance was that it is not possible to separate out one's presuppositions; our interpretation of things occurs within a social, political and historical context. This means, that as a researcher, whilst I can make my presuppositions known, they are part of my thinking and who I am; I exist with the phenomenon (Sloan & Bowe, 2014). Heidegger's quest to understand the Being of beings, saw phenomenology evolve from descriptive phenomenology to hermeneutic phenomenology.

My research question and hermeneutic phenomenology

Hermeneutic, or interpretive phenomenology is oriented to what it means to 'be' a person (Koch, 1999), pertaining to the human experience as it is lived. Hermeneutics comes from the Greek verb *hermeneuein*, which translates to "interpret" or "understand" (McManus Holroyd, 2007). My research question, *what is the lived experience of community-dwelling older adults waiting for community occupational therapy?* aligns itself with hermeneutic phenomenology. My research question is ontological; it seeks to understand the nature and essence of what it means to *be* waiting for community occupational therapy.

Hermeneutic phenomenology as a methodology is an interpretive exploration into the lived experience of a particular phenomenon. In this study, the phenomenon is waiting for community occupational therapy. The phenomenon of waiting for healthcare is a popular topic, habitually spoken of by clinicians, or publicised in the media alongside highly emotive narratives. Waiting is often brought into the public world when an individual, or group of individuals' health needs are not being met or something has gone wrong in their wait. In our daily life, we wait for all sorts of things – for traffic lights to change colour, for service in shops, and for appointments to meet our needs. Waiting is embedded in our everyday living. Waiting is a well-known and expected aspect of healthcare service delivery. It is this familiarity, alongside the normalness of waiting for

healthcare, which potentially conceals the deeper meanings of the experience of waiting for community occupational therapy. Further to this, in my experience as an occupational therapist, I have observed that older people, in their determination to stay at home, will do what they can to keep managing at home while waiting for the occupational therapist. This can also keep the phenomenon of waiting, covered over or even disguised (Crowther & Thomson, 2020; Lopez & Willis, 2004). In hermeneutic phenomenological studies, interpretation of text (which in my study is the data comprised of participant stories crafted from the transcribed interviews) is an attempt to reveal or 'point to' something, that is, for the most part, hidden (van Manen, 2016).

Hermeneutic phenomenology goes beyond a simple description of the phenomenon being explored. The methodology considers questions of ontology to understand what it is to be a human being in our everyday life world. In this study, it is an attempt to gain an in-depth understanding of the phenomenon of waiting for community occupational therapy. However, Heidegger reminds us that meanings and truths are often hidden behind the taken-for-granted and subjective accounts (Crowther & Thomson, 2020). For the people in this study, their lived experience of waiting is concealed in their social practices, culture, history and language; it is covered over in their ordinary everyday. To understand waiting "as a living moment *in its livingness"* (van Manen, Higgins, & van der Riet, 2018, p. 6) rather than simply an emotional response, it requires me, as the researcher, to put the text into words and language that illuminates what waiting 'is'. That is, it requires me to construct an interpretive description of the phenomenon of waiting that resonates with people when they read my work; they feel the experience (de Witt & Ploeg, 2006). Hermeneutic phenomenology is steeped in language. It is not only what is spoken, but it is also a form of writing (van Manen, 2016). Language is a way of understanding and then interpreting and articulating the phenomenon. The methodology of hermeneutic phenomenology contains a strong element of interpretation, and Heidegger and Gadamer point out that there is no one interpretation of human experience because there is always the possibility for new interpretations (Crowther & Thomson, 2020). Doing phenomenology is coming to understand that there are many ways of interpreting the phenomenon being studied. My research will offer one interpretation of the lived experience of waiting for community occupational therapy.

Heidegger's hermeneutic phenomenology is the 'study of Being'; a mode or way of being-in-the-world (van Manen, 2016), which captures a way of existing in one's lifeworld. The lifeworld encapsulates everyday experiences (Todres & Holloway, 2010) that are individually shaped by one's historicity[12] and through being in the world, with the possibilities available within it. In occupational therapy, it is understood that human beings are best understood in the context of their environment and that they are interconnected with it (Hooper & Wood, 2019). Similarly, phenomenology is underpinned by the notion that humans exist in a context with things and ways of doing things, and this is what makes humans human (Wright-St Clair, 2015). As a clinician, having this 'knowing', this innate understanding of human beings as 'occupational beings' existing within the context of their lives, is inherent within my clinical practice. My understanding of human beings Being-in their lifeworld aligns with Heidegger's philosophy of being-in-the-world. Gaining an understanding of what it means to be 'waiting for community occupational therapy', could lead to new ways of being an occupational therapist, or, through deepening our knowledge, improve the management of waitlists within existing services.

HERMENEUTIC PHENOMENOLOGY

The philosophies of Heidegger and Gadamer underpin the methodology of this hermeneutic phenomenological study. Their writings have significantly influenced this study. Some brief background information is presented here, followed by a discussion of their philosophies, which are interwoven throughout this thesis.

Heidegger

Martin Heidegger [1889 - 1976], born in Germany to Catholic parents, studied both theology and philosophy, and in 1917-18 became an assistant to Husserl (Harman, 2007). Heidegger built on Husserl's founding philosophy of phenomenology but challenged some of Husserl's assumptions. Heidegger believed that the focus of phenomenological inquiry is the relation of the person to their lifeworld (Lopez & Willis, 2004); humans exist in their world as both an individual and within their social context (Horrigan-Kelly,

[12] Historicity is an existential structure of Dasein. Dasein "*is* its past" (Heidegger, 1927/1962, p. 41); Dasein is oriented towards the future and brings the past with it. We are shaped by our past experiences (Munday, 2009).

Millar, & Dowling, 2016). Their history, culture, and situatedness in the world, shapes their understanding and subsequent interpretation of the world (Laverty, 2003). Heidegger could not accept Husserl's notion of reductionism (Heidegger, 1927/1962) and shifted the emphasis from epistemological concerns to an ontological paradigm of what it means to 'be' a person and how we understand our world (Leonard, 1994).

Heidegger's hermeneutic phenomenology

Heidegger described phenomenology as "the science of the Being of entities… [and] that the meaning of phenomenological description as a method lies in *interpretation*" (Heidegger, 1927/1962, p. 61). Heidegger dedicated his life's work to answering the question 'what is the meaning of Being?'; his fundamental ontology examined the meaning of being and the nature of our existence (D. Smith, 2018). To understand what it is to 'be', phenomenology draws on ordinary experiences. Heidegger believed that the most important mode of being human was in the ordinary everyday of human existence, and that for most of the time we are immersed in just getting on with our lives (Munday, 2009). Therefore, the way to gain a philosophical understanding of the human being is in its average everydayness. Absorbed in our daily activities, we are not conscious of our habitual patterns of behaviour or our actions. The context of one's life 'just is'. As such, we encounter things in a pre-cognitive manner or as pre-reflective experiences; we do not think about what we do. Phenomena remain covered over in the background familiarity of everyday living, and consequently, can remain meaningless (Crowther, Smythe, & Spence, 2014).

Hermeneutics is the theory and practice of interpretation (van Manen, 2016). Hermeneutic phenomenological research aims to describe a phenomenon as it shows itself to gain a deeper understanding of everyday experiences as we live them. It requires the researcher to enter into hermeneutic phenomenological inquiry with an attitude of wonder, openness to the world of others, and unboundedness (Crowther & Thomson, 2020). Through discourse with others or discourse with the written word, a phenomenon can be made visible through language. Hermeneutic inquiry deals not only with the actual text, but also with 'what' the text says and 'how' the text speaks (van Manen, 1997). The text, as such, offers different symbolic views through which an understanding of the phenomenon can be brought to light. Interpreting the textual stories within this study involves going beyond the spoken words and listening for what the words are showing of

the phenomenon. Interpretation is made possible through the commonness of language and being situated within a common culture and historical background. Living in Northland, where my study takes place, means that I have an already-made understanding, albeit partial, of the language and culture of the region. This understanding enables me to enter into and engage in the interpretive process. Through a process of phenomenological interpretation, an ongoing dialectic between the parts and the whole (Crowther et al., 2014), the phenomenon in question, the experience of waiting for occupational therapy, can show itself from itself (van Manen, 2016).

Heidegger asserted that through hermeneutics, the authentic meaning of Being could be articulated (Munday, 2009). In other words, phenomenology is more than how things appear through human consciousness. Rather, through a process of interpretation, a continuous activity of reflection and questioning, the 'being' of that entity as it is, is revealed or uncovered. However, language has a multiplicity of meanings (Gadamer, 1975/2004), and interpretation is always guided by one's innate ways of thinking, which stem from one's history and historicity[13]. Equally, one's history and historicity influences interpretation. Accordingly, one's past experiences should be taken into account in order to be true to the interpretation. Further to this, maintaining an openness to new ideas and re-interpretations can lead to a more enlightened understanding. Therefore, when undertaking hermeneutic phenomenological research, it must be understood that interpretations are open to re-interpretation, and that the phenomenon can never be fully revealed.

Phenomena, for the most part, remain concealed in their ordinariness. Heidegger's (1927/1962) phenomenology is about throwing a light on something that was already there, that is, to "show itself in itself" (p. 51). However, a phenomenon or entity can show itself "as something which it is *not*" (Heidegger, 1927/1962, p. 51). The notions of 'appearance', 'announcement', and 'semblance' are integral when seeking out and understanding a phenomenon. For instance, in this study, the phenomenon of waiting may *appear* in the difficulty participants have doing everyday occupations, but this is hinting at the phenomenon, not bringing the phenomenon to light. Alternatively, 'waiting' may

[13] History refers to past events, whereas historicity is one's understanding and interpretation of the events based on one's past experiences.

announce itself, for example, when the participants spoke of fear and despair. This indicates something of the phenomenon but is not the phenomenon. 'Waiting' is announced through these emotions but remains covered over. What is more, a phenomenon can look like or give the appearance of the phenomenon but is not the phenomenon (semblance). For example, sitting around and doing less could be announcing an ageing body rather than the phenomenon of waiting, which may look similar. Thus, as the researcher, it requires me to remain open to these notions in order to reflect on my interpretations, otherwise the phenomenon could potentially remain concealed.

Heidegger's political activity. Heidegger's view was that "every great thinker has only *one* great thought" (Harman, 2007, p. 15) and that the central tenets of a philosophy guide it through its lifespan irrespective of the life events the philosopher may experience (Harman, 2007). Heidegger also asserted that no philosophy is free from presuppositions, as all philosophy develops from a particular historical standpoint, and that life and environment are inseparable (Harman, 2007). Heidegger himself was born into his world at a time and place that influenced and shaped his life and lived experiences. World War One and the aftermath of the war in Europe influenced Heidegger's early academic career. The opportunity arose to work with Husserl and other people who influenced his thinking at the time, which led him to develop his philosophy. Had he been born at a different time in history, or a different place, then who is to say hermeneutic phenomenology would have evolved in the way it has? Heidegger's key work came about prior to his interest in, or inception into, the Nazi party.

In 1933, Heidegger, as Rector of Freiburg University, joined the Nazi party. It is unclear what Heidegger's motives were for supporting the Nazi regime, and the extent and duration of his support (Harman, 2007). On one hand, he enthusiastically implemented Nazi policy (Wheeler, 2020) and was an avid supporter of Hitler. He gave public speeches and declared his patronage for Hitler. Further to this, he integrated Nazi images and affirmations of support with the philosophy of Being and Time (Wheeler, 2020), and distanced himself from Jewish colleagues and friends. Yet, on the other hand he prevented the Nazi students displaying anti-Semitic posters and tried to prevent several Jewish professors from being fired (Harman, 2007).

Heidegger's decision to join the Nazi party as an active member affected his career, tainted his image, and casts a shadow over his life (Wheeler, 2020). It causes people to question his philosophy because of the association between his philosophy, his political stance at the time, and a 'knowing' of the atrocities which were inflicted by the Nazis. However, as a significant philosopher, and despite his involvement with the Nazis, the underlying premise of his philosophy has survived. There is a continuity of his philosophy between past, present and future.

My reflections. I had to think about embracing hermeneutic phenomenology as I learnt about Heidegger's allegiance to, and involvement with the Nazi party. While some scholars have questioned whether his association with the Nazis could discredit their work (Wright-St Clair, 2008), my thinking was more personal. Hitler's regime directly affected my family. His goal to remove and eradicate the Jews meant my family had to escape from Poland. From stories in my childhood, I am aware how influential Hitler was as a skilled and extraordinary orator. As a child, I met several older people who had survived the war and the concentration camps. It is a period of history that cannot be forgotten. Yet, that era seems far removed from my current life. When I consider Heidegger, a great philosopher caught up in this political movement, I do not feel that I can judge him. He was living in a different time and place and experiencing intense influences that I have not known. This, however, is no excuse for the decisions he made. While some of his actions are objectionable and damaged his reputation, I feel that what is of significance is his philosophy. His original thinking came about prior to his involvement with the Nazis, has withstood time and has encouraged debate, and nurtured an insight of what it means to *be* a human being. His philosophy has provided the foundation for many studies. Phenomena, such as waiting for occupational therapy, which have been explored using alternate methods, can now be explored in a new way, thus providing a depth of meaning not previously known.

I am aware of my own limited knowledge and understandings of much of Heidegger's work, including what he wrote of, or spoke about during his time when he was associated with the Nazi party. Although the actions of the Nazis are unspeakable, and Heidegger was linked to this in some way, I feel comfortable using Heidegger's phenomenology to guide my study based on what I do know and understand. In choosing to use hermeneutic phenomenology, I have come to develop an appreciation of this philosophy, which has

enabled me to explore and capture the lived experiences of older people waiting for community occupational therapy.

Gadamer

Hans-Georg Gadamer [1900 - 2002], a student of Heidegger, extended Heidegger's ontological exploration of understanding (Koch, 1996). He agreed with Heidegger that language and understanding are inseparable, and are key elements of being-in-the-world, and he strove to progress Heidegger's work into practical application (Laverty, 2003). Gadamer's philosophical hermeneutics provides an account of the nature of understanding (Malpas, 2022). He believed that understanding can only come about through language, and language is interwoven with understanding (Sloan & Bowe, 2014), understanding always involves interpretation, and interpretation is always evolving (Laverty, 2003). While Heidegger spoke of the 'forestructure of understanding', that is, our background knowledge and understandings, which can influence understandings and interpretation, Gadamer used the term 'prejudice' (Koch, 1999). All understanding involves prejudices (Gadamer, 1975/2004), which are rooted in tradition (Gadamer, 1996/2016). The concept of prejudice often has a negative connotation, which Gadamer rejected. Prejudice or prejudgment can have either a positive or negative value (Gadamer, 1975/2004). Further to this, understanding and interpretation is shaped by our historically-determined situatedness (Malpas, 2022). Gadamer asserted that prejudices need to be understood, or brought forward when entering the hermeneutic circle. Like Heidegger, Gadamer considered that 'bracketing' one's pre-suppositions was impossible.

Gadamer has a strong emphasis on dialogue and language. Gadamer, through hermeneutics, focused on how language reveals *being* (Sloan & Bowe, 2014). He described the task of hermeneutics "as entering into dialogue with the text" (Gadamer, 1975/2004, p. 362). Dialogue is simply the back and forth of question and answer. However, the art of questioning is the art of thinking, and this 'dialectic' "is the art of conducting a real dialogue" (p. 360). Language is central in hermeneutic phenomenology as it unlocks meaning and allows interaction between people. Language shapes all situations and experiences (McManus Holroyd, 2007) and enables people to make sense of feelings, or relate to each other within a culture (Leonard, 1994). Language enables understanding. Understanding is being in a dialogue that encompasses one's self-understanding and understanding the matter, or text, at hand (Malpas, 2022). Differences

in the social or cultural backgrounds between people having a conversation may lead to difficulties with interpretation (Fjelland & Gjengedal, 1994). Although I have worked in Northland for many years and am familiar with the various social and cultural contexts, and have some rudimentary knowledge of te reo[14], I was aware that the differences in the background and culture between me and the participants could affect my understanding and interpretation of the text. Not only was there a generation gap between us, but I am of European descent. I arranged to meet with the Takawaenga[15] after the stories were crafted to ensure that the interpretation of language used by Māori participants was understood in its context, because, as a Pākehā[16], I have a different standpoint and historicity to the participants who were Māori.

van Manen

Max van Manen [1942 -] is a scholar of note who has specialised in 'doing' phenomenology. His work has helped in my understanding of hermeneutic phenomenology and its application. van Manen's methods are influenced by the work of European phenomenologists from the 1960s. His background in education/pedagogy and phenomenology have enabled him to publish literature and books that support human science researchers, like myself, to draw on phenomenology to understand human beings in the reality of their lifeworld. van Manen (2016) asserts that gaining a real understanding of phenomenology can only be achieved by 'doing it'.

van Manen is not a purely descriptive or interpretive phenomenologist. He pulls together features from both traditions (van Manen, 2016) offering a methodology for engaging in human science research by using language "to make intelligible and understandable what always seems to lie beyond language" (p. xviii). He postulates that language itself can be inadequate to describe an experience, as words can miss the fullness and uniqueness of one's world, yet it is through the "collectivity of language that we can access experience" (p. xiii) and bring meaning to it.

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[14] Te reo – meaning Māori language

[15] Takawaenga – pronounced tuck-a-why-en-ga – meaning "mediator, liaison, intermediary"; "to assume the role of mediator…" (Te Aka Māori Dictionary, n.d.-h). A Māori advisor or support person working in the DHB.

[16] Pākehā – pronounced paa-ki-haa – meaning "New Zealander of European descent" (Te Aka Māori Dictionary, n.d.-g).

van Manen (2016) described hermeneutic phenomenology research as a 'writing' activity, by transforming the lived experience into a "textual expression of its essence" (p. 36). Writing is interwoven into the research activity. Writing aids reflection as it enables the researcher to separate and distance himself or herself from what is known, and simultaneously draw them in more closely. Writing and re-writing allows the researcher to move back and forth between the parts and whole in order to create a piece of writing that brings into the open the hidden meaning of the phenomenon being studied.

I will now draw together what I have learned from Heidegger, Gadamer and van Manen and talk to the key philosophical notions that I have drawn on in my study.

PHILOSOPHICAL NOTIONS

Several fundamental philosophical notions are discussed in Heidegger and Gadamer's work and are essential in understanding and applying hermeneutic phenomenology as a methodology. I have primarily turned to Heidegger to guide my study and the interpretation of the text; hence, I discuss the key notion of Being-in-the-world, which is central to understanding his work and its influence on my study. Other Heideggerian philosophical notions that I have drawn upon to interpret the participant stories are defined in the three findings chapters. In the present chapter, I then move on to discuss van Manen's lifeworld existentials followed by Gadamer's philosophical notions of horizon of understanding, the hermeneutic circle, and language, which are key to ensuring that researchers enter into hermeneutic phenomenology inquiry with an openness to the possibilities that the text presents.

Being-in-the-world

Being-in-the-world is an essential characteristic of Dasein[17], and is the totality of our being. That is, we are inseparable from the world; we are in the world with our history, culture, traditions and previous experiences. We have an innate understanding of the world and the entities within it, which comes from being-in-the-world. It is a familiarity with the world that allows us to live in it; an intuitive understanding of why things are done in the way that they are (Wrathall, 2005). This 'understanding' comes through a

[17] Heidegger uses the word dasein, which comes from the verb 'to exist' or 'to be there, to be here' (Inwood, 2019). It is his way of referring to the human being and to the mode of Being (Wheeler, 2020).

process of interpreting the world from our own horizon and situatedness. This situatedness in the world offers different potentialities-for-being and determines the possibilities that are available or not.

Heidegger (1927/1962) explained that Being-in-the-world is hyphenated to reflect its unified structure; 'Being' and 'the world' are not separate entities but are bound together. Being-in is more than simply being in a physical space, rather, Being-in means 'to dwell' (Heidegger, 1927/1962), and signifies a way of being-in-the-world that feels familiar. Dasein is immersed or absorbed in the taken-for-granted familiarity of its everydayness, involved and occupied with people and things, even when it feels lonely or alienated (Harman, 2007). Human beings are always doing something or experiencing differing ways of Being-in-the-world, such as "having to do with something, producing something, attending to something and looking after it, making use of something, giving something up and letting it go, undertaking, accomplishing, evincing, interrogating, considering, discussing, determining…" (Heidegger, 1927/1962, p. 83). All these ways of Being-in are ways of concern or care. Care embodies Dasein and is a mode of Being that is active in all behaviour. The things that matter show themselves through care. Care is based on being-there and gives meaning to existence because it is a way of being in the world with others and oneself (Cestari et al., 2017).

Lifeworld existentials

Lived experiences occur within the complexity of the lifeworld. Human science research explores the lived world as it is experienced in everyday situations (van Manen, 2016), drawing upon four lifeworld existentials. These existentials (corporeality, temporality, spatiality, and relationality) occur within the lifeworld of all human beings regardless of their history, culture or social situatedness and can be used to guide reflection of the lived experience (van Manen, 2016). Although each existential is described separately, they cannot be considered in isolation. Applying these four existentials, briefly described below, has helped me to interpret, understand and illuminate the experience of 'waiting for community occupational therapy'.

Corporeality. Human beings are "always bodily in the world" (van Manen, 2016, p. 103). The lived body is an "open, incomplete, participatory, sensuous dimension of Being" (Finlay, 2006, p. 21). It merges into the world. Everything we experience, we

experience through and with our body. The uncomfortableness of a changing body is brought forward though the upcoming chapters. Experiencing difficulty performing or attempting to perform ordinary, at-home occupations draws the participants' attention to a body that is not working as it once did, or needs to do, in order to complete ordinary activities. Through using our bodies in everyday activities, we can perceive the world, relate to others and learn about ourselves (The Open University, 2017).

Temporality. Human beings regulate our lives by time. Time is a way of Being. Yet, lived time is subjective; it is our temporal way of being in the world. This time is measured by moments and can be influenced by mood or the environment. It is how we experience time and ascribe meaning to an event (Tuohy et al., 2013). We talk of time going by, sometimes slowed and sometimes fast. Time involves the three-fold structure that is the past, present and future. Time makes up the horizons of the temporal landscape, and at any time, we are influenced by the future and the past. We reflect on our past and anticipate the future. The stories illuminate the complex temporal nature of the lived experience of waiting for community occupational therapy that reflect a future life to come.

Spatiality. Human beings usually think about 'mathematical' space, that is, the spatial dimension of length, height and distances. However, lived space is felt space (van Manen, 2016). It is the space in which the person is. To dwell in a house is not simply to be inside it in a physical way, but rather, to existentially belong there (Wheeler, 2020). Lived space may be experienced differently depending on one's mood or health. The participants' experience of waiting for community occupational therapy show changes to the felt space of home. Spatiality can also refer to the distance of an object, but not in an objective or measured way. Any object when focused upon is brought to our attention and into our awareness (Harman, 2007). Something may be physically far away, but as we focus on it, it is brought closer. The mailbox, the connection to the world outside, which can no longer be readily accessed, is just there, just down the steps; so close but so far away.

Relationality. Both Heidegger and van Manen recognise that humans are in the world with others, in spaces that we share (van Manen, 2016). Being-in-the-world is a with-world. It is through relationships that we influence others as they influence us (Tuohy et al., 2013). The findings will show how the relationship with the occupational therapist who is conspicuous by their absence, is there, but in a deficient mode; how the

relationships the participants have with others are often unnoticed in the ordinariness of waiting, but they are there.

Horizon of understanding

Gadamer introduced the notion of 'horizon' as a range of vision that is seen from an individual's vantage point. To 'have a horizon' means not being limited to what is in front of us but being able to see beyond it (Gadamer, 1975/2004). Our 'horizons' are made up of our pre-understandings, prejudices, pre-formed ideas and the new knowledge gained during dialogue with others. Shared understandings come from being able to look past that which is close at hand (Gadamer, 1975/2004), looking past what we think we know and keeping open to different perspectives. This process occurs in language, particularly dialogue. Dialogue can be a conversation with another person or it may be the reader engaging with written text. Understanding is an ongoing process. A person's horizon is not fixed and is therefore able to change and move with each new dialogue (Nielsen, 2013). Understanding is a fusion of one's historical horizon with the present horizon. A fusion of horizons can be described as "an expansion or enrichment of one's former horizon" (Nielsen, 2013, p. 12), where new shared understandings are reached.

Understanding in phenomenological research ensues when a fusion of horizons occur, that is, when the understandings of the researcher and participants' come together (Todres & Holloway, 2010) and their personal or historical distances merge (Crowther, Ironside, Spence, & Smythe, 2017). To achieve understanding there is a need to open up, keep open to all possibilities and be able to see things from a new perspective. Nielsen (2013) explained that through dialogue, text and remaining open, one's existing horizon could be transformed by integrating the ever-evolving understanding of the participants' experience. As horizons are always in motion (Gadamer, 1975/2004; Koch, 1996), the 'understandings' will never be complete (McManus Holroyd, 2007).

Hermeneutic circle

The hermeneutic circle is a circular structure of understanding (Gadamer, 1975/2004; Heidegger, 1927/1962). Being in the hermeneutic circle is engaging in an iterative process through which new understandings are developed. It is a structure that requires an openness to the meanings that emerge from the text, and being prepared for the text to tell something (Gadamer, 1975/2004). To do this, the researcher needs to situate themselves,

that is, to disclose their prejudices or forestructure of understanding. In doing this, the text can present itself and thus assert its truth against one's forestructure of understanding or prejudices (Gadamer, 1975/2004). Identifying and making explicit the researcher's forestructure is key to the methodology of hermeneutic phenomenology, as unconscious prejudices "make us deaf" (Gadamer, 1975/2004, p. 272); we cannot 'hear' what the text is saying. Because interpretation is a continuing and evolving process (Laverty, 2003), it requires the researcher to consider what is being revealed in the text by continuing to examine their own forestructures throughout the research process.

The interpretive process of the hermeneutic circle is dynamic and continuous. There is no beginning and no end. With each new insight, we are open to another understanding of the phenomenon. Understanding is achieved through moving between the whole in terms of the parts and the parts in terms of the whole (Gadamer, 1975/2004). The continuous process of examining and re-examining the narratives and interpretation through reading, re-reading, reflection, dialogue, challenging assumptions (Toles & Barroso, 2014), writing and re-writing leads to an expanding circle of ideas. This iterative process steers the researcher towards discovering the meaning of the experience being explored (Tuohy et al., 2013).

Forestructure of understanding. Dasein knows things from being in the world. According to Heidegger, "we understand and interpret something as something because we have a background of shared human practices. Understanding allows us to be involved in our daily activities as meaningful events … [and] interpretation is a derivative of understanding" (Plager, 1994, p. 72). We are all in the circle of understanding.

The forestructure of understanding comes from past experience (Tuohy et al., 2013) and links understanding with interpretation. Heidegger refers to the forestructure of understanding as "that which [is] taken for granted" (Heidegger, 1927/1962, p. 192). Interpretation is founded upon and grounded in a fore-having, in a fore-sight and in a fore-conception (Heidegger, 1927/1962). This connects the researcher to the subject matter being explored and studied.

Fore-having. *"Something we have in advance"* (Heidegger, 1927/1962, p. 191). As a researcher, I come to the research context with practical familiarity of waitlists and community occupational therapy practice that makes interpretation possible. For

example, I had an understanding of what the participants may be waiting for and how the system works.

Fore-sight. *"Something we see in advance"* (Heidegger, 1927/1962, p. 191). My background as an occupational therapist working in a service with a waitlist gave me a point of view from which I would make my interpretation. For example, I could fore-see that the less time people wait for therapy, the better their outcome.

Fore-conception. *"Something we grasp in advance"* (Heidegger, 1927/1962, p. 191). Both my background and extensive reading of the literature have given me some expectations of what may be anticipated in an interpretation. For example, I understand that older adults prefer to age in place and that a prolonged wait for occupational therapy may be detrimental to their ability to continue living in their home.

Understanding comes ahead of interpretation. My forestructure of understanding has given me a preliminary understanding of the phenomenon of waiting. Having some understanding of the concept of waiting, and what these older adults are waiting for, supports me to interpret the meaning of waiting. However, this forestructure influences how I interpret and consider information in relation to the world around me, at a given point in time. All interpretation involves forestructure (Inwood, 1997).

Language and dialogue

"Language is the universal medium in which understanding occurs" (Laverty, 2003, p. 25). Language and understanding are inseparable aspects of Dasein's being-in-the-world (Gadamer, 1996/2016). Through dialogue, the back and forth of question and answer, we come to understand others. Dialogue means not only a conversation between two or more people, but also a dialogue between reader and text. In both cases, dialogue and conversation enables understanding and interpretation (Gadamer, 1996/2016). Through dialogue there is dialectic – the art of seeing things and forming concepts through working out the common meaning (Gadamer, 1975/2004). Language, according to van Manen (2016) enables us to bring an experience into a conversational relation. He emphasises the "art of being sensitive" (p. 111) to the subtleness of language. That is, being a true listener, tuning in to the tonality of language, listening to what is being spoken, what things mean and what is not said. Language enables the understanding of text, and we come to understand the phenomenon by what it is and what it is not (Nielsen, 2013).

These key notions have helped to inform the method for my study. My forestructure of understanding has enabled me, as the researcher, to define my topic; to consider how to implement this study, who to consult with, and where I may be able to access potential participants; and, to reflect on what I bring to the study. Being mindful of the language I use when conversing with older adults is also important as it is through language and dialogue that we come to understand each other. Language is not only important when meeting and talking with participants but also in understanding and interpreting the text.

Summary

In this chapter, I have reflected on the philosophy and methodology of hermeneutic phenomenology and how this has guided me as I completed my research study. The philosophies of Heidegger and Gadamer are ontological. That is, they seek to reveal the underlying meaning of being, through the method of phenomenology. Through hermeneutics, a process of interpretation, the phenomenon of waiting for community occupational therapy and the way it is experienced, is able to be made visible. Underpinning the philosophy is understanding that interpretation is guided by the person's (researcher) historically embedded ways of thinking (Wheeler, 2020) and that interpretations are not absolute. This means that understanding the meaning of being is always open to new interpretations over time.

The methodology allows consideration of the research question through a sensitive and thoughtful inquiry of the experience of waiting for community occupational therapy. In other words, it requires the researcher to be continually reflexive; to enter the hermeneutic circle with an openness to the possibilities, so that new understandings can be developed; and to engage in a dialogue with others and the text so that the meaning of waiting for community occupational therapy, and an understanding of what really matters to older adults waiting for community occupational therapy, are able to be brought to light.

My evolving understanding of hermeneutic phenomenology as a philosophy and methodology has ensured congruency with my research methods, which I will discuss in the following chapter.

CHAPTER FIVE: METHODS

To get through the hardest journey we need take only one step at a time,
but we must keep on stepping and the journey continues.
One step at a time.
(Johnson, n.d.)

Introduction

In the preceding chapter, I explored the methodology that underpins this study. When using hermeneutic phenomenology as a methodology, there are ways of gathering data and analysing it to ensure congruency with the philosophy. In this chapter, I explain the research techniques and procedures I used when carrying out the research (Caelli, 2001). While hermeneutic philosophy has developed into a methodology, there is no prescribed method, process or system for doing hermeneutic phenomenological research. It requires the researcher to consistently return to the philosophy and its thinking to clarify and justify the methods. I have been guided by the practical approach described by van Manen, which is underpinned by the philosophical principles that require the researcher to be reflective, insightful, open to experience and sensitive to language (van Manen, 2016). Spence (2017) suggests that in being true to the spirit of hermeneutic phenomenology, researchers place their trust in the philosophy and put less emphasis on adhering to rules and procedures. In light of this, I have endeavoured to make the links between philosophy, methodology, and method clear.

Before undertaking this study, I consulted with work colleagues and the Occupational Therapy Professional Leader at the Northland DHB; all were supportive of the research. However, I also felt that it was important to ascertain if the phenomenon of waiting for community occupational therapy was confined to Northland, or if other DHBs within New Zealand were experiencing the same issue. I had a sense that waitlists for community occupational therapy services were not unique to Northland but wanted to confirm if this was occurring in other areas. To find out more about the extent of waitlists throughout New Zealand, I sent out a list of consultation questions in July 2018 via the Occupational Therapy New Zealand - Whakaora Ngangahau Aotearoa Special Interest Group for Health of Older People and Physical Community. In addition, the same set of questions was circulated among the Occupational Therapy Professional Leader's group to forward to relevant occupational therapy services within their regions. The consultation process

illuminated the presence of waitlists throughout New Zealand and exposed lengthy wait times for assessment (Fryer et al., 2019). This subsequently informed my decision to proceed with my research.

This chapter describes how this study occurred, from the early work of obtaining ethics and participating in my pre-supposition interview, through to recruitment and the process of engaging with participants. Subsequently, I explain how I worked with the participants' narratives, first crafting, and then interpreting the stories. This led to uncovering and then naming the phenomenological themes that characterise the phenomenon of 'waiting for community occupational therapy' as experienced by community-dwelling older adults. I conclude with a discussion about the trustworthiness of my study.

BEING REFLEXIVE

Being reflexive and reflective is crucial throughout the whole research process. Reflexivity plays a central role in the researcher's attempts to keep a check on their preconceptions, which originate from past experiences (Horrigan-Kelly et al., 2016), and also their hidden prejudices that may impact or limit the horizon of understanding (Spence, 2017). Reflexivity is the capacity to reflect on how political, social, cultural, gender, and class factors can shape the research (Crowther & Thomson, 2020), meaning, the way in which the researcher's horizon influences the study (Koch, 1996). Whereas, being reflective relates to examining ourselves to better understand the way we are (Crowther & Thomson, 2020). Being reflexive and reflective, on one hand, helps to ensure that the researcher does not arrive at a premature understanding of the phenomenon (Horrigan-Kelly et al., 2016), and on the other hand, aids with analysis and interpretation of meanings (Sloan & Bowe, 2014). Reflexivity begins at the outset of a study and continues throughout the research process. I examined the influences that brought me to the research, and importantly, continued to examine my own understandings during data gathering and analysis. Ongoing reflection and supervision aids in ensuring methodological trustworthiness (Wright-St Clair, 2015). Undertaking a pre-understandings interview, the use of a reflective journal and regular supervision were the ways I facilitated reflexivity.

Pre-understandings interview

The purpose of the pre-understandings interview is to help reveal the researcher's beliefs, opinions, assumptions, prejudices and interpretive lenses when entering into a study (Smythe, 2011). It provides an opportunity for the researcher to reflect on their understandings (Whitehead, 2004). With my personal experiences of waiting for healthcare and my professional experience of community occupational therapy waitlists, I had to bring my pre-understandings and prejudices of the topic into consciousness.

On 28th August 2019, prior to participant recruitment, I engaged in a recorded interview with two of my supervisors[18], which focused on my pre-understandings of the phenomenon of 'waiting'. I then transcribed this interview. The interview enabled me to reflect on 'waiting'. It helped bring to light my pre-understandings and prejudices as I entered into the research process, and how these could potentially influence my thinking during interviews and as I engaged in interpretation and analysis of the text. This process formed the basis for gaining insight into my forestructure of understanding, which I described in Chapter One.

Journaling

I kept a reflective journal from early in my doctoral research. Initially I used the journal more as a way of capturing what I was doing. However, as I progressed, I used it to capture my thoughts, reflections, and ideas following supervision and conversations with colleagues. When I started interviewing, I used my journal to write things down that I had observed or thought about after participant interviews. This was useful as I frequently referred to this information for context as I wrote up my findings. I jotted down my thinking about the findings and the notions as they emerged. My journal provided me with the space to think about my study and how it was impacting on me as a person and a clinician, and similarly, how my clinical understandings were influencing my thinking. Further, I referred back to my journal as I progressed through the study and was surprised at what I had written and how my thinking had changed. This journal was sustained through my research journey and some examples are captured in Appendix C: Journal Entries.

[18] Prof Valerie Wright-St Clair (who retired at the end of 2020) and Dr Jo Conaglen.

Supervision

I engaged in regular monthly supervision throughout my study. Being reflective during supervision helped me to keep open to the possibilities, rather than listen or look for what I already knew or wanted to hear. For example, my supervisors challenged my thinking and what I was 'hearing' in the participant stories by offering alternate ways to read them and listen to what the stories were 'saying' or 'not saying'. My supervisors offered their own insights and interpretations of the text based on their personal and research experiences. They asked naïve questions to encourage more critical thinking, and offered advice, but always left me to make the final decision about what was included or excluded. Engaging in supervision was a comfortable and valuable process for me. The collaborativeness of the conversation enabled me to reflect on the text and deepen my own understandings.

Understanding my 'horizon', my historicity, and continually having the opportunity to be reflexive with my supervisors allowed me to engage with my biases throughout the research process. Phenomenologically, being reflexive and reflective fostered the fusion of horizons between my preconceptions, the text, and the literature (Koch, 1996).

PARTICIPANTS

In phenomenological studies, it is suggested that potential participants have a period of time to experience the phenomenon being explored (Smythe, 2011), be able and willing to provide a good personal account of their experience (Todres & Holloway, 2010), and are diverse enough to enhance the possibility of rich and unique stories (Laverty, 2003). This informed my decision-making about the criteria for participation.

Being included

Potential participants were eligible to be part of the research if they were: age 65 years and older, or 50 years and older for Māori; able to speak conversational English; able to engage in a conversation about recent events and feelings; lived within the region covered by Northland DHB services; had been referred to the community occupational therapy service for assessment and had been on the waiting list for a minimum of three months, or within the past year had to wait a minimum of three months for a community

occupational therapy assessment[19]; and, to have been prioritised as high or medium risk on the referral.

Potential participants living in the geographical area in which I live and work were excluded. This criterion was set to manage the potential perceptions of relationship power and/or service bias, as the community is small and there is reasonable chance I would have provided, or would, in the future, provide occupational therapy services to these older adults residing in my community.

Rationale for inclusion criteria. The DHB Needs Assessment Service Coordination (NASC) service eligibility criteria for age-related services define an 'older adult' as age 65 years and older, or, age 50 to 65 years who meet the Government's definition of a 'person with a disability', consistent with the 'like in age and interest' policy (HOP Management Team, 2016). As Māori are known to have a reduced lifespan in comparison to Pākehā, and present with disability and either multiple chronic health conditions or a vulnerable state of health at a younger age, I included Māori who met the 'like in age and interest' definition in my study.

It is important to gather the stories of those people who have experienced 'waiting' in order to gain a true understanding of what it means to wait. Therefore, any older person waiting, or who had waited, three months or longer, was eligible for this study.

In phenomenology, participants need to be able to provide a good account of their experience. As cognitive impairment or dementia is more prevalent in older people, I needed to consider whether to include this group of individuals in my study and took this to supervision to discuss. From my clinical experience, I was aware that some people with these diagnoses are capable of telling their story and others are not. In a recent editorial, Brooke (2019) described how people with dementia have successfully been included in research. I decided that if the person could engage in conversation and talk about their experience, they were able to be included in my study. I determined this when I contacted each potential participant to check eligibility. Speaking on the phone provided the

[19] This criterion was added at the end of Stage One (see page 249).

opportunity to determine if the person was able to engage in conversation, understand the research purpose and be willing and able to share their story.

Referrals prioritised as high or medium risk (as based on the Ministry of Health framework in Appendix A: Ministry of Health Framework) was a selection criterion in this study. This criterion indicates that the person's function and safety is compromised and a delay in assessment could have greater impact on the person's ability to participate in their daily activities, in comparison to a referral identified as low risk. In this way, I understood that the people would be well placed to talk about their experience of waiting for the community occupational therapist due to the potential effect waiting was having on their everyday activities.

Checking eligibility. On receipt of the expression of interest and eligibility form (Appendix D: Recruitment Tools), I checked eligibility, i.e. that the person met the inclusion criteria and did not reside in the geographical area I worked in.

Achieving diversity. I aimed to achieve diversity, and therefore enhance the possibility of a range of rich experiences, by including participants of different genders, ages, ethnic, cultural, geographical, and social (i.e. lives alone or with others) backgrounds, and who had experienced different durations of time waiting.

Support person. Participants were offered the choice to have a support person present during their interview.

RECRUITING PARTICIPANTS

I aimed to recruit 12 to 16 older people and had ethics committee approval to recruit up to 16 participants. In phenomenological studies it is advised that between 12 and 20 participants is adequate to generate sufficient data (or text) for analysis (Smythe, 2011; Todres & Holloway, 2010) and that any more runs the risk of there being too much data to manage as a coherent whole. Additionally, my intention was to recruit at least 50% of participants identifying as Māori, as Northland has a high population of Māori people and I wanted to provide the opportunity for Māori to participate and have a voice in my research.

Participants were purposefully selected to: achieve diversity (as discussed above); to ensure that they had experienced the phenomenon of waiting for community occupational therapy; and, that they had the ability to share their personal account of their experience (Todres & Holloway, 2010) of waiting.

Recruitment process

Recruiting participants was completed in several stages with modifications being made in response to challenges recruiting people. Each new recruitment stage required an alteration to my ethics application as I made changes to both my recruitment strategy and corresponding patient information. A full description of the recruitment process is in Appendix E: Description of Recruitment Process. Recruitment occurred in three stages between 2019 and 2020 and is summarised below.

Stage One: September – November 2019. Recruitment was focused in the mid-North region. I spoke with relevant health professionals and provided them with information flyers and expression of interest and eligibility forms to hand out to their patients. Simultaneously, the same information was emailed to GP clinics throughout the region to ensure that older people not known to existing community services were not excluded. Interested people could respond via their health professional (who then forwarded the form to me) or contact me directly. Three forms were returned to me. Two of these people did not meet the eligibility criteria and the third person, after deliberation decided not to participate.

Stage Two: January – April 2020. Due to poor response in the mid-North, recruitment was expanded into the Whangārei region. Concurrently, I adjusted my inclusion criteria and submitted a request to the ethics committee to amend the study, which meant that I could approach my occupational therapy colleagues to assist with recruitment. Information flyers and expression of interest and eligibility forms were provided to therapists to give to their clients. Interested people could respond via their occupational therapist (who then forwarded the form to me) or contact me directly. Simultaneously, I reached out to local non-government organisations (NGO) who were also willing to help. I only recruited one participant. I reviewed and amended my recruitment strategy again,

obtained ethics approval and arranged to send out 50 'Letter of Introduction'[20] packs to older people on the waitlist living in the Whangārei region. Three more participants were recruited.

Stage Three: May – October 2020. Twenty 'Letter of Introduction' packs were sent out in the mid-North region. A further 20 packs were sent out in the Whangārei region, and I had requested that at least 16 were sent to people identifying as Māori. Ten people responded of whom nine met the inclusion criteria.

Personal reflection. I had expected to be inundated with older people (or their family) wanting to share their experience of waiting. I was unprepared for the lack of response and difficulty recruiting participants. This meant that my recruitment plan to select participants to achieve diversity was not possible. Due to time constraints inherent with doctoral study, I could not afford to miss interviewing those people who had already indicated their interest in participating and I could no longer delay working with the data. I believe that my final recruitment strategy – contacting people on the waitlist directly – was the most effective approach.

Informed consent

I endeavoured to protect the rights and interests of all participants by ensuring they were well informed and understood the purpose of the research and how their information was going to be used. On receipt of the expression of interest and eligibility form, I checked eligibility and then made contact. I answered any questions or concerns that were raised. If all inclusion criteria were met, then a detailed participant information sheet and consent form was mailed to each potential participant to complete and return in a pre-paid envelope. Receipt of the signed consent form indicated consent to participate and contact was made to arrange an interview.

Gaining informed consent from people with cognitive impairment was considered when deciding whether to include this cohort of older people in my study. A key ethical principle when undertaking research involving people is the minimisation of risk (Auckland University of Technology, n.d.). In my ethics application I had considered that

[20] This included: Letter of introduction, participant information sheet, consent form, pre-paid return addressed envelope (see Appendix D: Recruitment Tools).

individuals might experience some feelings of discomfort, frustration or distress. Nevertheless, I still needed to ensure that all potential participants were safe. Brooke (2019) cited several models developed to support people with dementia to participate in research. I drew on the review undertaken by Novek and Wilkinson (2019) who alluded to moving away from ethical issues such as gaining consent, to seeking and ensuring safe participation. During recruitment the son of two potential participants contacted me. He explained that both his parents were waiting for the occupational therapist but that his mum had dementia. When we discussed the research and what it entailed, he consented for me to visit. It was agreed that he would remain present to provide any necessary support. When I arrived at the house, I carefully explained why I was there and what I was going to do. Although the participant had already signed the consent form with her son's support, I ensured that she was still willing to be interviewed and be part of the research process. She consented and the interview was completed. All subsequent communication was made through her son who helped to facilitate the participant's engagement throughout the research process.

I reviewed the consent form with each participant before beginning their interview and left a copy with them. I presented the participants with a supermarket gift voucher to the value of $30 at the end of each interview to thank them for their time and contribution to my research project.

The study participants

Seventeen people from across Northland expressed interest in participating in the study, and of these, 14 were eligible. One person decided not to participate, and another could not be contacted to confirm her interview. Twelve older adults were interviewed (see Table 1) ranging in age from 68 to 88 years. Eight participants chose to have a support person present. Participants had a range of conditions from arthritis, cardiac disease, visual loss, dementia, loss of mobility, degenerative disease, and stroke. This information about their health conditions was gained during the interview.

Table 1: Study Participants

Pseudonym	Age	Gender	Ethnicity	Lives alone or with others	Urban or Rural	Duration of time on waiting list
Luckie	87	Male	European	With wife	Urban	12 months*
Maurice	88	Male	European	With wife	Urban	13 months*
Bert	82	Male	European	With wife	Urban	6 months**
Bruce	76	Male	European	Alone	Urban	6 months**
Betty	77	Female	European	Alone	Urban	9 months**
Bob	75	Male	Māori	With wife	Semi-urban	13 months*
Val	80	Female	European	Alone	Urban	6 months*
Russell	75	Male	European	With wife	Semi-urban	8 months**
Archie	75	Male	European	Alone	Urban	7 months**
Roger	80	Male	European	With wife and son	Rural	3 months**
Maryanne	74	Female	Māori	With husband and son	Rural	5 months**
Molly	68	Female	Māori	With husband	Rural	17 months*

Note. * these participants had already been visited by the community occupational therapist when they agreed to participate in the research. ** length of time on the waitlist when first interviewed (still waiting for first community occupational therapy visit).

COLLECTING THE DATA: A CONVERSATION WITH A PURPOSE

Interviews were used as a means of engaging with participants in conversation and sharing their experiences. In hermeneutic phenomenology, the emphasis is on the *lived* experience. Conversational interviews are used to gather stories, anecdotes and recollections of the lived experiences, and provide an opportunity for the researcher and participant to reflect on these (van Manen, 2016). I also needed to decide whether to interview participants alone or with others. Irrespective of the number of people in the room, it is imperative that the interview maintains its focus on the phenomenon. It is a conversation with a purpose.

The aim of the hermeneutic phenomenological interview is to elicit "pre-reflective experiential accounts" (van Manen, 2014, p. 314) of the lived experience, drawing out details of the stories as fully as possible, searching out examples, and inviting the participant's thinking and interpretation (Smythe, 2012; Wright-St Clair, 2015). However, K. Parsons (2010) cautions the researcher not to control the interview, but to help the participants unfold their story. Open-ended questions allow participants to tell their stories with depth and concrete questions encourage the participant to think of specific situations or events to explore the whole experience to the fullest (van Manen, 2016), and both types of questions were employed.

Interviewing separately or jointly. I had initially intended to interview participants alone. This would provide them with the opportunity to tell their story without the potential influence of others. Following consultation for this study, I recognised the need to offer participants the choice to have a support person present during the interview process. For many older people, particularly for Māori, the family or whānau[21] are an important part of their lifeworld. Including the whānau is respecting whanaungatanga[22] in Māori culture and therefore a support person or family member was invited to support the participant.

It would have been culturally insensitive not to recognise the importance of offering the option to have a support person present. Following this decision, however, I needed to determine if the support person's data would be included or excluded in the study.

There are both advantages and disadvantages to conducting one-to-one interviews, joint interviews, or a combination of both, and as the researcher, I needed to decide which data collection method to use. Taylor and de Vocht (2011) recognised that one-to-one interviews enable the participant to freely express their own view, as the presence of another person could affect the behaviour of the other and influence the experiences described. Alternatively, in joint interviews a partner or support person can supplement,

[21] Whānau – pronounced far-no – often translated as 'family' but means "extended family, family group, a familiar term of address to a number of people - the primary economic unit of traditional Māori society. In the modern context the term is sometimes used to include friends who may not have any kinship ties to other members. " (Te Aka Māori Dictionary, n.d.-j).

[22] Whanaungatanga – pronounced far-no-nah-tongue-ah – meaning "relationship, kinship, sense of family connection - a relationship through shared experiences and working together which provides people with a sense of belonging" (Te Aka Māori Dictionary, n.d.-k).

corroborate, correct or challenge the story being told (Taylor & de Vocht, 2011). However, it can be difficult to identify or distinguish the individual's experience from within a joint interview. Therefore, as my intention was to understand the older person's experience of waiting for community occupational therapy, I determined that this could be more readily achieved through one-to-one interviews.

Having said that, the Heideggerian concept of Dasein made me think about this from a different perspective. Drawing on Dasein, it is understood that the older person does not exist in isolation, but "occupies a place in the world together with other things … it continually interprets and engages with other entities …" (Inwood, 1997, p. 22). Therefore, while the individual older person is waiting for community occupational therapy services, this may not only affect the older person themselves, but also on those people within their lifeworld. Accordingly, I considered whether I should include the support person's data, as the phenomenon of waiting may have an impact on them too.

Adding another factor into my decision-making, as an occupational therapist and researcher, I was aware that some older people might be experiencing a degree of cognitive impairment. I have already discussed my thinking around this issue and inviting a support person to ensure their safety. Thus, it raised the question of whether their voice should be included. However, I was still being drawn to wanting to understand the experience of the older person waiting, rather than the experiences of their support person or family or whānau.

The decision of whether to interview separately or jointly and whether or not to include another person's perspective in the data needed to be made. Drawing these considerations together, I was aware that the presence of another person could affect the research process. However, older people, particularly those living alone, living in isolated areas or who may have cognitive impairment are vulnerable, and therefore participants were offered the choice to invite a support person to be present. As a researcher, I recognised and accepted that the presence of the support person may have some influence on what was revealed. As my aim was to understand the older person's lived experience of waiting for community occupational therapy, I opted to exclude data from others who were present; their data in the transcribed interviews was easily identifiable and was disregarded.

Conducting the conversation

All the participants chose to be interviewed in their home. This offered me an insight into each person's life, allowing what was significant to them show itself, as I was taken through their home. For example, Archie showed me his model planes and Russell pointed out his garden that he could no longer attend. I was often invited to share a cup of tea, and this helped to make for a more comfortable mood and atmosphere. Relationships are important in the research process and require time (Brewer, 2017). I ensured that I allowed adequate time to get to know each participant and this enabled me to gain an understanding of the person and who they were. This helped to build the research relationship and placed the person in a context, which is congruent with hermeneutic phenomenology. Building and nurturing relationships with those who identify as Māori is essential (Brewer, 2017), which I was aware of from my clinical practice. I involved myself in this by sharing my background and who I am. I was mindful of people's time and energy. Each visit took between 40 – 90 minutes. Interviews were audio recorded.

In accordance with the methodology, I conducted semi-structured conversational interviews. Conversation naturally occurred on my arrival into the participants' homes, and the interviews effortlessly evolved from this. My initial directions and questions were similar for each participant (Todres & Holloway, 2010). I used my pre-prepared questions (Appendix F: Indicative Interview Questions) to guide the conversation to help explore the experience to the fullest. I used a combination of open-ended questions such as "tell me about receiving the waitlist letter", followed by closed questions, such as "What happened then?" or "Can you give me an example?" to elicit detail and keep close to the experience. I remained aware of participants' body language and mine, and attuned myself to their tone of voice.

In phenomenological studies, data collection and initial analysis occur concurrently allowing additional questions to be asked as new understandings are generated. I added additional questions as new ideas emerged, such as "What good things have come from waiting? Is there a moment that stands out?" As the phenomenon of waiting is not a discrete experience, participants often spoke about general experiences and required prompts, such as "Can you give me an example?" or "And then what?", throughout the

interviews to think about particular moments as lived. Naturally, the conversation would veer away from the phenomenon and I was tasked to bring it back to 'waiting'.

My first interview initially felt successful, but was not. In trying to consciously not be a clinician and by consciously holding off from jumping in, I missed many opportunities to delve into Luckie's experience of waiting. Instead of rich stories of 'moments', I elicited generalised descriptions. van Manen (2014) acknowledged that it can be difficult to get participants to talk about an experience pre-reflectively, as it was lived. It took me several interviews to become familiar with this style of interviewing. There were times when I slipped into being a clinician, for example using terminology that I use every day in work, rather than the language used by the person. I found myself wanting to interrupt and jump-in with my interpretation. I also had to get used to being quiet and giving participants the space and opportunity to think and speak. This enabled participants to ruminate and then respond. The value of the silence could be revealing in itself. To supplement the interviews, I made notes that captured information, my observations and immediate reflections following each interview.

Were there enough participants?

I had initially aimed to recruit up to 16 participants. As I completed my 11th interview and arranged the 12th, I started to feel that additional interviews may not be needed. The interviews completed to date had elicited valuable anecdotes of each participant's experience of waiting, and although the aim of hermeneutic phenomenology is not to look for themes or similarities, or to aim for data saturation, there were some similar traits in the stories starting to emerge.

My supervisors were aware of the difficulties I had had recruiting, but also wanted me to be sure that I had sufficient data to be true to the phenomenon I was researching. Phenomenological researchers (Smythe, 2011; Todres & Holloway, 2010) caution against too many participants, as it is felt that depth and thoughtfulness within the analysis is forfeited. Malterud, Siersma, and Guassora (2016) proposed the concept of 'information power' to help determine the adequacy of the final sample size in qualitative research, that is, the larger the information power the cohort holds, the lower number of participants required. Although not specific to hermeneutic phenomenology, I used their model to determine whether I had enough participants. The model includes five related components

to make this assessment, which includes study aim, sample specificity, established theory, quality of dialogue, and analysis strategy, and are discussed below.

Study aim. When the study aim is narrow, with a clearly defined phenomenon of interest, such as in my study, fewer participants are required (Malterud et al., 2016).

Sample specificity. Fewer participants are needed when participants have the experience, knowledge or characteristics that are specific to the study aim. Additionally, a purposive sample, established with specific variations (as I had intended) may not always be feasible, indicating more participants may be required (Malterud et al., 2016). Fortuitously, the diversity that was inherent within my cohort of participants in addition to their varying experiences, added to the richness of the phenomenon being explored, strengthening my decision that I had an adequate number of participants.

Established theory. Theory and knowledge regarding waiting lists and the associated experience of waiting is already established within the wider health care milieu. There is extensive literature regarding ageing and the functional impact of delayed services for older adults. This study was exploratory with the intention of elucidating understanding, therefore, a smaller number of participants were required.

Quality of dialogue. As an experienced clinician, I am used to talking to older people and building rapport quickly and easily. I am aware that it took several interviews to get used to interviewing as a phenomenological researcher. However, I successfully gathered data that was able to be crafted into stories that could be analysed and interpreted.

Analysis strategy. My research was focused on in-depth analysis of narratives thus requiring fewer participants in comparison to other methodologies that require a larger number of participants (Malterud et al., 2016).

Outcome. When I weighed up each component of Malterud and colleagues' (2016) model, I was confident that there was sufficient 'information power' generated from my 12 participants to cease recruitment and move to data analysis.

AFTER THE CONVERSATION: CRAFTING STORIES

The recorded interviews were transcribed verbatim. I did not have the skill to transcribe the interviews and this was done by a professional service.

Within this research methodology, data is viewed as 'text' (Koch, 1996). Hermeneutic phenomenology is primarily concerned with understanding a phenomenon as a whole (Peoples, 2021) through the illumination of texts (van Manen, 2014). In this case, the text was comprised of participants' stories. Anecdotes or stories[23] are constructed from the transcribed interviews and capture something about the lived experience or phenomenon being described. Crafting the stories is the foundation of the researcher's dialogue with the text (Crowther & Thomson, 2020). Stories are able to bring forward and explain things that cannot be easily explained or conceptualised and are the knowledge of phenomenological research.

To uncover the deep rich stories, identify examples from the interview transcripts, and make sense of the phenomenon, I used the method described by Caelli (2001) who recommends that the researcher begins by reading and re-reading the transcribed interviews to get a sense of the text as a whole. First, I read each transcript while listening to the audio recording. I was listening for accuracy, pauses, silences, tone and mood. This helped me to re-live each interview and dwell with the data. I then read and re-read each transcript making small notes about the overall sense of what I was reading. Following this, I identified and deleted sections of the text that deviated away from the topic and I also deleted the questions and the support person's dialogue. I reconstructed the stories using the participant's words. All interpretations, changes made to the participant's actual words, or added words to help make sense of the story were bracketed. I then asked myself in what way the story revealed or said something about the experience [of waiting] (van Manen, 2014; Wright-St Clair, 2015).

Although it may not be necessary to complete more than one interview with a participant, a subsequent conversation offers the person an opportunity to tell their stories with greater clarity (Smythe, 2011). This can help to reveal conflicts, contraindications or something previously not revealed (Plager, 1994). To keep the dialogue open, and add to methodological trustworthiness (Wright-St Clair, 2015), I collated each person's narrative into a booklet which I returned to them (an example is in Appendix G: Example of a Booklet). This provided the opportunity for the participants to check that I had captured their individual experience of waiting, and also encouraged the dialogue to

[23] For consistency, I will be using the term 'stories'.

remain open (known as 'hermeneutic conversation'), congruent with phenomenology. I followed this up with a phone call or face-to-face visit if preferred by the participant. I asked participants if their booklet reflected their experience and if they wanted to say anything more. This second conversation was to allow the participants to reflect on their story and elaborate on what had been written.

I was quite anxious when I contacted my first participant back; what if I got it wrong? But I hadn't. Luckie really liked his booklet and he had shared it with his family. His son had commented that it had sounded just like his dad. Luckie did not feel the need to elaborate on his experience, but it was left open for him to contact me if he felt that something extra needed to be said. Other participants shared their booklets with family, carers and their health professionals. The ten participants that I followed up with a phone call stated that they were happy with their booklets and did not wish to elaborate further. One person requested that the name of her friend was removed, and another participant requested that one sentence was altered to better reflect their son. These changes were made. These follow up conversations were captured in my journal. It was different following up face-to-face. For example, when I met with Roger for a second time, he was relaxed and talked freely. During this conversation, Roger said something important – *"no one wants to go into a rest home".* Up until this moment, this sentiment had remained unspoken by all the participants (but was something I had sensed when I started to interpret my data). As I had begun to analyse my data, I described some of what I was interpreting with Roger, and it seemed to resonate with him. These follow-up discussions with participants helped foster the fusion of my horizon as a researcher (with knowledge gained from clinical practice, the 'text' and literature) with those of the participants (van Manen, 2016).

WORKING WITH THE TEXT: INTERPRETING THE STORIES

Koch (1999) described data analysis or interpretation as "digging out hidden messages" (p. 26) from the text. That is, it required me, through a process of interpretation, to bring to light what is ordinarily hidden in the everyday (Wright-St Clair, 2015), and "letting that which shows itself show itself" (van Manen, 2014, p. 48). Analysis in phenomenology is an iterative process of reflection, questioning, attentive reminiscing and interpretation of the meanings of the human experience (van Manen, 2017), and is not conducted by sorting, counting or coding. While some scholars have attempted to

describe systematic procedures for analysing or interpreting data in phenomenological studies, there is no one-way, or set method (Wright-St Clair, 2015). According to Gadamer "human existence cannot be approached as a methodical problem" (van Manen, 2014, p. 133) and contrary to the title of his book, *Truth and Method*, he cautions that "there is no method to truth" (van Manen, 2014, p. 133).

With no method to follow, I initially found the process of interpreting the stories quite daunting. Where to start? The hermeneutic circle is not a technique but rather a description of the process of understanding (Peoples, 2021). The process is about gaining an understanding of the whole transcript and starting to analyse it as a whole, then moving to the parts and analysing these, and then looking at the whole again. The process generates new understandings through moving back and forth between the whole and the parts. Peoples (2021) described the process as *spiral* rather than circular, as circular indicates one gets back to the same point, whereas in a spiral process, understanding increases, continually changing as new data are introduced. I entered into the hermeneutic circle to begin interpreting the stories.

I chose to employ the approach described by Wright-St Clair (2015) when interpreting the stories. I highlighted text that seemed essential or revealing about the phenomenon or lived experience within each participant's narrative, always thinking about my research question. I found myself being drawn to familiar words, phrases or ideas. To help grasp each participant's experience, I created a mind-map (see Appendix H: Interpreting the Stories for examples) for each participant, asking myself "What stands out here?" This helped me to maintain my focus on the phenomenon, and capture what mattered (Wright-St Clair, 2015). I started writing about the narratives and what they might mean, and highlighted different words or phrases within these stories that stood out (see Appendix H: Interpreting the Stories). This method of 'choosing' what seemed essential was based on my prejudices and pre-judgements. I recognised that what stood out on one day did not necessarily stand out on the next. Horizons, as asserted by Gadamer are temporal, always in motion (Koch, 1996). My first tentative 'interpretations' were descriptions, as seen in Figure 3.

Figure 3: Dialogue box 1

Example of text interpretation: A Call to Action

> *My son also put a ramp outside here so that I can take that walker out. It was quite good except it's too steep. I have to take my cup off otherwise it slips down. (Roger, 80)*

The walking frame has become part of Roger's being and who he is in the world. The ramp into the conservatory is quite good but too steep. Each time Roger walks down it with his walking frame, his hot drink or plate of food slides off it. Roger dwells in his situation thinking about his possibilities. He has always enjoyed going out into the conservatory. This space offers him a view of his property and a place to relax. He could wait for the occupational therapist to fix the ramp but the wait is unknown and he is aware that his time on earth is finite. He can stay inside and have his meal, or find a way to get back out into his conservatory as he used to.

Feedback from, and discussion with, my supervisors helped me to move past this description and begin the interpretation process. I wrote and re-wrote. I brought my own language and pre-understandings to each story. I thought about what may have been hidden or not spoken of. I moved between an individual's single stories and their story as a whole. I moved between the participants' stories. I tried to stay as close to the data as I could but at times 'over-interpreted' and with feedback drew back to the lived experiences and what the stories were saying. As my understandings and interpretation skills improved I was able to consider the tone of the text and the overall sense or mood in the data (Crowther & Thomson, 2020).

A challenge for me throughout the process was learning to dwell in and with the text. I needed to slow down and give myself space for "reflection that ponders, muses [and] contemplates on the meaning of things" (van Manen, 2016, p. 6); to let the stories speak, and be heard. When I became comfortable dwelling in the data, insights came to me when least expected.

The amount of data was overwhelming. I was tempted to look for common themes, and at times, I was drawn to patterns across the texts, but I was well aware that this was incongruous with hermeneutic studies. I needed to stay 'open' (Horrigan-Kelly et al.,

2016) to help me not to miss the meaning of the lived experience. There were times when I over-compensated for my prejudices. For example, I deliberately tried not to focus on 'occupations' believing that it could limit my openness and possibilities of 'seeing' something. But then, I was reminded that I came into this study as an occupational therapist, and 'occupations' are very much part of my interpretational lens. I became open again to seeing where such understandings were integral to participants' experiences. I also went back to the literature to help me to understand ideas or notions that were being revealed, for example, notions of autonomy, retaining control and accepting help.

Drawing on primary philosophical texts from Heidegger, Gadamer, van Manen, and secondary texts from authors who explained or used phenomenology in their own research, I started to weave through the philosophical notions that would help to illuminate the underlying meaning within the participant stories (Crowther & Thomson, 2020). As I continued to work with the stories and write more deeply, richer understandings and interpretation of the phenomenon occurred, as seen in Figure 4. These interpretations were not just mine, but were fused with what I learnt from the participants, the literature, and the ongoing dialogic structure of question – answer (Gadamer, 1975/2004) with my supervisors and peers.

Figure 4: Dialogue box 2

Example of text interpretation: A Call to Action

> *My son also put a ramp outside here so that I can take that walker out. It was quite good except it's too steep. I have to take my cup off otherwise it slips down. (Roger, 80)*

Roger is called to the conservatory. He does not think about why he goes there, but 'knows' it is a space where he can relax. It is also the intermediary space that links his home with the outdoors. But the loss of familiarity with his body affects his ability to move with the same ease as he once could. Roger becomes restricted to the inner space of his home. In the familiarity of the lived space of home, one can usually move about with ease as the lived body 'knows' this space well. But home is not just the inner space contained by the walls of the house, it is connected to the outer space. Heidegger speaks of a threshold; he interprets a threshold as a boundary, "as something to cross or as an invitation to pass" (Dekkers, 2011, p. 295). The phenomenon of a threshold enables a link between the inner and outer worlds and enables one to experience these lived spaces. The doorway at the boundary of the home is the opening to the conservatory, but Roger is unable to step through it on his own. The built ramp is an invitation to pass through, linking the inside and outside of his home, and enabling Roger to re-engage in the space of the conservatory. Now that Roger can move between these spaces, his familiar occupation of dwelling in the conservatory can be achieved, furthermore, he can now move through on his own.

Identifying emerging phenomenological themes

"Phenomenological themes may be understood as the *structures of experience*" (van Manen, 2016, p. 79) that help to see meaning. Identifying themes is not a rule-bound process (van Manen, 2016) but rather a 'pointing to' what is seen (Smythe, 2011); to point at the 'thing' that we are attempting to describe (van Manen, 2016). As I dwelled in the stories, I started to 'see' some key characteristics of the phenomenon of waiting. To help shape, describe and to get at the meaning of the experience (van Manen, 2016), phenomenological themes were crafted. These themes represent new understandings, not generalisable facts.

I initially grouped ideas into five emerging phenomenological themes: Waiting is not insular; Temporality/Never-ending; Active waiting; Silent adaption; and, This cohort. These themes were my foundation ideas of the main characteristics of the phenomenon. During supervision, it became evident that the fifth theme was not a theme, but rather some traits of these older people. Furthermore, I needed to refine my thinking and reflect on 'what's going on?', 'what am I living?', 'what am I hearing?', 'what am I not hearing?' Using the method of the hermeneutic circle I continued to move between the stories and the whole text of each person, and then across all the texts. I began to see some key ideas emerge that I thought were relevant to the participants' experience of waiting for community occupational therapy. I was simultaneously considering which stories helped to capture the variations and meanings within the developing themes. As I engaged in the process, three overarching phenomenological themes emerged. These themes were tentatively called: Waiting invisibly; Waiting is not insular; and, Actively waiting.

In hermeneutic phenomenological studies, writing and re-writing is the activity of doing phenomenology (van Manen, 2016) because "writing begets thinking" (Wright-St Clair, 2015, p. 62), and thinking opens up the possibility of "seeing" the phenomenal meaning in a moment of writing (van Manen, 2014). Through continually moving between the stories and the whole text, writing and re-writing and keeping open to feedback from my supervisors, the findings were brought to light. During this process, I also met with the Takawaenga (Māori advisor) to review the stories of those participants who had identified as Māori. As a Kaumātua[24], the Takawaenga is a respected Māori elder with knowledge of tribal history, genealogy, and tradition that younger people turn to (Higgins & Meredith, n.d.). The Takawaenga's role in the healthcare setting is not only about supporting staff to safely work alongside, and with, Māori, but also supporting Māori patients and their whānau when they feel unsafe or uncomfortable in the healthcare setting, or dissatisfied with their care. The Takawaenga was taken aback by the lack of reference to 'the whānau' within the stories. This was something I had not seen. He explained that historically Māori have enjoyed strong intergenerational relationships; that the whānau took care of everyone down and across generations. There was a strong whānau structure, which he believed was disrupted post World War I and II which

[24] Kaumātua – pronounced ko-mah-two-ah – translated as 'elder', a person of status (Te Aka Māori Dictionary, n.d.-c).

resulted in the breakdown of the care structure of the family. He was attuned to the sadness and loneliness in waiting. He felt that in the past, these Māori elders would not be reliant on others outside of the family and would therefore not be on the waitlist seeking help; the whānau would have taken care of them. But now, these elders have come to rely on the system because the whānau is not there, and the wait for help becomes intensified. I was saddened when I heard this, especially after many years working in the community without this awareness, but this conversation enriched my understanding and subsequent interpretation of these stories; a fusion of horizons.

I understood that the meaning of 'waiting for community occupational therapy' would never be fully revealed, but I had come to a place of being able to name three overarching phenomenological themes. Each theme had several sub-themes that described an aspect of the phenomenon of waiting for community occupational therapy. I sent a summary of the findings, formatted in a booklet (see Appendix I: Summary of Findings Booklet), to each participant who had indicated that they would like a copy of the findings. I included a pre-paid envelope, and offered each person the opportunity to provide feedback. No feedback was received from the participants.

Following a discussion with my supervisors regarding the theme and sub-theme headings, which were unclear due to the philosophical language I had used, I renamed two of the three phenomenological themes and several of the sub-themes within each chapter. The three themes: The Uneasiness of Waiting, Waiting as Being With, and The Not at-Homeness of Waiting, form the findings of this study, and are discussed in Chapters Six, Seven, and Eight.

ENGAGING WITH THE TAKAWAENGA

Engaging with the Takawaenga during the research process. My engagement with the Takawaenga during the course of the study was ad-hoc. I engaged with the Takawaenga in a similar manner in which I would usually ask for help with work-related concerns. That is, at work, I turn to the Takawaenga for guidance when I recognise that I require support to assist a Māori client or their whānau. In this study, I recognised that my background as a Pākehā would influence how I interpreted the text and that I could miss the meanings hidden within the stories and language of the Māori participants. Therefore, as previously discussed, I turned to the Takawaenga for assistance with

analysing the text from the Māori participants. His input informed my analysis of the text by deepening my understandings of the historicity of these participants.

Additionally, impromptu conversations arose with another Takawaenga during the latter part of my study, which often focused on my progress rather than directly informing my study. I found these conversations enjoyable as they often led to discussions about what was happening in the community amid the changes occurring in the health system. For example, the Takawaenga explained that with the new health model coming into effect, namely, Te Whatu Ora (Health New Zealand) and Te Aka Whai Ora (Māori Health Authority), under Te Aka Whai Ora, the Māori community would be able to direct what care, support and services they needed. This would provide an opportunity to put forward different ideas to improve the health of the community. These conversations enabled a flow of ideas and a strengthening of relationships rather than directly influencing my study.

ETHICAL CONSIDERATIONS

This research required ethics approval prior to the commencement of participant recruitment. Ethics approval was sought through the Auckland University of Technology Ethics Committee (AUTEC) in July 2019. Concurrently, as per the Northland DHB process for conducting research within the organisation, locality approval was obtained prior to the commencement of research being undertaken.

During the Covid-19 pandemic and subsequent Level 4 lockdowns, AUTEC suspended all ethics approvals until the alert level reduced to Level 2 or lower. This was to ensure the safety of all participants and researchers. The lockdowns interrupted data collection, which I resumed once back in Level 2.

Northland District Health Board locality approval

I met with the Northland District Health Board ethics committee on 23/07/19 who reviewed and approved my study. As part of gaining ethics approval, I met with the Northland DHB Kaunihera Kaumātua[25] representative. We discussed the purpose of my

[25] Kaunihera – pronounced ko-ni-hear-a – translated as ‘council’ (Te Aka Māori Dictionary, n.d.-d) and Kaumātua – pronounced ko-mah-two-ah – translated as ‘elder’, a person of status (Te Aka Māori Dictionary, n.d.-c), which together means ‘Council of elders’.

study and what my intentions were. The Kaumātua expressed their approval of the study, and I was able to proceed. Locality Assessment number: 2019-24 (Appendix J: Ethics Approval).

Auckland University of Technology Ethics Committee approval

Ethics approval was received from AUTEC on 13/08/19. Approval number: 19/215 (Appendix J: Ethics Approval).

Ethics approval was sought and received each time the recruitment strategy and subsequent participant information was modified.

Considering ethical issues

Including Māori participants in my research. Towards the latter stage of recruitment, I had requested that 80% of the research packs were sent to people who identified as Māori. I wanted to ensure that Māori people were included in my study because Northland has a significant, but not exclusive, Māori community. From the outset, I was cognisant that my study was mainstream research involving Māori, rather than Māori-centred research[26] (Cunningham, 2000). This approach could have dissuaded potential participants who identified as Māori from initiating contact with me, partly due to an innate discomfort sharing their personal experience with someone they did not know and who was not from their culture, and partly due to research being viewed with suspicion and implicated in the process of colonisation (Barnes, 2000). Therefore, to recruit people who identified as Māori, I also approached health professionals who knew me and who were working directly with older Māori. Their established relationships meant they could introduce the study and also vouch for me as a person, drawing on the Māori principle of whanaungatanga (relationships through shared experiences).

Managing ethical issues. I considered that I might observe a serious safety issue for those participants still on the waitlist. I had pre-determined that should this situation arise, I would discuss it with my primary supervisor within 1-2 days of the participant interview

[26] Mainstream research involving Māori – this type of research draws upon mainstream analysis and does not produce 'Māori knowledge', but rather, mainstream knowledge that includes Māori. Whereas, in Māori-centred research, Māori are much more likely to be involved at all levels, and it produces Māori knowledge (Cunningham, 2000).

to ensure a safe solution was found. Although all the participants had been waiting many months to be seen, none presented in this way.

However, I was not prepared when I was contacted by a family member who advised that his dad would be interested in being interviewed and if I could bring him a safe seat for his use in the shower. When I explained that I could not bring the shower seat, as my role in this situation was as a researcher, not a therapist, the family member was not happy and withdrew the offer for his dad to be interviewed. I talked to the family member about how valuable an interview with his dad would be given his current experience of waiting, even though I would not be able to provide him with the seat he needed. I was granted the interview.

I reflected on this ethical dilemma, knowing how easy it could have been to simply provide the seat and make him safe; no one would know. I did not provide the seat. I maintained my integrity as a researcher throughout and through supervision managed my own feelings about this situation, and other similar situations that arose.

Confidentiality and data security

Maintaining participant confidentiality and data security is an integral part of the research process. This was especially important as I was still working as a clinician alongside colleagues who had initiated contact with potential participants (who were still on their caseloads) on my behalf. I did not discuss participant interviews with their referring clinicians.

Confidentiality was respected by offering the participants the choice to select or be given a pseudonym for themselves, which was used throughout the research process following their interview. Participant details were not revealed or discussed with people outside of the research project. Participant information was stored on my password-protected computer. Each participant was assigned their own electronic folder labelled with their pseudonym. Within their folder, their audio recorded interview and subsequent stories and interpretations were saved. All electronic communication with participants, i.e. emails, was conducted through my university email address.

I had initially planned to store the paper-based consent forms at my home. However, these could not be stored securely. To ensure data security I stored this information in a locked cabinet in my office at work that only I could access.

The digitally recorded interviews were downloaded onto my computer before being sent on a secure link to be transcribed. I used a professional transcription service. The terms of engagement with their service ensured confidentiality. A confidentiality agreement was completed with the transcriber (see Appendix K: Confidentiality Agreement). Only the transcriber and I heard the original interview. Once the completed transcript was received, I erased the interview from the digital recorders.

As per AUTEC requirements, after completion of data analysis, the data was downloaded to a storage device (USB memory stick) to be stored in the primary supervisor's secure cabinet at Auckland University of Technology (AUT). Data will be secured for a minimum of 6 years, and then destroyed through erasing the memory stick. On completion of the research project, the participants' consent forms were delivered to AUT, to be securely stored for a minimum of 6 years, after which these will be shredded.

TRUSTWORTHINESS

In qualitative research, trustworthiness refers to the strength of the research design and that all procedures have been followed (Lacey, 2010). In hermeneutic phenomenological studies, there is no procedure to follow. Each researcher's approach is unique (Crowther & Thomson, 2020), therefore, demonstrating trustworthiness is the responsibility of the researcher (Koch, 1996). Whilst there are generic criteria to establish trustworthiness in qualitative research, these are typically philosophically incongruent with, and conceal the uniqueness of, hermeneutic phenomenological study findings (de Witt & Ploeg, 2006). Unlike the goal of quantitative research of finding a single truth and creating prescriptive models that tell people what to do or how to do it, hermeneutic phenomenology is about increasing our understanding of the human experience (Lopez & Willis, 2004), opening up possibilities, and providing the opportunity for evoking and reflecting on practice (van Manen, 2007). Phenomenology aims to transform lived experience into a textual expression of its essence and help the reader to move beyond what is immediately experienced to understand the phenomenon in a deeper manner (van Manen, 2016). Therefore, a true measure of trustworthiness, as argued by Crowther and Thomson

(2020), is that the study resonates with others, that is, those who hear or read the work 'come to feel' the phenomenon.

There are many activities a researcher employs to achieve trustworthiness. To capture these activities and demonstrate trustworthiness, I have drawn on the work of de Witt and Ploeg (2006) who introduced a framework that has incorporated the unique features of hermeneutic phenomenology to help readers determine the trustworthiness of hermeneutic phenomenological studies. In this framework, the authors use the term 'expression' of rigour, rather than 'criteria' of rigour, to align with the language of phenomenology. The framework separates and balances the expressions of rigour between the research process (balanced integration and openness) and the research outcome (concreteness, resonance, and actualisation). I will speak to each of these expressions to demonstrate how my study can be considered trustworthy.

Balanced integration. This aspect is demonstrated when three characteristics are present: articulation of the philosophical theme and its fit with the research topic and researcher; in-depth intertwining of the philosophical concepts within the methods and findings; and, a balance between the philosophical explanation and voice of the participants (de Witt & Ploeg, 2006). In this study, I have endeavoured to ensure congruence between the method and the methodology throughout. I have discussed how hermeneutic phenomenology is a good methodological fit to answer my research question, and how it is interwoven with occupational science and therapy philosophy. I have made my prejudices and biases clear and recognise that these are an integral part of the study findings. In light of these, readers can see my fore-conceptions and determine themselves if the meanings within the findings are reflective of the participants' experiences. I have ensured that all participants have been represented within the study findings. I have foregrounded the philosophical notions that I used, and these are woven through the findings and balanced with the participant voices to illuminate the phenomenon. Further, I have consulted and used both primary and secondary philosophical texts of Heidegger, Gadamer and van Manen to guide my thinking and interpretation.

Openness. Openness refers to the ability to demonstrate an explicit process to account for decisions made throughout the research process, which are open to scrutiny (de Witt & Ploeg, 2006). Openness is demonstrated through discussing and reflecting on how

interpretation and meaning was obtained, and integrating my decisions into the research process. I discussed how I came to decide whether to interview participants alone or with others and whose voice to capture. I shared my deliberations on whether to include older adults with cognitive impairment. Throughout the research process, I maintained a reflective journal, which I found to be a valuable tool as I worked through my study. It allowed me the space to capture my thinking and ruminate on what I was hearing and not hearing, and the guidance being provided by my supervisors. I have demonstrated my reflexivity and openness throughout the study as I worked with the text, and being cognisant of not drawing conclusions too quickly. I stayed open to the possibilities of what the text revealed, rather than being drawn to what I wanted to find. My understandings of the phenomenon have grown, as my 'knowing' fused with those of my participants, and new understandings were uncovered as I worked with the text and came to my conclusions.

Concreteness. Concreteness is evident when the study is written in a way that the reader can connect to the phenomenon in the context of everyday life, and that the findings are 'useful' within the context of clinical practice (de Witt & Ploeg, 2006). Through the remainder of this thesis, I will demonstrate concreteness by drawing on stories so that the readers can connect to the phenomenon and link it with experiences in their own lifeworld; including clinicians who can consider the findings in relation to their clinical practice, and Managers who may come to appreciate the meaning of waiting to effect change. I endeavour, through the telling of these stories, to show what it means for older adults to wait and to help the reader understand the lived experience of waiting for community occupational therapy.

Resonance. Resonance refers to the experiential or felt effect of reading the findings upon the reader, the moment when the understanding is truly apprehended in its depth. When the reader not only recognises, but feels the experience (de Witt & Ploeg, 2006); a "sudden perception or intuitive grasp of the life meaning of something" (van Manen, 1997, p. 364). When my supervisor stated how angry she felt after reading the findings, resonance was demonstrated. And, when I shared my findings with my occupational therapy colleagues, their responses were affirming. They could immediately grasp what was being said and the impact the waitlists had on older people. It provided them with new understandings and generated valuable discussion about the impact of waiting.

I also sent a summary of the findings to each participant with a letter inviting feedback, and a pre-paid envelope to do so. One response was received thanking me and another was from the wife of a participant advising that he had gone into care. I do not know if resonance was experienced by the participants.

Actualisation. This addresses the future realisation of the experiential effect of the study findings. Although the phenomenological interpretation does not end when the study is finished (de Witt & Ploeg, 2006), I am anticipating that this study will put the spotlight on the value of community occupational therapy, and the need to address the waitlist. The findings will continue to be read and interpreted once they have been published and presented. Personally, I made changes to my clinical practice in response to what I had heard from participants, and so too could other clinicians. I explore this in the Discussion chapter. In addition, my colleagues immediately recognised how some practical changes could be brought into effect straight away, such as improving the information that is sent with the waitlist letter. In the Discussion chapter, I have made recommendations and suggestions for further research, which opens the possibilities for others to explore different facets of waiting.

Summary

In this chapter, I have explained how I undertook my research and demonstrated congruence between methodology and method. Entering into the hermeneutic circle and immersing myself in the text meant 'trusting the process'. The dialectical process of moving back and forth between the parts of the text and the whole text whilst engaging in an iterative process of reading, writing, thinking, re-reading and re-writing, enabled my horizon of understanding to fuse with the text. Throughout the research process, I upheld my integrity as a researcher, particularly when conflict with being a clinician arose. The trustworthiness of this study has been discussed using the framework proposed by de Witt and Ploeg (2006).

The narratives provided unique stories related to older people's experience of waiting for community occupational therapy. Being reflexive, reflective and engaging in open dialogue with others and the text, through a process of questioning and answering, enabled me to understand, interpret and weave the stories into three phenomenological themes. In the following three findings chapters I turn to the stories and my interpretation

of these. Although each findings chapter is structured around a phenomenological theme, the themes are interconnected with one another. The themes are *The Uneasiness of Waiting; Waiting as Being With;* and, *The Not at-Homeness of Waiting.*

CHAPTER SIX: THE UNEASINESS OF WAITING

Time is free, but it's priceless
You can't own it, but you can use it
You can't keep it, but you can spend it
Once you've lost it, you can never get it back
(Mackay, n.d.)

Introduction

Waiting is so familiar that the experience could be described as 'ordinary'. Drawing on the participant stories, the next three chapters will explore the phenomenon of waiting for community occupational therapy and show that waiting for community occupational therapy[27] is a unique experience of waiting. The first findings chapter focuses on the unease of waiting for occupational therapy. The second chapter shows the relational nature of waiting, revealing waiting as a mode of 'being with'. The third chapter discloses how the participants experience waiting as 'not being at home' amidst the ordinarily familiar. In waiting, the participants are not engaging in all of their usual occupations, and their stories show how their occupations can be influenced through, and by waiting.

This first findings chapter sets out to uncover the 'Uneasiness of Waiting'. The term 'unease' means a state of discomfort or restlessness in body and mind (Dictionary.com, n.d.-c) and is synonymous with feelings of uncertainty, fear, anxiety, and worry (Wordhippo, n.d.). Finding themselves in the circumstance of requiring help has thrown the participants into a situation of waiting for occupational therapy. This situation of waiting is one they did not choose and is beyond their control. For some, it is a sudden need for occupational therapy help following a critical event that they had not anticipated nor foreseen, for example the inability to shower following a heart attack. For others, it has been a slow decline in their health that has caused functional loss. For all the participants, it is a need for occupational therapy help with 'things' or equipment to support them to perform essential daily activities. The need has initiated a referral by the hospital or their GP to the community occupational therapy service. The participants understand that the referral has placed their name on the waitlist.

[27] 'Waiting for community occupational therapy' is shortened to 'waiting for occupational therapy' or 'waiting for the occupational therapist' throughout the findings chapters.

These older adults have experienced waiting for numerous ‘somethings’ over their lifetime that have made waiting come to seem ordinary and expected. Their stories reveal that waiting for occupational therapy is a particular experience of waiting. The individual stories tell of the participants’ unique personal experiences and reveal the extraordinariness of waiting for occupational therapy. Collectively, these stories show that the experience of waiting for occupational therapy is one of unease. The ‘uneasiness of waiting’ for occupational therapy is a way of being-in-the-world and will be presented in three sub-themes: *Fearfulness of Waiting; Invisibleness of Waiting;* and, *Suspended in Time*.

FEARFULNESS OF WAITING

Fear is a mood that discloses the uneasiness of waiting for occupational therapy. The Heideggerian notion of mood does not refer to one’s state of mind as in feeling angry or sad, but rather one of the modes through which the world is experienced (Freeman, 2014) in a way that holds meaning and allows things to matter. Finding themselves waiting for occupational therapy uncovers a fear that is at once concealed and revealed by mood. When people encounter normally familiar things in their home as threatening, for example, the bath, it reveals the fearfulness. Fear brings into focus that which matters while waiting for occupational therapy. Being able to get into the bath to keep clean matters to the person struggling to get in or out of it. These changed experiences of what was familiar can influence whether a person chooses to turn away from the situation or whether to respond to its call and consider its possibilities. By attuning to the fear, it lets us glimpse waiting in a way that may otherwise remain hidden. The following stories capture the fear of waiting for occupational therapy and will be presented in two sub-themes: *struggling* and *uncertainty*.

Struggling

Learning that she must wait longer than expected upsets Val. She is concerned for the struggle involved in managing alone but also for being a burden to her son. Doing all of her everyday activities is becoming harder for Val to manage, and she has all but stopped going out, as she cannot use the steps. The fear of not managing and of being a burden reveals the struggle of waiting for the occupational therapist.

> *I've had a card, a letter from the hospital saying, we've got other people who've been waiting longer than you, so I'm sorry you'll have to wait a while. I was a bit upset about that because I sort of do struggle, but I try not to let it show too much. … I don't like to get my son upset because he does a lot for me. … I thought 'hmmm, okay I'll just have to wait' but I can get quite cross, but I try not to. (Val, 80)*

Val speaks of the *upset* that can come from joining the waiting list. Even though she appears accepting of the wait and tells of being *a bit upset* at having to wait, she is more than *a bit* upset. She is very upset. She is also *quite cross,* but the tempo of her speech quickens as she attempts to cover over her emotions. She minimises how she describes her feelings, as she does not want to make a fuss or be fussed over. Val is trying to suppress both her emotions and her struggle, trying *not to let it show,* as she does not want to appear as if she is not managing. She does not want to bring attention to herself for fear of letting others, particularly her son, see that she is not managing. Heidegger tells us that moods make the situation show up differently and allow us to focus on what matters. Val's upsetness and crossness could distract from her fear, but as she finds herself waiting for the occupational therapist, it is her fear of being seen not to manage that drives her to carry on.

Val's fearfulness reveals the hidden complexities and discord for her. On one hand, it is not easy and she needs help now. Her struggles are real and matter to her. They seem not to matter to *the hospital,* but they matter to her. She tries to keep her struggles hidden from others. She is uneasy, unsure how much longer she will be able to keep hiding them. On the other hand, Val talks about accepting the wait and waiting her turn, even though it is difficult for her. She deliberately keeps her emotions hidden from others as this would be 'making a scene' and this is not how one behaves. Culture and tradition provide a particular way of making sense of things (Withy, 2014). Val understands that an accepted way of behaving is being stoical and carrying on.

Understanding that she must wait her turn is an 'understanding', that ontologically arises from the "Being of the 'there'" (Heidegger, 1927/1962, p. 385). This is to say that she understands what is socially expected of her as an older Pākehā woman living in New Zealand; the 'should' and 'should not' of how to behave when waiting. Understanding that she 'should' be patient and 'should not' be angry, she underplays her upsetness. This does not disregard feeling upset but rather conceals it from herself and her son. Anxious

as to the possibility of burdening her son, she works to keep these physical and emotional struggles hidden from him. Ontologically, Dasein is not only concerned about itself, but also shows solicitude to others that it coexists with in the world (Escudero, 2013). Solicitude can be harmful or helpful. Harmful care dominates the other, whereas helpful care restores the other. Val tries to keep her struggles hidden from her son as a way of showing care, by not dominating his time and energy. Val does not want to be a burden; she just wants to stay at home. In the fear of others seeing her struggle, she hides it, or tries to. For the sake of appearing to manage life at home, she stays quiet and remains invisible to those who could help.

In contrast to Val who understands what the waitlist letter means, Roger tells of receiving his letter as 'one of many'. Roger has received multiple letters, impersonal and indistinguishable letters that he does *not understand*. Roger knows that he is waiting for someone to visit, someone who will help him. Roger finds himself in a system unfamiliar to him.

> *I've had that many different letters of different things that I can't understand. (Roger, 80)*

The multiple letters are of no help to Roger. These letters are meaningless to him as he struggles to understand these letters, what they mean and what he can expect. He is not sure if one of those letters is from the 'someone' who can help him with his struggle in the bathroom. The bathroom frightens Roger. He expresses several times that he is *"frightened of slipping."* Although he was given equipment for the bath and toilet when he was in hospital, to support him at home, this equipment is of no help. He *can't understand* why he must wait so long for help at home when it was possible for them to immediately provide what he needed when he left hospital. Because he does not understand the system, how it works, and who does what, he struggles to understand the wait. He knows that there is equipment that can help him to shower safely. And yet, with his safety in jeopardy he must wait. More than being concerned about not knowing how the system works, what matters to Roger is his struggle in the bathroom. Waiting for occupational therapy appears as a fearfulness that Roger must endure as he waits for help.

As Val and Roger contend with their struggle while they wait for the occupational therapist, it means finding themselves in the world fearful that they are unable to keep

managing. The situation in which they now exist is not in their control. There is no reassurance of when they will be seen. The vagueness of the waitlist letter contributes to a feeling of unease.

Uncertainty

Anticipating occupational therapy help, the participants live with uncertainty. The experience of waiting for occupational therapy shows their moods vacillate between hope and hopelessness. At times, they hold hope that the occupational therapist will arrive soon but mostly they have no hope, disclosing emotions of despair, fear, powerlessness and aloneness. The uncertainty shapes the participants' existence as they wait for the occupational therapist.

Russell lives with a sense of impending doom – he dwells in the fear of falling, *not sure* if he will get occupational therapy help. His fear of falling began with a fall outside, which resulted in a fractured pelvis that took many months to heal. Now the bathroom is a place he is very frightened of. The taken-for-granted ability to shower, an activity Russell has done all his life threatens the life he knows. Russell needs the occupational therapy resources and feels reliant on the occupational therapist. He cannot *fix* this problem himself, as he would have in the past.

> *It's been a while. It's been a few months. It feels like years. I'm not sure. It seems a long time you know. One day I'm going to fall or slip over. I've felt unsteady and grabbed hold of the shower holder thing. I didn't fall because the rail steadied me, but I ripped it out the wall, twice. I had to replace that rail, twice. Every time you go to get into the shower, I feel the crucial time is the getting out and getting in the bath. That's when you are on just one leg. The bath can be a bit slippery and that is when it's going to happen, in-between getting in and getting out. Since the fall outside I've really thought about it a lot. I feel I'm going to fall again in the bath. I want the bath removed, I want it to happen. It's just a pain sort of sitting and thinking, when, when, when are they going to fix it? So really, it's just frustrating nothing's happening. But if I go down and have a fall, I'll probably end up a lot worse off than I am now. (Russell, 75)*

Russell anticipates disaster. The first fall changed his life from being active and fully occupied to a life limited by fear of falling. Waiting for the occupational therapist to provide the things that he needs to perform his daily shower, Russell is filled with uncertainty. In a subdued tone, as someone whose silent pleas to get things fixed go

unheard, he analyses and worries about what could go wrong. He experiences a fearful uncertainty each time he steps over the bath. In the *in-between* of *getting in and getting out,* he is unsure if he will remain upright or slip over, and unsure if the rail will save him. As he moves between the certainty of solid ground and the uncertainty of the slippery bath surface, Russell is attuned to his fear. The bath and the rail, ripped out of the wall, remind him of the ever-present danger of falling. In his nakedness, as he precariously balances on *just one leg,* trying not to *slip over,* he feels vulnerable and afraid, uncertain of himself and his safety. He is on edge and senses that it is only a matter of time before another fall.

Russell experiences the uncertainty of waiting for the occupational therapist as *a pain,* an emotional pain. The constant apprehensiveness lingers in his thoughts and intrudes on his daily life, revealing the emotional toll of waiting on Russell. Powerless to change the situation he finds himself in, waiting for the occupational therapist, he has to bear not only his physical fragility, but also the incessant fear. His tone changes as he speaks of his frustration as the uncertainty goes on – *when, when, when* are they coming? Russell fears the worst. Uncertain when *it's going to happen* but convinced he will fall *again*. He is clinging to the rail, a rail that offers little stability. Waiting for a call from the occupational therapist, he feels his life slipping from his grasp. Uncertain about what could happen and when it might happen shows that time is *crucial;* waiting time could mean the difference between being safe and having a serious fall. A fall that could leave him even *worse off* than he is *now*.

The long days are spent *sitting* and ruminating over the situation, rather than doing. Russell dwells in the helplessness of waiting, *thinking* about his future *a lot*. Heidegger (1971) speaks of 'dwelling' as a 'staying with things'; it is the manner in which humans are attuned to, and experience, the world. It is being embedded in a particular place in the world (Wrathall, 2005). Russell is immersed in the world of falling. Ontologically, his sense of comfort and peace, a feeling of at-homeness, falls away. Consumed by the fear of falling, the 'falls' merge into an insurmountable event with consequences so dire that waiting is dreadful. He dreads 'they' may not come in time.

While the uncertainty of waiting shows Russell dwelling in fear, Bruce experiences the uncertainty of waiting for the occupational therapist as an aloneness. Bruce does not

openly speak of being alone or lonely; he speaks sadly of being let down by the system. His certainty in ever being seen by the occupational therapist is waning. He is waiting for *a knock*, something to tell him that he is not alone and that he matters.

> *I'm still waiting for somebody to come. It's just that I am getting so disillusioned, I seem to be going back, back, back down the list all the time. I have had no contact…. There's always some hope that there will be a knock at the door, but I've given up lately. I'm just puttering on in my own way. I am getting disheartened with the health system…. You're the only person that's ever come and listened to me. You listening to me, it's helped me greatly, it's given me confidence that maybe things are not as bad as I think. (Bruce, 76)*

Bruce has lost *confidence* in the system – a 'thing' that does not see or hear him. He has had *no contact*, no *knock;* no one has heard him or responded to his needs. Bruce experiences the uncertainty of waiting for the occupational therapist as silence. In the silence he feels increasingly insignificant, *going back, back, back* down the list. His name is not a person, rather, a 'thing' being moved *down the list* by another 'thing', the *health system*. Feeling disregarded leaves him uncertain of getting the help he needs. He vacillates between the hope of being seen and the despair of never being seen. The feelings of lost hope and sadness become greater as time goes by. He is *disheartened* – believing that getting to the front of the waitlist is an illusion – convinced that he is constantly sliding down the list, and that the front of the line cannot exist.

Filled with uncertainty of ever being contacted, Bruce carries on in his *own way*. As he *putters* on, alone, waiting for occupational therapy uncovers his aloneness. Although he does not openly speak of being lonely, waiting alone, in a void of silence, with no one to talk to, discloses a context of loneliness. Bruce is waiting for *somebody*, anybody, to come and listen to him. Loneliness increases the risk of hopelessness and a depressed state (Golden et al., 2009). During the conversation, Bruce spoke of *"the sheer sadness of having to wait."* The heaviness of Bruce's sadness is compounded by the loneliness. As Bruce *putters on*, trying to keep waiting, he is uncertain if the occupational therapist will ever call. Fearing they may never come, he loses hope, believing he will have to keep struggling on, alone.

As time stretches out Bruce is uncertain of ever being seen, abandoning hope but desperately clinging to hope. He does not want to give up on the system. For the sake of

being at home and doing what matters, he needs their help. As his emotions seesaw, he tries to maintain a sense of his own world and keep carrying on, doing what he can, in his own way. Bruce cannot rely on anyone, except himself. Alone in the world, he waits for some sort of sign. Anything that can reassure him that he is on the list and moving forward. Waiting shows Bruce as losing heart.

There is *a knock*, a sign that he is not forgotten, not alone. In agreeing to participate in this study, Bruce gets a space to speak and have someone *listen*; to be both seen and heard. For Bruce, this opportunity to be heard renews his certainty that *somebody* will come, and he wills himself to keep waiting.

Bruce experiences the silence of waiting, the uncertainty that 'is' waiting for the occupational therapist. Molly also experiences the silence; however, her experience offers a different perspective of the waiting. Molly's story reveals the powerlessness in waiting for occupational therapy. Molly experiences uncertainty as a fear to act. She vacillates between waiting for her turn, and ringing to find out how much longer it will be before she will be seen. Uncertain how they may respond to her call, she thinks twice about ringing *them.* She does not know *them,* these faceless people who have the power to make a difference – to help her – if only they would call.

> *It's over a year that's gone by. I couldn't say nothing. I don't want to say anything. I've been sort of quiet. It makes me quite alone. Waiting is frustrating for me, depressed. I've been wanting to know what's going to happen. Shall I ring them? No, I thought, I'll wait until they…. Sometimes I feel that if I ring them they will get angry with me or it's not going to happen, so I thought I'll be patient. (Molly, 68)*

Molly intuits that she has no control within this situation and that she is completely at the mercy of *them*. *They* hold the power and all that she can do is *patiently* wait for the occupational therapist. However, she wants to know her place in the queue and to know when she will be seen. The unknowing is unsettling. She is filled with uncertainty, and an unvoiced fear becomes apparent as she toys with the idea of ringing the occupational therapist. Calling them may cause offence or anger, which adds to her indecisiveness and unease. She does not want to be seen as a nuisance as *they* may make her wait longer or not come at all. She feels *quite* alone in her wait as she tries to decide what to do. There is no one else to talk to, to share the burden of her decision. So she wills herself to *be patient*, deciding not to call them. Molly does not articulate where her understandings

come from, but ontologically these 'understandings' come from being-in-the-world. Gadamer talks about understanding the horizons of others. We understand ourselves from being in our family, society and way in which we live (Gadamer, 1975/2004) and that each person has and brings their own culture, history, and prejudices into their life situations. Molly's decision not to contact the therapist has been legitimised by "tradition and custom [that] has an authority that is nameless … the authority of what has been handed down to us … [which] always has power over our attitudes and behavior" (Gadamer, 1975/2004, p. 281).

Molly is Māori. Māori have, and continue to experience institutional racism, leading to inequity and discrimination within healthcare services (Came, 2013; Ministry of Health, 2022a). As an older Māori woman, Molly has had previous experiences of the Pākehā health system. She talked about her GP telling her *"you need to wait"*, and rather than feeling supported by her GP, Molly is left to wait. The imbalance of power between Molly and the system may account for her indecisiveness, in fear of causing offence to the system and the possibility of retribution. Molly understands that the Pākehā system gets *angry* with Māori, so it is best to keep quiet for fear they might deny her their service. Prejudices, which outweigh judgement, make up the reality of Being (Gadamer, 1975/2004). Molly has learnt it is best to stay unseen and unheard. Heidegger associates the notion of 'falling' with Being-alongside the 'world' and "Being-lost in the publicness of the 'they'" (Heidegger, 1927/1962, p. 220); 'they' points to the tacit knowing of what people in general think and do. In waiting, Molly 'falls' into her 'they-self' and conforms to the 'they', 'they' who inconspicuously dominate and intrinsically shape the world. Molly understands that she cannot assert influence over the system and is powerless in the face of the system. As Molly conforms, she does not take a stand for herself, choosing instead to remain unheard. As she continues waiting, she is uncertain if *they* will ever call.

Molly continues to wait, hopeful that she will receive the phone call she is waiting for and have her patience rewarded. In contrast, Bert is done waiting. As an older member of society, Bert understood that in his time of need he would be helped. But the uncertainty of waiting makes Bert feel insignificant. He insinuates that younger people are more important and being prioritised. He alludes to the negative way older people are portrayed and thus discriminated against. His 'understandings', always situated, unspoken and unconscious, shape his prejudices. All understanding involves some prejudice and

prejudices can have a positive or negative value (Gadamer, 1975/2004). As Bert waits for the occupational therapist, he feels insignificant. He is attuned to suddenly being old.

> *I'm pissed off. I'd like them to be able to see me earlier. This has dragged out for over six months now and we're still waiting. But I'd like to know what they can recommend and if they can do anything to help me. But this just sitting waiting, all the time, don't know when they're coming…. You're forgotten, you're old, you're pushed to the back of the heap, and no one really wants to know what's wrong. Sometimes I think that they don't want to know me. I may as well curl up in a hole and die. I can't do the things that I'd like to do. I'm no use to anyone… (Bert, 82)*

The long wait fuels Bert's emotions. Bert despairs of being helped and experiences the uncertainty of waiting for occupational therapy as being disregarded, as being *pushed to the back of the heap* where he cannot be seen. Bert is *pissed off*. He is angry that he has to wait so long, but he is slightly embarrassed to use this type of language that he would not ordinarily use, and so laughs it off. However, the strength of these two words hangs in the air, engulfed in the mood that prevails in the room – one of despair and hopelessness. No longer being respected as a person with something to contribute he is made to feel *old*. Being old, he understands *they* do not really *want* to help him; fearing he is just another old person, forgotten and not worth worrying about. In being old, Bert is both discarded and disregarded by 'them'. His life lacking purpose in the wait as he is forced indoors. Bert has devoted his time, *six months*, waiting for the occupational therapist in the hope of being helped, curious to know what they can do for him. But he is losing hope and any certainty of being helped is waning. With much of his identity based on being independent, his sense of self is being challenged. Bert cannot actively participate in his life. The physical and functional losses that accompany his degenerative neurological disease continually gnaw away at his autonomy and disrupt his day-to-day life, exposing a sense of uselessness underlying his despair. *They* cannot see the depletion of his life nor understand what is being lost to him in waiting. In waiting, he feels his age, and it reveals to him his finiteness; fearful that there may not be much time left. Although time is endless, his time is running out. In not being able to do what he would like to do and in being no use to anyone, Bert speaks of death. He speaks of hurrying towards death, as there is no point in living this way, *no use to anyone*. His life feels futile in the wait. *They* have discarded him. In his despair and sorrow, he experiences the loss of the life he

envisioned for himself. He suggests he may as well give up and let 'them' put him in the ground now. He is done waiting.

The 'fearfulness of waiting' exposes the struggle and uncertainty. The fearfulness is a way of being attuned to, and by, the world and discloses the uneasiness of waiting. The participants experience fear, despair, powerlessness, dread and aloneness. However, there are glimmers of hope interwoven in the stories. Hope that the occupational therapist will call, hope that they will knock on the door, and hope that they can help. Having hope, the participants live towards the possibility of being helped and returning to and resuming their 'normal' activities once again. However, the uncertainty of the occupational therapist arriving outweighs the hope of being seen and that the therapist is not too late to be of help.

INVISIBLENESS OF WAITING

Thrown into waiting for occupational therapy, the participants experience the invisibleness of waiting as they find themselves invisible to the system and to those who can help them. The Heideggerian notion of thrownness refers to the way human beings find themselves in a particular situation that they did not choose nor is it in their control. Thrownness has an origin that lies in one's story of getting to where they are (Withy, 2014). Finding themselves in the situation of needing help, the participants have been referred to the occupational therapy service. Living in New Zealand means that people understand that they have access to public healthcare, with the expectation that they will be seen when needed. To be 'thrown' into a situation [waiting for occupational therapy] is the way in which people are 'delivered over' to circumstances beyond their control (Wrathall, 2005). Rather than being seen immediately, they are delivered over to an occupational therapy waitlist that renders them invisible by name and person until such time as their name appears at the top of the list. Until they are contacted, they are invisible. The participants are waiting because they do not have the tools ready-to-hand to care for themselves, and are thrown into a new situation with which they must deal. Being thrown into waiting for occupational therapy reveals the possibility (or not) of being helped.

From the moment they are thrown into waiting for occupational therapy, the participants are invisible. As they wait unseen and not noticed, their needs and experiences are hidden, so too, their experience of waiting goes unseen. To be invisible is to be hidden, incapable

of being seen and not perceptible by vision. It stems from the Latin *invisibilis* meaning 'kept out of sight' and is related to 'inconspicuous', a weakened sense of 'not readily seen or noticed' (Online Etymology Dictionary, n.d.-a). Waiting for occupational therapy is being inconspicuous, not noticed, and not seen by the service. Waiting for occupational therapy shows its invisibleness. The sub-themes *no end in sight*, *visibly patient*, and *disappearing* reveal the layers of the invisibleness of waiting, and how this shapes the experience of waiting for occupational therapy.

No end in sight

It is commonly understood that to access public health services, you have to wait. In waiting for service, a person joins a queue, awaits their turn to be seen or helped and then leaves the queue when their needs are addressed. The queue is a system that is understood to provide order and fairness to access services. A public health service waitlist is a virtual queueing system unlike the familiarity of physically queueing for service. The health service waitlist has no continual sensory input to keep us engaged, no visible line or visible somebody waiting to serve.

Waiting manifests over the passage of time. Weeks stretch into months. A number of participants are reminded of their wait each day, as their ability to do things is restricted. As Luckie waits for months on end, with no end in sight of being helped, the experience of waiting for the occupational therapist makes him wonder if he is still on the waitlist.

> *Waiting in the bank is a bit annoying but you can see that the person has done their transaction and moved out of your way so you're one step further forward all the time, one step further forward, which is great. But when you're waiting for somebody like the therapist you don't know whether they are coming or whether they've gone away and forgotten about you. Or even thrown the paper referral in the wastepaper basket and forgotten about you. (Luckie, 87)*

Luckie reflects on waiting in a queue at the bank as *moving forward all the time*, suggesting that waiting is associated with being in a queue that moves, and there is a feeling of progressing *forward*. However, as Luckie waits for the occupational therapist, he cannot see the queue or feel himself move forward closer to the front of the line. The queue is invisible to him, he does not know his place in the queue, how far from the front he is, how far he has to 'move' to reach the front, how long the wait will be. Because there is no seeing or a feeling in the queue, there is no knowing about its movement,

whether it is moving quickly or slowly or whether he is moving forwards or backwards. Hage (2009b) describes this as 'existential immobility', a lack of felt movement usually experienced in a situation where the person is 'waiting out' a crisis situation. Luckie's situation is a crisis for him as he cannot get himself out of bed and be engaged in his world, doing what he always does. His daily routine is disrupted and his life as he knows it to be is changing in the wait for occupational therapy. He waits inconspicuously, in a queue that cannot be seen.

Luckie is one of many waiting in line. Despite the fact that he waits alone in the queue, ontologically, he is waiting-with others. He knows that he shares the queue, but the invisible nature of the queue means there is no sharing in the experience of queueing. Unlike a physical queue where you know you are not alone, standing together, shuffling forward together or fidgeting restlessly together as the queue slows or stops, this queue is different. Luckie feels the aloneness of queueing for the occupational therapist. The shared mood of queueing is lost. Luckie becomes increasingly ill at ease with the aloneness of waiting for occupational therapy.

The invisibleness of the queue gives rise to Luckie's unease of ever being helped. He wonders if they have *forgotten* him. Luckie experiences waiting as being unseen and feeling overlooked. The invisibleness of waiting leads him to question if they have *thrown* his referral *in the wastepaper basket,* or *gone away* and are not coming, suggesting his faith in the system is wavering. Thinking about *whether they are coming,* likely leads to the question of 'when'. How much longer must he wait to get to the front? His life feels to come to a stop as he waits in the queue that does not feel to be moving. Waiting is never ending with no end in sight.

Visibly patient

Waiting for the occupational therapist requires patience, that is, the ability to wait calmly in the face of adversity, without complaint (Merriam-Webster, n.d.-b). The participants wait with an outward appearance of calm, but their stories tell us something different. Many are uneasy and distressed in the invisibleness of waiting. Yet, unlike the other participants, there is something different about Archie and Betty's experience of waiting for occupational therapy. They are both visibly patient as they wait for the occupational therapist.

Archie's experience of waiting is different to the other participants because it appears that for the most part, he can get on with his day as he talks of *"just carrying on with what* [he] *normally does."* Archie is visibly patient; he is not consumed by waiting for the occupational therapist.

> *I can't remember exactly when I first heard from them. The therapist said it would be a while before we'll get back to you, so I haven't worried about it or fretted about it or anything like that, when it happens, it happens… (Archie, 75)*

Archie is not worried about waiting. He cannot recall when he was contacted, but the contact he has received enables him to wait. He knows he has been waiting for several months already, but this does not upset him. He knows he is one of many people waiting to be seen, knowing that his turn will come. He does not feel lost or forgotten in the waitlist. He is patiently waiting his turn, trusting that he is on the list. Being informed of the wait puts him at ease and he accepts the wait for now. He has been told it will be *a while* so he is just getting on with what he normally does. Archie is reassured by this knowledge. He has no reason to doubt that his appointment will not come. The uncertainty of when he will be seen does not seem to bother him, as if he has all the time in the world.

There is no sense of urgency for help as Archie patiently waits for the help he knows will come. He does not *worry or fret* as this can make waiting unbearable. He describes himself as *"fairly relaxed"* and someone who *"tries to work in with everybody else".* Archie conveys a sense of being comfortable with waiting. He spends many hours building model planes and he does not think about waiting when he is occupied in doing something meaningful. Archie accepts that *when it happens, it happens,* and even though he remains out of sight and inconspicuous to those he is waiting for, he does not feel invisible or forgotten at this time.

While Archie knows that he is waiting, and projects an acceptance of the wait, Betty has been waiting so long that the wait has become invisible even to her. Betty is visibly patient waiting for occupational therapy, but really, she had forgotten that she is waiting for the occupational therapist and what it was she was waiting for. As the conversation progresses, she remembers what it is she is waiting for.

> *Well, it is too much of a hassle trying to get the walking frame and me up and down the steps. It stops me from going out. … Oh yeah! I was waiting for a ramp. (Betty, 75)*

Betty suddenly remembers the ramp. *'Oh yeah… the ramp'* comes as a revelation to herself. It has been many months since she first considered the benefit of a ramp and asked for help. In the invisibleness of waiting for occupational therapy, Betty *stops going out*. She wants to go out but it is *too much of a hassle*. It is simply too difficult to get out of her home. The effort to negotiate the steps with her walking frame overwhelms Betty, and instead, she chooses to stay inside. Over time, she finds her own way of being at home. She is no longer dwelling in waiting for occupational therapy.

Forgetting that she is waiting for the ramp, Betty appears to accept her situation and 'waiting' is not seen to be a problem. Her patience reveals letting go of community connectedness as she forgoes occupations outside of her home. These become lost to her, yet they do not appear to be a loss. Betty dwells within the comfort of her home. She becomes accustomed to not going out. Rather than going out, Betty dedicates her time to sitting and watching the neighbourhood from the comfort of her chair. However, research shows that access to the immediate environment and community outside the home is important to mental health and well-being in older adults (Green et al., 2005). As Betty speaks, she is alerted to what has become lost to her in the wait; she speaks of watching her garden turn to weeds, of no longer going swimming, driving into town, or visiting her neighbour. Waiting for occupational therapy means living a new normal that is less physically demanding, the role of observer; a life less full of activity. In the invisibleness of waiting for the occupational therapist, Betty appears visibly patient, but waiting means becoming invisible to the world.

Disappearing

Like Betty, Val is confined to her home. But Val is *hanging in there*, waiting for the day when she will be able to get out of her home, where she can see and be seen. This will make the wait worthwhile. Meanwhile she tries to find a way to wait. Endeavoring to hold on to her life stuck inside she glimpses the world outside, but she is no longer actively part of it. She can see the outside world, but the outside world and those within it, no longer see her. In the protracted wait for the occupational therapist, Val is disappearing from her world.

> *I just carry on. Just hang in there. My friend rang me up one day. She said "I don't know how you manage to stay in like that and not be able to go out". I said "well you can't do anything about it can you?" I don't go out anywhere because I can't get down the steps.*
>
> *One day I sat on the seat of the walking frame at the back door and I looked at the sunshine, but I couldn't get down the steps. That's where patience comes in I suppose. I can watch TV and I can watch people go by. I get fascinated by these children, but they annoy me because they take our papers. They take them and we never have any papers. I can't get the papers because I can't get down the steps. Before I fell on my knee I could do it. I got myself down every day. That was my achievement but I can't do that so I have to ask the carer. Some of them say "I'll do it when I come back" and then they forget all about it. (Val, 80)*

Val is trapped by the steps, which create a barrier that she cannot get past. In her resolution to remain in her home, she resigns herself to an inside world, and becomes less visible to the outside world. Before her fall, the steps made it possible to come and go from the house and were not a barrier, but rather something that enabled her to get out into, and connect with the world. Heidegger (1927/1962) would describe the steps as ready-to-hand. Val could go out and see her friends, or do her shopping, or collect her newspapers and feel rewarded by this *achievement* each day. Now, the steps have become a barrier. In Heideggerian terms the steps are made present-at-hand now that they are in her consciousness, and unready-to-hand because they are unusable. They make the world a distant place to her, one that she is disappearing from.

The world is losing its shine as Val tries and fails repeatedly to make the most of her situation. Val is *hanging in* by seeking new meaning in her inside world. She searches for activities to fill her days at home as valued community-based occupations disappear. But Val has been taught to endure and *just carry on*. She must trust that her turn will come and that she will become visible to the occupational therapist. She hopes that she has not been forgotten, like *they* forget to bring in her newspapers, her needs disappearing from their consciousness. Although the steps keep Val confined to her home and invisible to the outside world, she has not given up. There are still a few things she *can* do, hidden away and out of sight.

Past the steps is the outside world, a place Val can only *watch* from inside her home. Her world is slowly disappearing as she becomes disconnected from it. Val's horizon has

changed as she becomes housebound; she only has a partial view of the world from inside. Determined to ca*rry on* at home, she finds something to do. Val is actively watching the world. She *watches* people go by and the children who both *fascinate* and *annoy* her. She *watches* her newspaper disappear as *those* children run off with it, the thing that provides some connection to the world. She *watches* the sunshine but cannot get out to enjoy it. Val is used to doing things. In the invisibleness of waiting, those occupations that give her a sense of *achievement* disappear. They are lost to her, taken from her in the wait.

The 'invisibleness of waiting' reveals an aspect of the uneasiness of waiting. Being unseen and feeling forgotten, some participants experience a sense of unease, unsure if they are still on the waitlist, and whether they will get to the top of the waitlist and be seen by an occupational therapist. Yet, Archie's story shows that having contact with *the therapist* put him at ease, allowing him to carry on, and Betty's story reveals how waiting can become invisible to the person themselves. For some, waiting means disappearing from their neighbourhood. A world they can only watch. The invisibleness of waiting hides how meaningful occupations disappear and are lost, and how people are pressed into finding things to do that may be less demanding or fulfilling. In the invisibleness of waiting, their world and what they are able to do becomes smaller. While the participants appear calm and look to be patient, as they endure the invisibility, there is an uneasiness about waiting for occupational therapy.

SUSPENDED IN TIME

The unease of waiting for occupational therapy distorts the experience of time. Waiting for the occupational therapist is being suspended in time, living in a state of uncertainty, feeling that life is on hold, or even interrupted. Time normally has a synchronous flow that helps to organise daily lives and routines. Heidegger's notion of temporality is understanding that Being as a whole, is always considered against the background or horizon of time (Heidegger, 1927/1962). But this is not the time measured by clocks and calendars but rather to understand "the ambiguous way that time is already at work in our environment before we have noticed it all" (Harman, 2007, p. 27). Chronological time, or *chronos*, is different to, but interwoven with *kairological* time – lived time – the richness of the lived moments of one's life (Bandak & Janeja, 2018; Harman, 2007). Waiting for occupational therapy is experienced as felt time. Regardless of the actual length of time waiting, it is the participants' perception of time. Time is experienced

differently when one is busily involved in something compared to being impatient, unoccupied or bored. The participants use words such as *stretched out*, *dragging on,* and *drawn out* to describe waiting for occupational therapy. Time spent waiting for occupational therapy is irretrievable. Time is precious. As the participants in this study are older, their time of life cannot be ignored as Dasein is finite. There is a knowing that while time is endless, *my* time is running out, it is finite and ends in death (Heidegger, 1927/1962). Waiting brings to light the interruption to the natural flow of time. Time speeds up, slows down, holds people in a state of uncertainty, and introduces a split between the past – of what 'I' could do – and the future – of returning to doing these things again. As the participants experience waiting as being suspended in time, the sub-themes *in limbo, time interrupted* and *losing time* show how time takes on a new form waiting for the occupational therapist.

In limbo

To be in limbo is being "on hell's border" (Dictionary.com, n.d.-b); neither here nor there. It is being in an uncertain condition or in a forgotten or ignored state (Merriam-Webster, n.d.-a). The stories of waiting for the occupational therapist show the participants in limbo. They are in a situation where they do not know what will happen or when. They are unsure of whether they exist on the waitlist or if they have been cast aside, unsure whether they will be helped, or not. Stuck in this liminal state of waiting, they are in limbo. Participants no longer feel they have agency over their time and there is nothing they can do to move things along. The participants' sense of time affects the experience of waiting for occupational therapy.

Russell is concerned about his safety. Not knowing when the occupational therapist will come attunes him to the passing of time.

> *It's been a while. It's been a few months. It feels like years. I'm not sure. It seems a long time you know. One day I'm going to fall or slip over… (Russell, 75)*

Russell *feels like* he has been waiting *years* for the occupational therapist. Lived time is measured by moments, and several near misses in the bathroom, together with the fearful anticipation of falling, alters Russell's sense of time. Fear leads to a surge of adrenaline, a quickening of the heart, and this arousal speeds up the brain's internal clock, leading to a feeling that more time has passed than actually has (Jarrett, 2021). However, underlying

Russell's fear is an uneasiness, a discomfort in the mind. As Russell waits, not knowing if he will be contacted, or when, he experiences waiting time as being in limbo, a state of apprehension and discomfort. Suspended between a time of not falling and a time of having another big fall, Russell is not comfortable in this space of not knowing when 'it' will happen. Worrying about the inevitability of a fall is waiting on hells border; he is neither here – safe, nor there – fallen, and for Russell, *it feels* like *a long time* waiting.

As Val waits with *nothing to do*, her experience of waiting for occupational therapy shows another aspect of lived time. Time slows as Val tries to find things to do. She is *fed up* and *bored.* Heidegger delineates three forms of boredom. The first form is becoming bored by something, such as one's general situation (Freeman & Elpidorou, 2020), which resonates with the situation Val now finds herself in. It is not the waiting that bores Val, but rather that she is attuned to her boredom. She cannot escape but is "held in limbo… as time drags along" (Harman, 2007, p. 86). Endeavoring to fill in her days, she wills herself to be patient as she waits for the occupational therapist.

> *Usually I'm very patient. I don't go out anywhere because I can't get down the steps. So I try the TV. If there is nothing on I turn it off again and look at a magazine. I tend to read a book or I like doing word finds. So I do that and I get bored with that and maybe there's something on TV and I end up watching the food programs. And then I get fed up with that and think 'there is nothing to do'. But waiting around, I have got a lot of patience. (Val, 80)*

Val is *usually* a *very patient* person and feels that she can *wait around.* However, as she tells of waiting for the occupational therapist, she lets slip that she *"gets ratty"* with the unending waiting. Val is willing herself to be patient, but not knowing when the boredom will end, leaves her in limbo. She cannot change her situation and is being held in a space of wanting to do things and not gaining any satisfaction from what she can still do, whilst waiting for the time when she can return to doing what she enjoys. In this time of waiting, she is *bored* and time drags. Stuck inside, she cannot go out and do the usual things she enjoys like getting the newspaper or visiting others, which would usually fill in the day and break up the monotony. She experiences waiting for occupational therapy as long days, unable to find meaningful occupations that sustain her attention or give her satisfaction. Instead, she is restlessly trying out ways to fill in her time. Val is neither unoccupied nor fully engaged in her world. Waiting for the occupational therapist is being forced to linger and drive away the time (Harman, 2007), and shows itself in Val's

restlessness. Val is not as patient at *waiting around* like she thinks she is. Instead, she is enduring the wait, waiting for her turn, and being a good citizen (Hage, 2009b). A good citizen does not complain and Val understands this from her historicity. Held in limbo she is biding her time, as time drags by waiting for the occupational therapist.

Time interrupted

Waiting interrupts the flow of time. The situation of waiting for occupational therapy announces the divide between the past of what 'I' could normally do, and a future of returning to doing those things. Hannah Arendt speaks of life "as being lived in an 'interval between past and future'" (Bandak & Janeja, 2018, p. 2). By this she means that the 'present' is a gap in time in which we are being-there, existing. Humans reflect on their past and anticipate the future, but we live and exist in the present, now. Waiting for occupational therapy is being in a temporal gap that breaks up time into the past and future.

Maurice's life is interrupted in the wait. Before his admission into hospital, Maurice was in control of his life and kept himself busy. As he waits for the occupational therapist, his ability to 'do' is disrupted. He is waiting, suspended in the interval between his past of being able to do, and a future of returning to doing those things.

> *I couldn't go out, I couldn't walk, and I couldn't go anywhere. Prior to that even though I was blind I could still walk, still go out. [After that] I couldn't do anything. I was just confined to the house. Everything's changed. I was the main driver, but my wife had to take over driving. … It's like being in prison, you're imprisoned. There's only my wife to talk to, there's no one else, unless people came here. But when somebody's sick in the house people don't want to come around. ... So it was just hopeless. The fact that I couldn't see and do anything, my wife couldn't do anything. But around us things were still happening. Those trees in the front were growing and growing and growing, and I couldn't do anything about it. I was paying for the lawns to be done, but normally I would have done them. You know I've worked hard all my life… (Maurice, 88)*

Maurice has become *imprisoned*. His spirit ebbing as he can no longer partake in his life. He *couldn't walk, couldn't go out* or *go anywhere* at all, a prisoner in his own *house*. His life is now restricted, his freedom curbed as he waits indefinitely for help. His life on hold by no choice of his own, forced to wait, and yet, all the while he wants to be doing the things that matter to him. His wife – his cellmate – the only person he sees each and every

day cannot help him, and *there's no one else* to talk to, to break up the monotony of time. As Maurice looks out, past the confinement of his house, to the world outside his window there is a sense of despair and lost hope. Being in this temporal gap, waiting for occupational therapy, leaves him feeling unsure if he will get back outside and do what he has always done. His view of the world is bleak from where he sits. His life is one of existing in the present, seemingly powerless to do anything. Despite that, he is still attuned to world outside. There is still a flicker of hope, and a possibility to re-engage in his life, once he is set free through what the occupational therapist might be able to offer him.

Maurice speaks of 'before' and 'after'. Before he became unwell, he *could still* do things, go out, walk, and enjoy his freedom. It was a life where he had choice and control, where he was in command of the situation and in charge of maintaining his home and property. The unexpected interruption to his life means *everything's changed*. Waiting for occupational therapy shows the gap between a past of doing and a future of re-engaging with what is important to him. He can see the passing of time with the growth of the trees as he fights to keep existing. Outside there is continuity. *Things* [are] *still happening*. Everyone else and everything else is still living. As he waits, he is losing his ability to stand his ground. The combination of his change in health, and the loss of choice, control and freedom contribute to feelings of dependence and the sense of emptiness in his life as he waits. From inside his prison, he notices nature outside his window. But Maurice has no choice but to wait. The temporal dislocation to his life while waiting for the occupational therapist attunes Maurice to his mood of disempowerment. To return to the life he previously enjoyed means waiting for the occupational therapist. In this unexpected gap in time, his life is suspended as he waits towards the future of re-engaging in the life he knew.

Losing time

Time is squandered sitting and waiting, not leaving the house for fear of missing the phone call. A meaningful life is lost in the wait as valued activities are pushed aside in order to wait. A new occupation of 'waiting' emerges. It is self-directed and intentional, but is experienced as lacking stimulation and any sense of achievement. Time passes. This time that cannot be retrieved, and there may not be enough time left to make up for what is lost in waiting.

Molly sits and waits. She is missing out on the normal everyday activities both within her home and out in her community. She places her life on hold as she waits to be connected to an occupational therapist. She does not want to miss her opportunity to be seen when her turn finally comes.

> *I'm bored just waiting. And I don't want to do anything but just wait. I've got that appointment coming to me. I need to do something for my health because I am diabetic. I could at least go for a walk or do something other than having to sit. I'm just waiting for that phone call. (Molly, 68)*

For Molly, waiting is not participating in the occupations she likes to be doing or knows she should be doing. She understands that not being active is detrimental to her health. But *that appointment* is important to her. She knows it is *coming* but not when. She sits and waits. No longer *doing anything*, she disengages from her previous activities. She dare not miss the call. Her new occupation of 'waiting' surpasses other activities but offers her little fulfillment. Waiting is boring. It appears passive and lacking in action. Yet, Molly is actively waiting. While she is alerted to the need to be involved in more active occupations, to act and do things, she feels compelled to sit and wait for the phone to ring. Waiting for its sound, which will signal the end of her wait; when she will be connected to a person, someone who can help. But for now, she is doing waiting. Her life is suspended as she waits for a call she understands will come, but not when. Time is lost as Molly intentionally waits. Intent on receiving the call Molly makes herself available by being near to the phone at all times. For fear of missing the call, she dare not go for a walk. And so she sits and waits.

Molly has become so focused on waiting for the call that she stops doing other things that matter and her world withers around her. Molly dwells in waiting. The waiting encompasses her life as she confines herself to her home, scared to miss the phone call she is so desperately waiting for. It is a long and lonely wait. But it is too much of a gamble to leave the house and risk missing the call for that longed for appointment with the occupational therapist. She does *not want to do anything* else except to wait. As she speaks, she becomes aware of how much time and energy she has spent on waiting for the occupational therapist and how diminished her life has come to be; the opportunity to spend time on other occupations is now lost to her. Her life is placed on hold as she waits for the phone to ring; time lost that she cannot relive.

Time becomes conspicuous when waiting for occupational therapy. As the participants wait, suspended in time, time warps as it speeds up and slows down. Time is interrupted, revealing a past of meaningful 'doing' and a future of returning to 'doing', and time is lost as they wait. Waiting attunes the participants towards the passing of time, and living into their future, hoping that the occupational therapist will be there in time. As time is brought into their awareness so too is the finitude of life, and at this stage in life, there may not be much time left.

Summary

In this chapter, I have drawn on Heidegger's notions of mood, thrownness and temporality to help uncover the uneasiness of waiting for occupational therapy. In waiting for occupational therapy, the physical struggle to keeping doing and the emotional toil of the uncertainty of being helped is exposed in the fearfulness of waiting. The fearfulness is a way of being attuned to, and by, the world, and shapes the participants' existences. The things that matter come into focus as the participants live in fearful anticipation waiting to be contacted by the occupational therapist. In the invisibleness of waiting they are unseen by the occupational therapist. They are left alone in a virtual queue that cannot be seen nor felt in its movement and has no end in sight. Being invisible and feeling forgotten, leads to feelings of doubt of whether they will ever be seen. The stories also show how some people disappear from their world in the wait for occupational therapy as the physical effort to engage in activities or social occupations outside of their home becomes too much and these are substituted with less demanding, indoor occupations. The participants experience a loss of purpose and agency, as they struggle to hold on to a familiar way of life and doing what matters. Living through the fearfulness and uneasiness of waiting for occupational therapy, meaningful occupations are replaced, modified, or lost. The participants' faith in the health system is tested as time passes. The uneasiness of waiting for occupational therapy changes their experience of time. Time speeds up, slows down, is interrupted, and is lost. In the unease of waiting for the help they seek, the participants vacillate between hope that the occupational therapist will arrive in time to help, and dread that they will not.

CHAPTER SEVEN: WAITING AS BEING WITH

No man is an island entire of itself; every man
is a piece of the continent, a part of the main;
if a clod be washed away by the sea, Europe
is the less, as well as if a promontory were, as
well as any manner of thy friends or of thine
own were; any man's death diminishes me,
because I am involved in mankind.
And therefore never send to know for whom
the bell tolls; it tolls for thee.

(Donne, n.d.)

Introduction

In the previous chapter, the phenomenological theme, 'the uneasiness of waiting', brought to light the interwoven sub-themes of fearfulness, invisibleness and suspended in time. The uneasiness of waiting uncovered what mattered to the participants, and revealed the significance of being and doing at home. In waiting, meaningful occupations were replaced, modified, or lost. As the older person waits, another facet of the phenomenon shows itself, that waiting involves others.

This chapter, 'Waiting as Being With', captures waiting for occupational therapy as occurring in the world with others. 'Waiting as being with' brings to light the relationships that participants have with others and how these are often hidden in the everydayness of waiting for occupational therapy. As the participants find themselves in the unfamiliar position of needing help to perform life activities, the experience of waiting for occupational therapy shows how the participants are thrown into ways of being with others that they had not anticipated. These 'others' may be family or whānau, friends, neighbours, and/or paid carers. In the thrownness of waiting for occupational therapy, it reveals the participants' possibilities for turning towards and accepting the help of others, or turning away from being helped. 'Waiting as being with' also uncovers the 'relationship' the participants have with the occupational therapist in their absence. The participants understand that the occupational therapist has the things they need in order to do what matters to them, and the therapist, while absent, is 'with' them in thought when they think about the wait or what they need from the service to be managing at home. Some participants experience waiting for occupational therapy as being cared for, which enhances their connectedness with others, while some participants experience waiting for

occupational therapy as not mattering to others, and their relationships with other people are seen to diminish.

"The world of Dasein is a *with-world*" (Heidegger, 1927/1962, p. 155), a shared world. Being-with [mitsein] is a fundamental mode of Being. Being-with is hyphenated to make it distinct from the ontic notion of physically being with other people in a shared space. In an ontological sense, being-with is always being in the world with, and alongside others. 'Others' are not everyone else but 'me', rather, as Heidegger explains, 'I' am part of everyone and indistinguishable from them; it is the way we understand ourselves, others and our world in the average everyday. That is, our decisions, behaviours and 'understandings' are intrinsically shaped by belonging to a world we share with other people. In the wait for occupational therapy, the participants are finding ways to stay at home because typically in New Zealand, staying at home matters. In the context of being at home, the participant stories hint at the differing ways others are there (or not there) showing their care. 'Waiting as being with' is a mode of being-with-others and will be presented as *Waiting as Being Cared For* and *Waiting as Not Mattering to Others*.

WAITING AS BEING CARED FOR

Waiting for occupational therapy, the participants find themselves in the situation of needing support and care from others. Everyday Being-with-one-another [miteinandersein] shows itself as solicitude, that is, how humans express concern for each other (Crowther & Thomson, 2020). Through solicitude, we show care. Heidegger speaks of Besorgen – taking care of *what* needs to be done in a practical way, and Fürsorge – solicitude – nurturing others (Reich, 1995). 'Care' is active in all behaviour (Cestari et al., 2017) and can be experienced in a deficient or solicitous way. Waiting for occupational therapy opens up the space for others to show their care. The following stories show the participants being cared for, and is presented in two sub-themes: *family caring-for* and *letting others help.*

Family caring-for

Without the family being there and caring-for, many participants understand that the possibility of remaining in their home would be arduous or impossible. The care being provided by the family buffers them as they wait for the occupational therapist, and is covered over in the normalness of a family helping. Family play a significant role in the

lives of older people, supporting them to maintain mastery over their life (Janssen, Abma, & van Regenmortel, 2012). Waiting for occupational therapy shows how the family are being with and caring-for.

Without his wife, Bert does not know *what he would do*. At 82 years of age, Bert has become fully reliant on his wife for all his daily activities as a neurological condition slowly alters his body, taking away his freedom for doing. Bert's story shows how his wife is just there, always at the ready to help him, and Bert readily accepts help from his wife. Bert cannot see a life without his wife being there, caring for him.

> *My wife has got to take my hand and get me over to the car, and I go around the car to the passenger side to get in. I can't walk on my own. I haven't driven for four years because I simply can't see. If it wasn't for her, Christ, I don't know what I'd do. My wife has to cut the toast for me because I can't see where to cut. Most of the time I've got to eat with a spoon because I end up with half of it on the floor. She chops my meat for me, growls at me. She tucks me in bed, makes sure I'm in bed properly, because I sit on the bed and I can't get my legs up over the edge of the bed, it's not as if it's high or anything. They just won't come up. (Bert, 82)*

Bert knows how important his wife is to his being at home. She plays a significant role in his life providing the constant support he needs. She is always there for him, ready to help. Bert tells of his experience of needing help with simple and taken-for-granted activities like eating and getting into bed, which his wife supports him with. He tries to make light of this when he adds that she *growls at me* as he has a deep knowing of the reality of his situation; he could not survive on his own. Because Dasein's being-in-the-world is being-with, there is an implicit understanding of others (Heidegger, 1927/1962). This is seen in the relationship between Bert and his wife who share a common world, which has intrinsically shaped their relationship and the meaning of everyday things to them, and their ways of how things are done. After many years of being with one another, she inherently understands him and intuitively knows what he needs. He does not need to ask for help as she *chops his meat* and *cuts the toast*, she simply does these things for him. It is a kind of knowing from being-with him in his everydayness. Her ability to 'leap ahead' is a way of being caring and supportive, and enhances Bert's possibilities. Her manner of caring is guided by considerateness and forbearance. Heidegger speaks of this manner of caring as being solicitous. By 'leaping ahead' and anticipating Bert's needs she preserves his dignity, allows him to keep doing things, such as feeding himself, and

she keeps him safe. The support his wife provides by just being there and doing things for him is hidden within the ordinariness of the everyday, but makes it possible for Bert to be in his home waiting for the occupational therapist. As Bert speaks of waiting for the occupational therapist to visit, his awareness is heightened as to how much his wife does for him on a daily basis to ensure he is cared for and their home is maintained, serving as a reminder of what is lost to him. Being cared for shows the care his wife has for Bert as she readily supports him. However, Bert is hopeful that the occupational therapist will be able to provide something that will allow him to be more capable, thus easing some of his perceived burden that he feels he places onto his wife day after day.

Everything we do is through and with our body. Remembering a time when he could do these taken-for-granted things unaided reveals what is lost to him. Bert spoke of a time when he could do *"anything and everything"*; his body was taken-for-granted. Bert could effortlessly engage in and with the world and interact with others. Now his body is changing and not doing what he expects it to do. There is a shift of attention. Ontologically, the disruption to his lived body causes Bert to become conscious of it and attend to it. Furthermore, his wife caring for him, leads to another ontological dimension of the body, namely bodily self-consciousness (van Manen, 2016) – that under the gaze of others, we live our body in a more self-conscious way. Bert is attuned to lost capabilities in those moments when he encounters failure. Little moments, such as when his legs *just won't come up* throw him into despair, serving as a reminder of the constant help he needs. His wife, always there to help, makes him more conscious of his body, a body that no longer works as it should. In waiting for occupational therapy, Bert accepts being helped and being cared for.

While Bert is fully reliant on his wife, who intuitively understands his needs, Roger's story shows a different perspective of the family caring. Roger is in charge of his care, still able to give direction to the family for the support he needs. Roger experiences waiting for occupational therapy as the whole family helping. The need for help has provided the opportunity for his family to show they care, and in doing so, his relationship with the family grows and strengthens. The family being present in an intentional way means that the relationship with his family changes from simply spending time together and doing things with him as a family, to doing things for him.

> *They'll be coming here as much as possible. My daughter works. My son has been living here for the last two and a half months doing all the bits and pieces in the bathroom, and stuff outside. One of my daughter's sons came up one weekend to cut trees down that I wanted cutting down. … I worked on the farm out here for twenty odd years on and off. I know how to do all that. It's gone now, hasn't it? (Roger, 80)*

Roger speaks of his children and grandchildren rallying around to help with tasks that he used to manage with ease. As Roger comes to accept his new body, and what he can and cannot do, he understands that to stay in his home, he needs his family's help, and he accepts their care. No longer being able to work on the farm or get out into his garden means that Roger is no longer participating in valued long-standing activities that he cared about and which gave him a sense of purpose. Instead, in his wait for occupational therapy, Roger sits inside thinking about what needs to be done. As the family help, Roger dwells on his past and what he could previously do. This does not mean he is living in the past, rather, it shows how his past can be present-at-hand and have an effect on the present (Heidegger, 1927/1962). By this, I mean that in these moments of a family helping, Roger's past is brought into his consciousness, and he brings these memories with him into the present. He still *knows how* to do things but physically cannot. Now he can only guide and direct what needs to be done. His family, helping and doing what he cannot, are a reminder of what is lost. Understanding that *it's gone now* is a consequence of ageing, he consciously lets go of doing some activities and accepts assistance from the family. However, he maintains a sense of self-determination and control by directing what work is to be done. He recognises that as he ages and his body changes, he can no longer do all that needs to be done to manage his own self-cares as well as the property. To prevent his situation from worsening as he waits for occupational therapy, he accepts the care being provided by his family.

Roger can no longer use the bathroom as it is. In the wait for the occupational therapy service, he is able to take control of the situation because his family are there and able to do what he asks of them. The difficulty Roger endures with getting into the bath exposes the other jobs that need doing, which may have ordinarily remained hidden. In caring for Roger, his family show their care in a practical way by taking care of things for him. His son, understanding what is important to his dad, and 'knowing' Roger's way of doing things, fixes *bits and pieces* in the bathroom. The family also nurture Roger as they 'leap

ahead'. Heidegger speaks of solicitude as having the possibility of 'leaping ahead' to give back care to the other, and in doing so, returning their freedom. Roger's family are anticipating ways to care, and gifting Roger the freedom to do the things that matter to him, such as being able to shower himself. Waiting for occupational therapy gifts Roger time and space to enjoy the closeness of family being with one another.

Drawing on the strength of family enables Bert and Roger to continue to engage in their life at home as they wait for the occupational therapist. Having help doing those occupations that are increasingly difficult to do buffers the loss. Waiting for occupational therapy illuminates the connectedness of the family as they are being with and caring-for.

Letting others help

Not overtly said, but clearly understood throughout the conversations was the participants' strong desire to remain living in their home. And to achieve this, many grapple with accepting help. Not everyone has family, and for those who do, their family may not be able to provide all the support or help that is needed. For those participants who do not have family around, coming to the realisation that trying to persist alone could be their possible undoing, provides an opening to let others help. These 'others' are mainly paid carers. The experience of waiting for occupational therapy uncovers the differing ways that the participants turn towards, or away from, accepting help.

Val tells of her hesitance of letting someone else help and take over activities that she has always done. Her control over how things are done in her home is at risk, and in waiting for the occupational therapist, she holds onto her usual ways of doing for as long as possible.

> *"You've got to let them do things for you". I said "yes, I know that and I will do in due time". And I have started letting them do a bit more for me. Anyway, he, the Needs Assessor, said "and you wanted to have somebody to help you with washing, your clothes and that", and then he said "have you got a clothes dryer? If you had a clothes dryer you could do it." I said "I've got a clothes dryer" and he said "well that's alright, wash it and stick it all in the clothes dryer. You don't have to worry about doing this and that". But that's not the point. (Val, 80)*

In agreeing to being helped and letting others into her home, Val comes to realise that she is not yet prepared to fully let go. She tolerates *them* being there doing things for her, and

speaks of her carer as an 'other', a *them*; separate from herself and her world. *Somebody* who is there to do a job. Val keeps her carer at arm's length. Older people, like Val, can find themselves caught in a situation between their desire for independence and their increasing need for help (Fjordside & Morville, 2016). To maintain some sense of control over her life and give meaning to her everyday existence, Val wants to do the things that she is still capable of. She is making a conscious effort to hang on to what she can still do. She is not yet ready to relinquish these activities. Val needs time to adjust. This is her home, her place in the world that provides her with the space for self-determination and choice – doing things her way. But, her ways are being questioned by the Needs Assessor[28].

Val feels frustrated that the Needs Assessor does not appear to hear her. She senses her ways of 'doing' are disregarded. She understands that there are other ways of doing things, but this is not her way. Her habits and routines are engrained through many years of running a household and they bring a sense of certainty and familiarity into her everydayness. In agreeing to being helped she feels disempowered, as she is no longer able to do things her way in her home. Nevertheless, she needs their help in order to remain in her home. She vacillates between letting others help and not. She understands that she might need help, but letting them help is letting go of some control in her home. She does not want *them* to 'leap in'. 'Leaping in' is the kind of solicitude whereby a person can be dominated. Val does not want them to take over and render her dependent. She compromises on what is important to her, acquiescing to *them*, knowing that she cannot do it alone. Val experiences waiting for occupational therapy as hesitantly letting others help.

Val cannot get out of her home without help. The steps stop her. She likes to get out and go shopping with the carer. She holds on to being able to do those things that add meaning to her life. It is during a typical outing that Val finds herself in an arduous situation at the supermarket. An unanticipated change in her ability to 'do' propels her into letting go and turning towards accepting help.

[28] A Needs Assessor allocates support services, such as home help. These supports are publicly funded via the DHB.

> *The last time I went shopping it was an ordeal. I had to keep stopping. I sat six times. And then I'm sitting waiting for the carer to go round and do the shopping. So I'd sit in the café. Then I had to get up and I had to walk to pay for the things. I think it's better that I let her go, she's alright, she does very well for me. So I just let her go and I've accepted the fact that I can't do that. She comes home with hot chocolate and a couple of biscuits, and my magazines so that's really nice. (Val, 80)*

The effort of getting out of her home and then doing *the shopping* is suddenly too much for Val. The unfamiliar need to *keep stopping,* to sit and rest, is distressing for Val and changes her experience of shopping from being an enjoyable outing into an *ordeal*. In her anguish she is forced to come to terms with her ageing body and admit to herself that she can no longer do the shopping with the carer. Ontologically, Heidegger's mood of anguish is not something that renders one powerless, but provides an opening to one's existence (Cestari et al., 2017). In anguish, Dasein is brought "face to face with its world as world, and thus bring it face to face with itself as Being-in-the-world" (Heidegger, 1927/1962, p. 233). The experience of this *ordeal* brings Val face to face with her own frailty and provides her with an opening to let her carer 'do' for her. Being together in this shared experience changes their relationship. In the effort to preserve her sense of self, Val consciously decides to delegate the shopping to her carer. Her carer gains Val's confidence as someone who can be relied upon. Through being-with-one-another, the carer shows her care. The carer is no longer an 'other'. The concern shown by the carer enhances Val's well-being. As her carer 'leaps ahead', Val feels that her needs are being considered. *Her* carer is being thoughtful and caring, making Val's life more comfortable without Val feeling that she is losing her control over her situation as she stays at home. In waiting for occupational therapy, Val comes to realise that she must gradually loosen her hold on her ways of doing and release her doing to others. Val is finding the balance between retaining her independence and letting others help.

In contrast to Val's experience, Russell is receptive to receiving help and support. During his lengthy wait for occupational therapy, several accidents in the bathroom have heightened his fear of falling. A carer has been allocated to provide him with assistance for showering.

> *Since the fall, I've really thought about it a lot. I want the bath removed because I feel I'm going to fall again. The lady that helps me comes on a Monday, Wednesday, Friday and Sunday. She's a very nice person. She has to help me into the shower, and that makes me think about the wait. She gives me a scrub down. She's here for an hour, I mean it doesn't take an hour but she has a cup of tea and a chat. It's great having someone pop in and have a chat. We get on well so it's good, it's good. (Russell, 75)*

Russell is vulnerable when showering alone. Letting the carer help makes a shower still possible, and he seems to be comfortable relinquishing his *scrubbing* to her. The carer being alongside him provides him with the physical assistance he needs. However, the physical help provided by the carer is a reminder that he is still waiting for the occupational therapist. Heidegger tells us that in these moments Russell is being-with the occupational therapist, even though they are not perceived or present-at-hand. They are there when Russell *thinks about the wait*. In contrast, Russell's paid carer is there, providing him with the help he needs to shower. He experiences her assistance as supportive, not only through 'what' she does but 'how' she performs her care. Russell is receptive to being helped and cared for. Supportive relationships and the acceptance of one's vulnerability are important mechanisms for older adults striving to maintain control of their life (Janssen et al., 2012). Although Russell is aware of his vulnerability, he still holds onto the belief that if he had the tools ready-to-hand to shower himself, he would.

Although the relationship with his carer is a formal arrangement – she is there at an agreed time and day to provide a service – Russell does not perceive her manner of caring as formal. Russell experiences being cared for as a person being kind, attentive and comfortable; her presence is like that of a friend, someone who is *popping in and having a chat*. Her support enhances his well-being. Taking part in the cultural and social custom of sharing a *cup of tea* gives Russell the opportunity to show his appreciation for her support, but more importantly, enables this 'working' relationship to evolve into a caring relationship. The regular time spent together provides him with some company and social connectedness on each of the days she is there. Letting others care means experiencing waiting for occupational therapy as feeling safe and being cared for.

Like Russell, Betty receives personal care help. But unlike Russell, Betty is not ready to let others help her, she *likes her independence*. Their support is tolerated out of necessity. Betty lives alone. She is in the habit of doing things for herself, and even as her ability to

do things changes, she is not actively searching for help. Betty does not speak of family, referring only to friends and neighbours. Betty experiences waiting for occupational therapy as coming to be reluctantly reliant on '*a somebody'*. In the meantime, she lets a variety of some-ones who might be there, help her in the moment.

> *I sit here and I can see the mailman if he puts anything in, then I know to go out. The neighbour or somebody will bring it in if they go past. That neighbour over there comes over if I've got a lot of rubbish. I don't like that. I like to be independent. I'd rather do it myself.*
> *(Betty, 75)*

Betty does not want to rely on others; she would *rather* do it herself. This attitude towards independence is supported in a review by Fjordside and Morville (2016) who found that older people want to look after themselves and retain their independence for as long as possible. Living alone fosters Betty's self-determination. However, her strong desire *to be independent* creates a confronting situation for her. On one hand, she is trying to retain control, and on the other hand, she has an increasing need to rely on others for assistance. To help maintain her independence, she preserves her energy by only going out of her home when she must. It is too much of an effort to simply go outside to enjoy her garden or visit her neighbour; going outside has a purpose now. As she sits and watches for *the mailman*, she is waiting for her cue, her reason to go outside. Yet the neighbour is there. He is somebody that is seen to be helpful, as he considerately 'leaps ahead' and brings in her mail, thus saving Betty from the effort of going up and down the steps. Preferring to get the mail herself, Betty is uncomfortable with having it brought to her. By 'leaping in', a neighbour's act of kindness is taking away Betty's independence. This solicitous care lessens the need for Betty to make the effort to go outside and so removing an opportunity for her to engage in the outside world.

Even though Betty *likes to be independent*, her experience of waiting for occupational therapy is not lived alone. Almost everything Dasein does or is, involves others (Inwood, 2019). Although Betty is reluctant to let others help, she is still with and alongside other people as she goes about her everyday. She watches them from her window, and the sporadic connection with the *neighbour or somebody* is a way of being-with. The intermittent support that Betty receives from others is helpful and lessens the everyday difficulties she experiences as time passes. In waiting for occupational therapy, she concedes and reluctantly lets others help her.

The care being provided by carers enables Val, Russell and Betty to be at home. However, their stories capture how they grapple with letting others help. Val and Betty show how they are making a conscious effort to hang on to their occupations for as long as possible, whilst Russell has made a considered decision to let go of his showering activity. In waiting for occupational therapy, coming to accept the help of others lets them be at home.

'Waiting as being cared for' captures the relationships the participants have with other people. In waiting for occupational therapy, the participants have come to rely on the help of others to support them at home with their daily life activities. For those who are cared for by family, the stories show the intuitive way that family anticipate ways to care by 'leaping ahead'. Their manner of caring is guided by considerateness and patience thus supporting the person to be at home. Similarly, for those participants receiving support from paid carers, they too experience care as kind and helpful. The kindness and helpfulness make it possible to let others help while waiting for occupational therapy. When they accept having others 'leap in' and 'take over', the participants experience waiting for occupational therapy as less onerous as the effort of doing daily occupations is shared. For those people who struggle and resist letting others help, they experience waiting for occupational therapy as a gradual letting go, as they consciously release their 'doing' to others. 'Waiting as being cared for' reveals the increasing connectedness with others as the participants wait for occupational therapy.

WAITING AS NOT MATTERING TO OTHERS

The ensuing stories will show how the participants experience waiting for occupational therapy as a negative mode of being-with-others. That is, feeling let down and being alone. These stories uncover the absent 'others'. These 'others' may be family or whānau, friends and/or the occupational therapist. Ontologically, being-alone is being-with in the world (Heidegger, 1927/1962). Because we co-exist in the world, we can never be fully alone. In everyday moments we can still 'be with' those who are absent in our thoughts and memories (Wright-St Clair & Smythe, 2012), such as family who are not there or the occupational therapist who has yet to make contact. Waiting for occupational therapy, the participants' stories point to 'others', and the lack of care, the feeling of being passed by, and for some, the subsequent loss of relationships. 'Waiting as not mattering to others' is presented in two sub-themes: *being let down* and *being alone.*

Being let down

The participants anticipate being contacted by an occupational therapist. They have asked for help, and as they continue to wait for the help they need, they experience waiting for occupational therapy as being ignored and let down. No one is responding to them, or recognising their need for help. They experience the lack of response as not mattering to the occupational therapy service.

Maryanne experiences waiting for occupational therapy as an absence of care. She understands that a referral has been made, a call for help to *the service* who has what she needs to get in and out the bath. But her request for help remains unanswered, as if she does not exist. Maryanne is a softly spoken woman, and a combination of her arthritis and early dementia is making it difficult for her to get over the bath. She does not have the tools that she needs ready-to-hand to easily get in the bath. She wants help. But Maryanne has not heard from anyone – they, are absent. Her gentle demeanor hides her frustration as she speaks of her experience of asking for help and being disregarded.

> *I guess they will come. The sooner the better. It is difficult getting in and out the bath. I try to manage but it's difficult to get in because I have arthritis in my knee. I get frustrated. Only those in the service understand why some people have to wait for ages. But when you need it yourself and you've got to go through it and say "it's happening to me", it's the waiting. When they know about it, when they know that you need it. You don't go asking for these things if it's not needed. It just makes it easier for you. When it's out there and you know it's out there. … I used to look after one of those people who had access to the things that they needed to help get in and get out the bath.*
> *(Maryanne, 74)*

Believing she would be helped, Maryanne feels let down by the lack of contact from *the service*. Knowing what is out there from her own past experience as someone who has looked after others, she knows that she is waiting for that service; the service that has *access to the things* she needs to lessen the effort when *getting in and out the bath*. The waiting is distressing. *They* are indifferent to her needs and unresponsive to her call for help. *They* do not understand what it means to be waiting when you really need help. It is different to be the one waiting, the one *asking* for help and not being heard. Maryanne is disappointed with the (lack of) service; she experiences absent care waiting for occupational therapy.

Maryanne *needs* help now. She is not *one of those people* who need *looking after;* she accepts that she needs *things* to help her. *Things* that will enable her to get in and out the bath more easily and retain her ability to 'do'. She is trying to manage but the arthritis in her knee announces itself each time she must climb into the bath and she can no longer ignore it. In these moments, she is 'with' the occupational therapist who is conspicuous by their absence. It has been *ages* since she asked for help. She is *frustrated* and disillusioned by their absence of care. She is waiting for them and they do not acknowledge her increasing need for help. Waiting is being disregarded. She needs those *things, things* that you *don't ask for* unless it is necessary – a last resort when nothing else is working.

Maryanne is unsure when *they* will come, or if *they* will come at all. She is hoping it will be soon but she really does not have any idea when it might be. She feels let down by the service, which has failed to fulfill her expectation of being helped. They have not responded to her call for help. As time passes in the wait for occupational therapy, the increasing physical effort to get in and out the bath is brought into her consciousness. She intuitively knows from her work as a carer what happens to older people who can no longer manage in their home. But she also *knows* that the solution to her problem is out there. The wait feels eternal as *they* do not respond to her plea for help. There is an underlying fear that if they leave it too long, it could be too late. *They* must know there is a problem because she is seeking their help; she would not ask if it was not really *needed*. Maryanne experiences waiting for occupational therapy as not mattering to those who can help her.

While Maryanne is waiting for the things that she knows will help her, Maurice is left waiting with equipment that is no help to him, and for months, he has been struggling to get in and out of his armchair. Maurice's story is offered to illuminate another perspective of waiting for occupational therapy as being let down. Maurice wants to be helped. Instead of being helped, he feels cast aside, and experiences waiting for occupational therapy as carelessness.

> *When they send you home from hospital somebody should come around and see what the conditions you're living in at home. They didn't even come round to find out. And so of course the chair wasn't raised because my son had no idea how to fit it. My son's used to looking at computers rather than looking at chairs. We had to walk around it, this bundle of wood that was meant to be a lift for my armchair…. Eventually somebody came around and said "oh, this is easy". I mean, simple for somebody who is used to putting those things together. But it's not simple for somebody who is not. (Maurice, 88)*

Maurice is waiting for *somebody*, anybody, to see him at home. He assumes that he will receive the help he needs. Instead, he feels passed by and that he does not matter to them. Maurice has an implicit expectation of the health system – that 'it' will be there for him in his time of need. This 'knowing' is a kind of Being, which belongs to Being-in-the-world (Heidegger, 1927/1962). That is, people's lives take place against a backdrop of past experiences that set up expectations for future experiences (Nenon, 2015). Maurice was expecting to be helped by *somebody* from the hospital. That someone would *come round*, check on him at home and be there to help soon after discharge from hospital. This is what he expects from a service that cares. But they do not care, no one comes. Instead of receiving care, the care he experiences from the service is one of carelessness and indifference. In waiting, Maurice must manage on his own. Rather than getting the help he needs, both his *armchair* and the *bundle of wood* are present-at-hand as they intrude on his daily life. As he waits for the occupational therapist, he must continue to persevere with getting in and out of his armchair.

Maurice feels let down and abandoned by the healthcare system. Following a sudden and acute admission into hospital, Maurice unexpectedly finds himself in this new world of being unwell and vulnerable, without the help he considers necessary. In this new situation, Maurice is trying to make sense of the circumstances he finds himself in. Since coming home from hospital, Maurice cannot lay flat and has no option but to sleep in his chair, but the chair is too low for him to easily get in and out of. The *bundle of wood* meant to raise the armchair is of no use, as it cannot be fitted. His son is there and willing to help, but his unfamiliarity with this 'thing' means he is unable to help in this situation. As such, Heidegger (1927/1962) would describe the *bundle of wood* as unready-to-hand, as it cannot be used as it should and cannot be integrated into Maurice's everyday life. Furthermore, it is a daily obstacle for both Maurice and his wife as they carefully *walk*

around it. It sits there as a constant visual reminder of the wait for *somebody* to come. This *somebody*, who has let him down, an indefinite 'other' who inconspicuously dominates, and is 'there' in the everyday (Heidegger, 1927/1962) 'with' Maurice in the wait, dominating his thoughts. Maurice ruminates over the daily struggle and the feeling of not mattering to those who can help. He must navigate his wait alone, powerless to change anything. Maurice continues to wait for somebody to see his *conditions at home* and *put things* right so that he can once again freely engage in his daily life.

Eventually they came. Instead of being cared for, he experiences their care as careless, and is once more let down. They are insensitive towards, and dismissive of, Maurice, reinforcing his feelings of inadequacy and powerlessness. In waiting for occupational therapy, Maurice experiences a lack of care, but worse than this, he finally gets to see a therapist and their flippant manner makes him further self-conscious of his inabilities.

While Maryanne is yet to meet an occupational therapist, and Maurice has finally been visited, Bob's story illuminates another aspect of being let down. Bob has already been seen by an occupational therapist. However, his needs were not adequately addressed and he was let down by this ineffective service, and he is now waiting for their help for a second time. He has now been waiting for over a year for them to return. Bob is skeptical of whether they will help based on his previous experience but he requires their assistance, the type of assistance that neither he nor his wife can provide. Bob experiences waiting for occupational therapy as being let down twice.

> *One of the things the occupational therapist came to do was to fill out the Lotteries grant. And then when it didn't go anywhere the occupational therapist who did that came back and they said that they would redo it all. I never saw them again. And that makes you think 'oh, I wonder if they're all like that?' I tend to think that they were. And so, we had to buy our own van ourselves. All the things that are done here, we've done it or had it done for us. That ramp out the doorway there, another one through there. But we didn't want to spend all our money that we'd saved, we need a bit of help. I feel sorry for my wife. [Saddened voice] (Bob, 75)*

Bob has exhausted his financial resources in the effort to re-engage in his life. The first occupational therapist did not deliver the help he needed. *They* came, made promises to come back, but never did return. Their failure to return showed carelessness. Finding themselves thrown on their own resources Bob and his wife did what they could. They

installed ramps and purchased a vehicle that would accommodate his power wheelchair, but they still *need a bit of help.* When the first occupational therapist did not follow through on what *they* said *they* would, their manner of caring was apathetic, and was experienced by Bob as half-hearted and uncaring. Further, in being indifferent to Bob's needs, it has limited his ability to do what matters, consequently, he is waiting for occupational therapy for a second time. Let down by the first occupational therapist, and believing that all occupational therapists must be *like that*, Bob experiences doubt and uncertainty in waiting for occupational therapy. He is uncertain if they will come, and uncertain if they will help him. But he needs their help and so he waits. Bob feels let down again as he endures the wait for help.

The stories of waiting as being let down illuminate waiting for occupational therapy as an absence of care and carelessness. Maryanne, Maurice and Bob feel passed by and of not mattering to the occupational therapy service. They persevere with their daily occupations in the wait for occupational therapy, and in these moments they are 'with' the occupational therapist who is there in their thoughts, and conspicuous by their absence.

Being alone

As the participants wait for occupational therapy, the following stories illuminate the aloneness some people feel. The stories disclose the loss of relationships with family, whānau and friends as they cannot be with others outside of their home, or others are not there, with them. Betty does not want to ask for help, even if it means missing out on doing the things she enjoys most. The *effort to get the walker down the steps* means that in waiting for occupational therapy, she stops going out and subsequently is losing her connection with others.

> *I hadn't been doing anything because it's too much of an effort to get the walker down the steps to go for a walk. I haven't walked over the road to see my neighbour since January. I used to go about once a week and we'd have a natter and I'd come home.*

> *I like crocheting and knitting, and things like that. I can't do gardening so my garden's all weeds. But I really miss going down to the pool. I miss those fellas down at the pool. I'm allowed to go swimming but it's getting out and having a shower and getting dressed to go home. It's an effort. And I can't say to somebody "come in and dry me". (Betty, 77)*

The thing Betty misses most is being with others. But the *effort* of being with others is *too much*. Finding herself increasingly housebound, Betty is alone. In the ontic sense, she is physically alone, but ontologically, Betty is being-with others when she thinks of them *down at the pool*, or looks across to her neighbour. The aloneness experienced in the absence of their company is a deficient mode of being-with. It does not have to be this way. If Betty could bring herself to ask for help from her friends, her life could be different as she waits for occupational therapy. But she does not ask. Her story hints at her discomfort of asking for help. Betty weighs up the physical labour of getting down the steps with going out and being with others, but the exertion overshadows the pleasure of being with them. She consciously stops doing things because of the *effort*. Anything that involves going out of her home – going swimming and the regular visits with her neighbour – ends. Betty experiences lost connections with friends and neighbours as she waits for occupational therapy.

The physical exertion to get out of her home and then needing help at the pool is *too much* for Betty. Betty *can't* ask for help at the pool, even if this means she could go. Instead, she stays home, inside, and her social occupations cease. She cannot get out into her garden and she watches it turn to weeds. The weeds are a reminder that she cannot do what she previously could. Betty considers doing indoor activities like *knitting* and *crocheting*, but these are solitary activities and do not alleviate the loneliness. In the wait for occupational therapy, Betty becomes isolated from others, inconspicuous to them as they go about their daily lives. Betty attunes to her aloneness disclosing how being with other people matters. Betty experiences being alone, and in not mattering to others, she is being passed by. Waiting for occupational therapy, Betty is living through the gradual loss of valued occupations and an increasing disconnectedness from others.

Molly's story offers a different perspective of waiting as being alone. Waiting for occupational therapy exposes how Molly's extended *family* are not there with her, heightening her feelings of being alone. Not only does Molly feel as if she does not matter to the occupational therapy service, worse than this, she experiences waiting for occupational therapy as not mattering to her family.

> *I can't bath myself and getting in the bath and out was difficult for me. I even have my husband to help me. I had my 15 year old grandchild and she can't pull me out, it's my weight. He's seeing it's hard for me. He's the same age as me and we've both got sore backs and it's not fair on him…. Before, my family we all got together, a happy family. But now you're on your own. There's no family that want to come and help me. I feel lonely and it's the same as waiting you know.*
> *(Molly, 68)*

Waiting is *lonely.* Molly envisages her *family* being with her. Being-with is being part of the family. Molly does not distinguish herself from her family; rather, she is one of them. For Māori, the whānau is an extension of their being. Whānau is more than immediate family, it includes extended family relationships, which are connected through shared ancestry and kin networks. Being part of the whānau is "fundamental to identity in later life" (Butcher & Breheny, 2016, p. 53). Within Māori models of well-being, whānau is one of four core components for holistic health (Durie, 1998). Furthermore, within the Māori worldview, there is a collective responsibility towards whānau. Molly's 'knowing' that her family should be there comes from being part of her whānau. Her deeply held understandings of being Māori and being part of the whānau are brought to light through the situation she finds herself in, her whānau are not there with her. Molly feels alone and isolated from her *family*. They do not *want to come and help*, they are not there. She experiences their care as one of indifference. The disconnectedness from her family affects her health, physically and emotionally, exacerbating the wait for the occupational therapist. Older Māori view their role in the whānau and community as sustaining the links between generations through whānau relationships, which are intertwined within daily life (Butcher & Breheny, 2016). In the past, Molly's family were *happy* and used to *get together*. They were there, together, being with one another. Now, in her time of need, when the extended whānau would usually come to help, they are not there to provide the physical, emotional or spiritual support she needs; she is left *on her own.* Although, in waiting, Molly draws on her faith – *"all I can do is pray"* – she feels abandoned and alone, her whole being affected by their absence in being passed by.

Unlike in Western cultures where Europeans value their individual autonomy (Lloyd et al., 2014) and doing things alone (Hillcoat-Nalletamby, 2014), Māori embrace both interdependency and self-sufficiency to achieve autonomy (Butcher & Breheny, 2016). This interdependence is not considered burdensome; it is being part of a whānau. While Molly feels that all her family are missing, she is not completely alone. Her husband and

granddaughter are there to help. She does matter. But she worries about them. Molly speaks of herself as a physical *weight* and does not want to hurt them. She also speaks of the *weight* or burden of care that she places onto her husband as being *unfair*. She feels that the burden of her care should not rest solely on him; her whānau should be there to help. Much like she would help them if it were needed. What is more is that he has to help her with her bathing, something she feels that he should not have to help her with. That is why her granddaughter is there to help, but she is not physically strong enough and so Molly must rely on her husband. There is no one else. In waiting for occupational therapy, they are together and alone.

Although Molly feels alone in her wait, the Heideggerian notion of being-with says that she is not alone. Heidegger (1927/1962) tells us that even when Dasein is on its own or has to manage without others, it is a way of being-with. While her whānau are not physically there, ontologically, in their physical absence, they are being-with, through their ancestral connectedness, and they are in Molly's thoughts. While her whānau pass her by, not to be forgotten are her husband and granddaughter. They are there with Molly. They show their care by being there. Molly knows her husband gets angry because he sees how difficult it can be for her and how much her life has changed in the wait. He wants her to be safe and happy. Being with each other they wait together, concerned for each other. Devoting themselves to a common concern is being authentically bound (Heidegger, 1927/1962). In waiting for occupational therapy, they work together, caring for each other.

'Waiting as not mattering to others' captures the lack of help and support, and waiting is experienced as onerous and as aloneness. Ontologically, the participants experience a deficient mode of being-with. The stories illuminate the participants' need for help, and their expectations of being helped. However, they experience waiting for occupational therapy as being let down and alone. As a result, they must work harder to manage their everyday activities. The stories reveal the loss of relationships as as they cannot be with others outside of their home, or others are not there, with them. 'Waiting as not mattering to others' exposes the increasing disconnectedness from others in the wait for occupational therapy.

Summary

The Heideggerian notion of being-with brings to light how waiting for occupational therapy is occurring with, and alongside, others. Other people are being-with as being physically present, or they are being-with in thought or memory, a deficient mode of being-with. Waiting for occupational therapy is always being-with. The stories hint at the differing ways that others show their care, and in doing so, the participants live through waiting for occupational therapy in an increasingly or decreasingly onerous way. In 'waiting as being cared for', the stories show how the family and carers are with the person, anticipating their needs and supporting them in their home, thus enhancing the possibility for the person to be at home. In this manner of caring the participants experience care as considerate, thoughtful and kind. There is a connectedness with others and relationships are enriched as the participants willingly accept the help of others. As a result, these participants feel supported with their occupations, which lessens the difficulty of doing what matters. In contrast, some participants grapple with letting others help them. Some participants experience care as dominating, perceiving their independence will be taken away, they reject help while determinedly hanging on to doing their occupations. Others come to the decision to let go of some of their occupations. Nonetheless, their carers are with them, supporting them to be at home, and waiting for occupational therapy is experienced as a connectedness with others.

In 'waiting as not mattering to others', the disconnectedness with others is illuminated. As the participants wait for occupational therapy, the lack of response from the occupational therapy service is experienced as indifference and carelessness. Moreover, the absence of a tangible relationship with an occupational therapist highlights the participants persevering with their meaningful occupations. In the wait for occupational therapy, other relationships also diminish. The participants experience the loss of relationships with other people, as the decision is made to cease participation in social occupations outside the home, or family and friends are not there, with them. Waiting for occupational therapy is experienced as onerous and as aloneness when there is a lack of help and support.

In 'waiting as being with', there is an intangible 'relationship' with the occupational therapist. Factually, the occupational therapist is not present, ontologically, their absence is experienced as a deficient mode of being-with. The participants understand that the

occupational therapist has what is required to help them do what matters. In this way, the therapist is ‘with’ them when they think about the wait, or in those moments when they cannot do what they would like to do, or need to do in order to be at home.

The effort to carry out once familiar occupations is woven through the participants’ stories. In the wait for occupational therapy, despite efforts, some valued occupations can no longer be performed and are lost, while other occupations can only be achieved by letting someone else help. Letting others help means that some occupations may change in the way they are carried out or experienced, but lets the participants remain at home. ‘Waiting as being with’ reveals the relationships with others as the participants actively turn towards accepting help, or turn away from help, or, do not receive the help they seek, as they wait for occupational therapy.

CHAPTER EIGHT: THE NOT AT-HOMENESS OF WAITING

I remember every stone, every tree, the scent of heather...
Even when the thunder growled in the distance,
and the wind swept up the valley in fitful gusts,
oh, it was beautiful, home sweet home.
(Potter, n.d.)

Introduction

Stories of waiting for the occupational therapist show that many of the participants are restricted in what they can do and are largely confined to the house. In the preceding chapter, waiting for occupational therapy was occurring in the world with others. Other people showed their care to the participants in varying ways, which shaped the nature of participants' being at home, and also their doing. As the participants wait for the occupational therapist, another facet of waiting shows itself. Waiting for occupational therapy reveals how the changing body is changing the experience of being at home and doing everyday occupations.

This final findings chapter sets out to uncover the 'Not at-Homeness of Waiting'. In everyday life, being-at-home is a way of being in the world in a state of comfort and being absorbed in the familiarity of the world. Ontologically, to be-at-home is to have a sense of comfort and familiarity in the world, hence it is hyphenated to make it distinct from the ontic notion of being 'at home', referring to one's physical presence in the home. Being-not-at-home is a primordial aspect of our existence (Heidegger, 1927/1962), which is, for the most part, covered over in our everyday (Dekkers, 2011). Being-not-at-home is always situated, that is, it presents itself when doing "this thing, in this place, at this time" (Wright-St Clair & Smythe, 2012, p. 34). Waiting for occupational therapy discloses being-not-at-home as the participants are no longer at-home in their body, nor are they at-home in their house. The stories reveal the 'not at-homeness of waiting' as a way of being and doing waiting for occupational therapy.

For Heidegger, dwelling is not purely an activity within a physical or material environment, but it is also an existential mode of being-in-the-world. This means that 'dwelling' is the manner in which humans are attuned to, and experience their world. To dwell is 'always a staying with things', a settling into the present moment, and accepting

things as they are; to "'come home' to what is there with oneself and the world" (Todres & Galvin, 2010, p. 5447). In contrast, when people experience something ready-to-hand is missing or broken, such as a favourite chair that one can no longer get in or out of, or a dining chair that is so uncomfortable it makes sitting at the dining table with family impossible, the discomfort is experienced as being-not-at-home with that thing, at that time, and in that place. 'The not at-homeness of waiting' for occupational therapy is a way of being in the everyday when unable to perform once familiar daily occupations, and is presented in four sub-themes: *Dwelling in the Unfamiliar; Dwelling in Precariousness; Dwelling in Action;* and, *Occupation Lacking.*

DWELLING IN THE UNFAMILIAR

Being-at-home is experiencing a state of comfort and ease which embodies a sense of peace and 'at homeness' (Todres & Galvin, 2010). Waiting for occupational therapy brings the participants' body into their consciousness when prevented from performing daily occupations. The change in their bodies be it from ageing, disability or illness, affects their ability to perform these occupations or activities that matter to daily living. At these times, they experience existential uncanniness. Heidegger (1927/1962) refers to 'uncanniness' as a general uneasiness or an unsettling existence, experienced when the familiarity of one's world falls away. In other words, as the participants experience a change in their ability to do what matters, their state of comfort and sense of peace falls away and they no longer feel at-home. The disconcerting experience of the world as unhomely and strange comes with the awakening to the certain finitude of life (Madeira, Leal, Filipe, Rodrigues, & Figueira, 2019). No longer feeling at-home in their body subsequently disturbs the participants' experience of being-at-home in their home. To wait for occupational therapy means rediscovering the world in relation to what their body will and will not let them do. The sub-themes *the strangeness of my body, the strangeness of my home,* and *the strangeness of being disconnected from others* show how waiting offers a new perspective of their world.

The strangeness of my body

Heidegger did not explicitly discuss 'the body' as an ontological notion. He saw our body as always being-there, and that the person is not to be thought of as a Thing or a substance; "the person, is rather the *unity* of living-through" (Heidegger, 1927/1962, p. 73). That is, everything we experience, we experience through and with our body. In waiting for

occupational therapy, the participants experience the discomfort of a body that feels strange or behaves in unfamiliar ways amid the usually familiar world of home.

Bert experiences his body changing over time. He is very much aware of the compounding and overt bodily changes that affect his daily life. He cannot use his body in the way he always has. It has become a foreign object to him that no longer behaves or feels like his body. It prevents him from engaging in the things he likes to do.

> *For me, it's not my body. I used to be a farmer and I used to do anything and everything. Now I can't. I can't even see a nail to nail it in. My feet don't do what I want them to. They'll go in the wrong direction at times or I'll stand to move and I seize up. I just cannot move or I'll go backwards. Sometimes I go backwards other times forwards and when I start going forward, I can't stop. I hit the wall, BANG! It's a wonder I haven't gone through it. I can't go off the property. I have to stay inside, that's all there is. The other day I wanted to go outside and see my wife in the garden. I don't know, sneak out and, I got as far as the entranceway, and I seized up. That was it, I couldn't move. This is what happens. Body doesn't cooperate. Even sitting here my body is not straight and sometimes I'll be sitting here and feel a tug on me and she'll be pulling me back up to a straight sitting position. I don't know why I go to the left all the time. (Bert, 82)*

Bert's body is no longer recognisable as his. This body cannot see, move, stay upright, or be centered. This is not the body he knows. In his waiting, he is considering the strangeness of this body that *can't* and will not do what it could once do. He notices the unfamiliarity of this body that no longer lets him do his usual occupations. Bert speaks of a moment of defiance when he mischievously attempts *sneaking out* of the house. In that moment, he embodies his youthful self, only to be sharply reminded that he can no longer trust his body to be spontaneous or experience his world in an unthinking way. Experiencing the strangeness of this body that *doesn't cooperate*, that will not go forward or back at will, Bert is no longer at-home in his body. He is restricted by this body that brings forth the possibility of a future and way of being in the world that is different to the one he had anticipated for himself.

Bert feels confined to the house. He can only leave if he is helped. It is strange to have to rely on someone else for something as simple as walking down the steps. This experience of being stuck inside is out of the ordinary for Bert, who has lived his life outside 'on the land' as a farmer. Although he is no longer farming, he takes pleasure in being in the

garden and in the open spaces that the outside offers. At least, he did take pleasure until this time of waiting for the occupational therapist. As Bert tries to do the things that embody his being, the dynamic relation between his body and his world is revealed when he cannot get outside on his own. Bert remembers a time when he could move freely between the inside and outside of his home. But this body is no longer 'his' body. This body alters his sense of self, as he can no longer see himself as capable and strong, as someone able to do anything. 'It' no longer moves effortlessly letting him do what he wants, consequently limiting his possibilities and his way of being in the world. The strangeness of this body and the resulting unfamiliarity of not being himself through doing what is meaningful to him is illuminated as he sits inside waiting for occupational therapy.

The strangeness of my home

Maurice no longer experiences being-at-home in his home. Home no longer feels like a place that provides him with comfort and safety. Home is no longer a place he can live in, in his previously familiar ways. Since becoming unwell, Maurice is unable to move like he used to. He is waiting for occupational therapy for the physical aids he needs to return to a familiar way of living. In the wait for occupational therapy, he finds himself in the strangeness of living in the lounge.

> *I couldn't sleep lying down. I couldn't sleep in my bed. I had to sleep in my armchair so that I could breathe. I was there, in the lounge all the time. It was uncomfortable for everybody. People came in and out but I would just sit in the lounge, in the chair. I couldn't really move, only to get up go to the toilet and come back again. Most of the time I used the bottle, which meant that I had a table by the chair with the bottle on it. It was most embarrassing. I've got nowhere to go private. I was out in public. If people came round, I was there. I was on show for everybody. If my wife wanted to watch the television and I wanted to sleep it was difficult like that. I was in that chair for quite some time. (Maurice, 88)*

In his own home, Maurice is on show. His home no longer provides him with a private retreat from others. He is forced to sit in his chair in the lounge, day and night. He is living in *the lounge*, the family room, under the constant gaze of others. Others can see everything he does; even the things that should remain private are now exposed. Maurice loses the feeling of being-at-home in his home as the everyday familiarity collapses into the unfamiliarity of being confined to his chair in the lounge. Inhabiting the lounge, Maurice is confronted by the inadequacy of his body, which is no longer able to engage

in the taken-for-granted habitual movements and behaviours that previously allowed him to be in his world and move through it.

Maurice feels embarrassed that he is unable to freely move about and get himself to the toilet. A proud, hardworking man now reduced to *going* in a *bottle* (urinal bottle). Worst of all, everyone can see *the bottle* and knows what it is for. The personal space of a toilet or a bedroom, protected by the walls and a closed door, usually respected by others is gone. Anyone can, and does, intrude on this private activity and catch him unaware. The space of home usually provides a safeness where one can be relieved of the constant anxious alertness of being in the world (Bollnow, 1961). However, the ever-present possibility of being 'caught' toileting in the lounge heightens Maurice's anxiety, which contributes to the feeling of being extremely uncomfortable. The experience of performing personal bodily functions in the family room is being-not-at-home.

The lounge was once a place of relaxing and socialising for the family, but now the lounge as a place of comfort falls away. The living room is no longer simply a space to relax in and be with others, a space to come and go from. Now it is also the bedroom and bathroom. There is nothing comfortable about this once homely space. Everything is out of the ordinary and feels foreign to him. His armchair in its rightful place, shaped from use, comforting and familiar, now feels strange and uncomfortable. This armchair was the place he could choose to sit and relax, but that has unexpectedly changed. There is no choice but to be in this chair, this chair that enables him to get by and be at home while waiting for the occupational therapist. Sitting in the armchair is different now. He is no longer at-home in his chair in the lounge.

Being in that chair, the same chair all day is in itself uncomfortable, but also leaves Maurice with little to see and do. He cannot see behind him or what is happening in other areas of his home. He can only see what is in front or to the sides of him. His view of the world is as restricted as his being in it. He comes to be reliant on his wife coming to him. Being there *all the time* disturbs the usual rhythm of how things are managed within his home, which also unsettles his wife. This is no longer their home as they wait for the occupational therapist. Ontologically, the whole place and everything within is connected. When Maurice's ability to sleep in his bed is compromised, the milieu of home is disrupted and the environment announces itself (Heidegger, 1927/1962). In other words, the home environment is no longer an inconspicuous backdrop to daily life, rather,

the home environment is brought into Maurice's consciousness as the familiarity of home as a safe and comfortable place, falls away. His bed, unready-to-hand, alters his experience of sleeping, but more so, alters his way of being at home. In becoming unwell, Maurice is deprived of being able to use his body in its normal way; his body is no longer 'home' and the familiarity of at-homeness, which Maurice experienced prior to becoming unwell is lost. In waiting for occupational therapy, he dwells in the lounge, but he no longer experiences being-at-home in his lounge.

The strangeness of being disconnected from others

The participants live in a social world, a with-world. Being involved in everyday events enables people to maintain valued relationships and roles with other people within their lifeworld. At first glance, Bob's experience draws the focus to 'bad equipment', but it is more than the equipment – it, is that it prevents him from being with *everyone*. Bob's story is presented to illuminate the strangeness of being disconnected from others. In the wait for occupational therapy, Bob persists with maintaining habitual activities and occupations to be with other people. However, as he waits, he experiences the unfamiliarity of being disconnected from family and friends.

> *When I was in hospital, I had a stroke chair that was comfortable. The hospital OTs wanted me to come and sit at the table, just so I would look normal. They gave me a chair to use at home, but it's upright and it's so uncomfortable to sit in. My back hurts all the time. It's really painful. I'd sit on the chair for breakfast and you'd feel sort of 'ooh I'm going to slip over'. But the OT won't change the chair. Thinking of excuses is one of the worst things you have to do. Then I'd have an argument in here [in my head]. 'Why don't you just put up with it and get on with things, toughen up boy'. So sometimes I would grit my teeth and just bear it. But it would get too much and my wife would put me to bed. But I'd still want to be with everyone and talking with them. I would rather be in the chair, with people going in and out, than being locked away in my bedroom. I felt I'd spent enough time lying in bed. So we bought a recliner chair that I could stretch out and be comfortable. It's much better than going to bed all the time. (Bob, 75)*

Bob persevered with the chair the hospital therapist gave him to the point of pain so that he might *look normal*. Family is important to Bob, so he *grits his teeth* and *bears* the pain for the sake of being seated at the dining table and participating in family mealtimes. He suffers without complaint. A man must be tough, as he reflects on what he has been taught

in his youth, to *toughen up boy*. Bob endures the pain, but his wife knows that this chair causes him insufferable pain, and in caring for him *puts him to bed*. Unable to be in the lounge *with everyone*, Bob loses his familiar place within the family. He is there, but not there.

Bob knows that there are alternate chairs but at this time, he cannot have one. *They won't change the chair* so he has to put up with the stroke chair he has been given, knowing that there are more comfortable options. In not having a suitable chair, Bob draws on his inner strength and resilience and lives through the pain to participate in familiar family routines. Townsend et al. (2013) stated that disabled people face pervasive messages that they are not good enough as they are, and that they somehow need to change to become more 'normal'. These same authors challenge occupational therapists to consider their underlying prejudices and whose 'normal' they are trying to enable. Bob feels that he was given the chair to *look normal* rather than giving him what he needs to **be** normal, that is, what he believes he needs to be at home in the manner in which he chooses. The Heideggerian notion of the 'they' and the influence 'they' exert may help to understand Bob's experience. Dasein submits to the power of the 'they' because that is what 'they' say and it must be true (Inwood, 2019). Believing that the occupational therapist knows and understands what is best, Bob trusted that 'they' would provide the best chair for his situation. But they didn't and they *won't*. The occupational therapist has knowledge and understanding of what people like Bob need to be 'normal', but what Bob may not be fully aware of is the power of the 'they', the institutional environment, the system in which the occupational therapist must work within. The system dictates what can and cannot be provided. Bob can only see and feel what directly affects him, that 'they', the occupational therapist, has not provided what he needs. Bob experiences the influence of others, which shapes his ways of being and doing things at home and his sense of at-homeness.

Bob will not accept that being *put to bed* is a 'normal' solution. He wants to be *with everyone*. In our everyday existence, we inhabit a shared world with others (Wrathall, 2005). Being in the world with others means we have an implicit understanding of the world and the people and things within it. No one comes to see Bob in his bedroom. There are cultural and social conventions that are associated with space (van Manen, 2016) and the bedroom is a private space, not a social space. Being *put to bed,* Bob is alone and

disconnected, isolated from others. He feels *locked away* and no longer able to be part of the family. Heidegger's notion of Being-with is that we are social beings and that we are in the world with others (Heidegger, 1927/1962). For Bob, this means sharing a common world with his wife, his family and their friends. Sharing a common world shapes the meaning of things and the way of doing things; they socialise in the lounge. Usually, the lounge is encountered in a ready-to-hand world of equipment or furniture that enables socialising with others. Yet Bob's chair, provided by the occupational therapist to enable him to be part of the home milieu, is so uncomfortable that he cannot use it to enjoy the social world of the lounge. This chair makes the lounge unready-to-hand as a place for socialising. This chair means being *put to bed* where he can be comfortable, but it removes him from his social world, to a place where he is on his own. This imposed isolation is unfamiliar and upsetting to Bob. In dwelling, he loses the sense of kinship and belonging. Bob is not-at-home on his own. Bob suffers in his wait for occupational therapy, unknowing when he will be helped. To restore both his physical comfort and his feeling of being-at-home, Bob seeks out and finds a solution so that he can once again be with others.

As Bert, Maurice and Bob dwell in the unfamiliar, their experience of waiting shows how the lived body transforms into an object-body, a biological thing (Finlay, 2006), as it loses its familiarity of being 'my body'. The participants become conscious of the many ways their body no longer feels or performs in the taken-for-granted ways that lets them live in the familiarity and comfort of their home. Waiting for occupational therapy is experienced as embodying the uncomfortableness of body and home, illuminating the not at-homeness. The sense of being-at-home in the world is overturned and the participants become attuned to their discomfort. Home becomes unhomely. Ageing, illness and disability shape how the participants experience their body and their home, which affects their ability to lead a familiar life, revealing the unfamiliar, as they wait for the occupational therapist.

DWELLING IN PRECARIOUSNESS

"To *dwell* is not an activity like any other but a determination of man in which he realizes his true essence" (Bollnow, 1961, p. 33). Bollnow, like Heidegger, perceives that dwelling is a fundamental mode of being human. Bollnow explains that we dwell in a house, which provides us with a specific space that both situates us in a place and that

sets us apart from the rest of the world. Our dwelling place offers security and peace, and a place where we can be true to ourselves, where we can be at-home.

In the wait for occupational therapy, Val is working hard to carry on in her home. Despite her effort, her situation feels precarious. She worries about physically *toppling over*, but underlying her fear of falling is an unspoken fear of her life at home toppling over if she cannot keep on doing what she needs to do. Ordinarily, 'doing' is the lived body effortlessly engaging within the world. Existentially, 'doing' can be understood as being-at-home in one's body, thus keeping the being-not-at-home, which is always there, from becoming perceptible (Dekkers, 2011). Val is determined to not give up and to keep living a familiar way of life. For many older adults, not giving up is an important affirmation of their will to live (Lloyd et al., 2014). However, in dwelling, Val's sense of being-at-home is teetering, as once familiar activities are no longer habitual and effortless, her body no longer engaging seamlessly within her world.

> *I can't walk too far. When I go into the kitchen to wash the cat bowl and then feed her, I'm on a walker in the kitchen. I'm on the walker quite a lot. Even hanging washing up on the airer. I don't know, lots of things have changed that I can't do, but I don't let it get me down. I was trying to walk. Well, when I stand up from here, I've got this walking frame to help me to stand up straight, but I won't let it go too high because I'm worried I might topple over or something. So, I get hold of anything to try get my legs started, and that's quite annoying that I can't. It stops me from going to do what I was going to, a job or something, like taking those dirty dishes. I clear this and I put them on the seat on walking frame, and turn around and I go into the kitchen. And I'm tired, ready to sit down. So, I sit down and put everything on the bench, and then try to get up again, yeah it's very hard. (Val, 80)*

Val speaks of the effort of doing simple daily tasks. Tasks that she has done all her life, which now cause her to be uncertain in her abilities. Because everything feels precarious it takes extra effort to carry out these tasks in a safe way, and she quickly tires. In these moments when her body *stops her* from doing the things she has always managed, the experience of no longer being-at-home in her body reveals itself. Val opens up and shares that l*ots of things have changed* for her. Tasks that she could once do habitually with little effort are brought to her consciousness, as they are tiring and *very hard* work nowadays. She is conscious of her body in all that she does now. As she speaks, she comes to the realisation that there are some things that she can no longer do, but she pushes this fear of no longer being able to 'do' aside. Val embodies a knowing of her situation and the

possibilities it presents to her – to keep doing her *jobs*, or to stop. She chooses to keep doing the ordinary mundane activities as these familiar activities help to sustain her sense of being-at-home and cover over the not at-homeness. The possibility of not living at home is left unsaid, but it is there as Val determinedly carries on.

Describing how she performs these tasks shows Val's knowing of what is possible in the precariousness of living at home. Val accommodates her changing body by walking less and sitting more. Her *walking frame* offers some stability and goes with her wherever she goes. Using a walker has become an integral part of living life. More than a thing separate from her, it is now part of her. The walker is, as Heidegger (1927/1962) discusses, ready-to-hand. It is an extension of her being and Being-in-the-world. This tool is not just an object, but a means of doing something, taken for granted in its everyday use. For Val, the possibility of falling is always there, threatening her way of being at home, but using the walker helps to keep her balanced and safe and stop her from *toppling*. However, this walker, which helps her, is the same tool that announces her wait for the occupational therapist as it becomes unready-to-hand when she cannot get it up and down her steps. In the wait for occupational therapy, Val persists in familiar ways that could *topple over* at any time. The possibility of being at home feels to be tenuous.

Val's sense of self oscillates between the need to be strong in order to carry on and weariness in her ongoing efforts. Living through her everyday calls for her to be strong for the work of carrying on, but the weariness is unfamiliar and unsettling. In these moments of feeling unsettled, Val can turn away from the possibilities her situation presents or seize upon them (Heidegger, 1927/1962). For the sake of staying at home she seizes upon her possibilities by persevering with what she still can. She does things bit by bit and rests in between. She is constantly pushing herself to a point of being so *tired* that she worries she might *topple over*. The continual exertion, constantly getting up and sitting down takes effort and uses up her energy. Today, it is *very hard* but she finds the little bit of extra energy to push on and finish what she started. The not at-homeness may remain hidden or disclose itself in any one moment, "it is not predictable" (Wright-St Clair & Smythe, 2012, p. 34). Unexpectedly feeling out of energy doing what she always has, discloses the feeling of unhomeliness; Val is not at-home in her body. The unfamiliar feeling of running out of energy is worrying. Her lessening physical capabilities and consequently her fragility and the finitude of life (Madeira et al., 2019) announce

themselves. Ontologically, the 'inauthentic' notion of an infinite existence is replaced by the experience of an awareness of the possibility of one's own death. In other words, through this discomfort, a person can contemplate their existence, and reflect on not a physical death, but the death of the previous Dasein (Madeira et al., 2019) and consider their possibilities. In these moments of being out of energy, Val glimpses her true existence. For Val, running out of energy to carry on could be the 'death' of her way of life as she knows it to be and the possibility to be at home. In the wait for occupational therapy, Val dwells in precariousness.

DWELLING IN ACTION

Finding a way to restore a sense of comfort and at-homeness may spur a person into action. In an ontological sense, Heidegger (1927/1962) speaks of 'conscience', that is, the call to do something; the call to make a choice and to take action (Inwood, 2019). Managing the everyday difficulties arising from a body that is not working in the way it always has, the stories show how people choose to build things, buy things, or try finding new ways of doing things. Older people have developed various skills and abilities over the decades, and their ability to *do* depends on the fit between their physical capacity, the demand of the occupation and the environment in which it occurs (Polatajko, Backman, et al., 2013). If the environmental demand exceeds the person's ability to perform, then the person may experience a loss of their familiar world. Unable to freely participate in their home, the changing lived body becomes apparent. As some participants dwell in the fear of relying on this body, *my body,* that 'I' do not know and can no longer trust, together with the occupational therapist not being there, the following stories illuminate waiting for occupational therapy as a call to action.

Home is not just the inner space contained by the walls of the house; it is connected to the outer space of the garden and beyond that, the local community. Roger speaks of getting outside. Being prevented from doing what he knows to be possible, he is called to action.

> *My son also put a ramp outside here so that I can take that walker out. It was quite good except it's too steep. I have to take my cup off otherwise it slips down. (Roger, 80)*

Roger is drawn to the conservatory. Being drawn to this place implies a desire to dwell in the comfort of its homeliness. He does not think about why he goes there, but 'knows' it is a space where he can relax. The only thing between him and the conservatory is the step. It was not a problem before, but in his weakened state, he has become used to using the walking frame. The frame feels familiar and he is comfortable using it. He moves about with confidence in the house but he does not trust his body to get him down the step into the conservatory. Heidegger speaks of a threshold; he interprets a threshold as a boundary, "as something to cross or as an invitation to pass" (Dekkers, 2011, p. 295). The phenomenon of a threshold enables a link between the inner and outer worlds and enables one to experience these lived spaces. To cross that threshold, Roger envisages a ramp. To make this happen, Roger turns to his son to help bring the conservatory home to him.

The ramp is an invitation to pass through and enables Roger to move freely between the home and conservatory. Regaining this sense of familiarity is an existential 'homecoming' (Todres & Galvin, 2010) as Roger recovers the feeling of comfort and at-homeness. Roger dwells once again in its homeliness.

Waiting illuminates ingenuity. However, it was not this way at the start. Roger always had the skills, but these lay dormant, not being utilised as his body no longer felt strong and dependable as it did prior to being hospitalised. In addition to this, Roger had understood and expected that he would be helped when he returned home. He did not consider that he would have to wait so long to be helped. The waiting brings forth his fear, specifically the fear of relying on this body. Fear has re-awakened his inner drive to find a way to help himself. Ontologically, Dasein is called to do something, an appeal to itself (Heidegger, 1927/1962); a silent call of care that brings one back to oneself (Critchley, 2009). Roger's drive to find a way to be in his conservatory is a silent call that comes from concern for homely comfort. Being in his conservatory and having his meal there lets him be comfortable. To make this happen, Roger thoughtfully adapts his walking frame to meet his needs (see Figure 5). He builds a wooden device that accommodates his cup and plate so that they cannot move or tip over when he walks down the *steep* ramp his son built. He is proud of what he has accomplished. His tone of voice changes and there is an energy in him as he shows me what he has done and how each piece works. Through utilising his skills, Roger can do what is important to him. Roger experiences success with adapting his frame. He is once again at-home.

Figure 5: Roger's walking frame

Roger is repeatedly called to action to maintain his sense of being-at-home in his wait for the occupational therapist. In a non-recorded follow up conversation, Roger speaks of the new experience of having trouble getting out of bed. Waiting for occupational therapy is experienced as solving one problem at a time. Roger is determined to find a solution as he states that he *"does not want to go into a rest-home".* He perceives the world of a rest-home in a negative way, a place where he would no longer have autonomy and freedom, a place that he cannot imagine being-at-home. Rather than wait and risk falling out of bed, he searches online for what he needs to feel safe. Technology allows for immediacy and in this current technological landscape, there is no need to wait. The solution is literally 'at your fingertips' if you know what you are looking for. Modern technology changes Roger's sense of the world and how he experiences it. Everything is readily available and ready for use when it is wanted, day or night, weekdays or weekends. This sense of everything being obtainable and on-hand alters his sense of waiting. It enables him to maintain his feeling of at-homeness. Despite actively searching for and finding what he needs, Roger continues to wait for the occupational therapist. He does not say why. Maybe it is his 'knowing' that they have the skills and access to things he needs to help him prepare for an unknown future.

Dwelling in action, Roger adapts his world to make it work for him, whereas Bruce must adapt **to** his world. Bruce is called to action to maintain his habitual occupation of showering as he waits for the occupational therapist. As Bruce takes action, he

experiences waiting as dwelling in lost pleasures. Bruce has always showered every day. This engrained habit presupposes a form of 'understanding' that his body has of the world (Moya, 2014). Bruce's habitual body 'knows' how to shower, how to move in the bathroom, how high to lift his leg. By continually making small adjustments, it keeps him safe on the slippery bath surface. But Bruce is now fully aware of his physical body and knows that trying to get into the bath to have a shower, is no longer safe for him. In the wait for occupational therapy, Bruce compensates for the bodily changes occurring by actively adapting his occupation of showering.

> *I'm getting along alright but I just have to be so careful now. It's just if I had somewhere I can shower. I'd love to be able to have a shower, just to stand under the shower. I tried to get into the bath again a few weeks ago, but that was a disaster. I slipped. I managed to save myself on the hand basin. I'll never try that again. To wash, I put a bathmat down with a big towel on top and then a chair to sit on which I use when washing my hair. I've got a little plastic bowl to tip hot water over my head. Then I stand up, wash my body completely all over standing at the hand basin. As the soap fills up the basin I empty it and fill it with clean water. Then I get another facecloth. I use different facecloths for different parts of my body. I use several towels to dry myself. It's fairly hard work. If I had a shower I wouldn't have to do all of that.*
>
> *Waiting affects me. I always think 'am I clean going out?' only having a sponge wash. I use the very best soaps. I go through face cloths and towels and I never go without shaving. (Bruce, 76)*

Washing with water is not the same as washing in water. Bruce remembers the simple pleasure of taking a shower. He yearns to be able to *just* step in and turn on the tap and to feel the water on his skin. Bruce would do anything to just bathe in water and feel clean. In his desperation, he puts aside his fear and uncertainty. His body fails. He can no longer trust his body to safely step into the bath and negotiate the slippery surface. The changes in his body and the bodily experience turn what was previously pre-reflexive, familiar and satisfying to something exposed and frightening (Madeira et al., 2019). This body denies him the luxury of having a shower. Not even using the best soaps or using copious linen can replace the ease and pleasure of standing under the shower. Bruce holds onto this pleasurable memory, but it makes him impatient for the occupational therapist to provide the things he needs to shower. In dwelling, we "'preserve the fourfold in its essence' by building things peculiarly suited to our local world" (Wrathall, 2005, p. 110).

Heidegger (1971) speaks of the 'simple oneness of the fourfold' – earth, sky, mortals and divinities. The unity of the fourfold structures our relations with things around us (Wrathall, 2005) and allows us to dwell with things as they are (Todres & Galvin, 2010). As Bruce washes himself at the hand basin it gathers the fourfold, which shows itself in the moment: Earth – the physical environment of the bathroom and a shower he cannot use; Sky – the passing of time is marked by his daily morning wash as he waits for the occupational therapist; Mortals – although Bruce lives alone, he is in the world with others, including the occupational therapist, who remains invisible by their absence; and, Divinities – the cultural and spiritual value Bruce places in being clean and cleansing himself. To preserve his sense of self and his safety, there is a call to action, to adapt. However, this constant effort is unsustainable; Bruce knows that he needs a new *shower*. The shower is more than simply a resource to him. It will enable him to reclaim his essence and to experience the comfort of being-at-home. But he must wait.

Dwelling is the manner in which humans are on earth (Heidegger, 1971), that is, to be-at-home, to be at peace, by having a way of living that is satisfying and suited to one's needs. As Bruce attempts to preserve his world, he worries whether he is *clean enough* to go out into his social world. Bruce takes pride in his appearance. Looking clean and tidy is not only Bruce feeling at-home with himself, but also projects an image that is acceptable to others. Being *clean* and tidy enables Bruce to unassumingly get on with what he needs to do without bringing negative attention to himself. He understands the expectations of others; the people that he is with and alongside. Heidegger speaks of the norms of society being dictated by the 'they' (Heidegger, 1927/1962). While 'they' may not be interested in how Bruce keeps himself clean, 'they' will respond in a prejudiced way if Bruce appears or smells unclean. Bruce is determined to keep up his appearance; otherwise, 'they' may *think* he is not managing. The sustained *hard work* to keep himself clean illuminates waiting as effortful dwelling. He draws upon his inner strength to keep carrying on; a silent call that comes from Bruce's concern for being clean and feeling comfortable with his appearance so that he is able to go out into the world of others. Although Bruce says he is *alright*, really he is not, as it should not be this *hard* to keep himself clean. Ironically, as he goes about washing himself and laundering the linen, the need for help is covered over. He gives the appearance that he is managing to others who may be looking in. Each day the washing is done, so he must be doing okay. As Bruce

adapts in order to keep doing what matters, it reveals dwelling in action as a mode of waiting for the occupational therapist.

Betty loses sight of being helped. She keeps on going because she must, but it is being unable to do the *little things* that show a different perspective of dwelling in action as she carries on.

> *The other morning, I got up and nothing went right. It's just a bad day. You go and do something, try and do something to take your mind off it. You're so tired that you can't be bothered doing it. Another day tomorrow, I'll have a rest instead. It is an effort. … It's a lot of little things that you don't realise till you go to do them, and you can't do them. (Betty, 77)*

Betty unexpectedly finds herself in the situation of *nothing* going *right*. In this moment she becomes of aware of her body, a body that feels depleted of energy and worn out. She is confronted by her own debility, which announces itself when least expected. I can hear her annoyance as her tone changes when she speaks of things going wrong, as it is tiring trying to put things right. As Betty reflects on what she can no longer do, the laughter in her voice drops away. Silence. When she speaks, there is weariness. Betty has no energy to deal with the out of ordinary. Her familiar way of existing is changing. It is not just *a* bad day; this is how her days are now. The effort to keep on going is exhausting. Tomorrow will be a good day, and so today, she *rests*.

Determined to carry on, Betty defers doing things; tomorrow will be a better day. Betty is living into the future, where she awaits the possibility of once again doing these things. However, underlying her determination, Betty embodies a knowing that trying to carry on may be becoming too much for her. Betty is noticing all the *little things* that she can no longer do. The 'big' things are still happening in the background of her life, with the support of her carers who are paid to come at, and for, a set time to help. Left alone, Betty is in charge of the *little things*, things that ordinarily go unnoticed and are embedded in dwelling in the everyday. But they have announced themselves. Doing these *little things* takes energy that Betty no longer has. Betty is *tired*. Her body is *tired*. To preserve some sense of being-at-home, these small annoyances are pushed aside. Betty accommodates the changes occurring within her body by consciously ceasing to engage in activities. Betty dwells in inaction. She has virtually stopped going out of her home because of the

effort to get up and down the steps. In putting off or delaying doing things within her home, in waiting for occupational therapy, Betty is gradually disengaging.

The stories told by Roger, Bruce and Betty reveal the exertion of dwelling in action. Whether it is making changes to one's home, adapting to one's environment, or adjusting one's ways of doing things, waiting for occupational therapy requires ongoing effort to sustain one's comfort and sense of at-homeness. But the effort is unsustainable, and the uncanny feeling of being-not-at-home announces itself in the moment of doing this thing, at this time, and in this place.

OCCUPATION LACKING

Dwelling is doing. Ontologically, "'*one is'* what one does" (Heidegger, 1927/1962, p. 283). 'Doing' is a basic human need and "we are constantly up to something" (Inwood, 2019, p. 45). Engaging in occupation brings meaning to life. It organises time and brings structure and rhythm to the day. However, when a person ceases to engage or there is a change in a person's typical patterns, it can be an indication that something is amiss (Polatajko, Backman, et al., 2013). The sub-themes *carrying on* and *dwelling in ennui* show how in waiting, occupations can appear to sustain the older person and bring a sense of at-homeness, but also how occupations can lose their sense of meaning, fade away or become lost, revealing one's existence as no longer being-at-home in the world.

Carrying on

Archie notices the changes in his ageing body as it no longer performs how it used to. He speaks of his painful shoulder, of seeing less clearly, and of moving slower as he carries out his daily routine. In the wait for occupational therapy, Archie describes how he *just* carries on, trying to maintain a sense of familiarity amid the gradual changes occurring in his body. For Archie, keeping to his daily pattern brings a rhythm to his day and lets things happen. This busyness covers over the not at-homeness in waiting.

> *Each day is much the same, it's just coping with things that's all. Just the usual daily life things, just carrying on with what you normally do. Just doing the same things every day, if I can. I go over to the dairy, take a walk over there, and spend a bit of money over there, and come home again, that sort of fills in a bit of the day. Or there's a little café across the road here, I sometimes go and sit over there with a coffee, just to get out of the house. But other than that, 'it goes on' as they say. Just keep on keeping on. It's just getting through it. It's just coping with life, I suppose you'd call it. It's hard. (Archie, 75)*

Life goes on. Archie's daily routine keeps him busy. This daily structure helps streamline the day and lessen the physical and mental effort and energy needed to carry on. There is a comfort that comes from knowing what to expect. Archie can *just* carry on without trying to find ways to fill in his day. Ontologically, he dwells in the familiarity of the average everydayness, experiencing waiting for the occupational therapist as a mode of being-at-home.

On the other hand, the ordinariness of each day is tedious. Archie does not speak of being bored, but it is present in the way that he tells of doing. These everyday occupations do not engross him. These routine activities simply fill in part of the day. There is no feeling of contentment; there is merely a sense of *just* going through the motions. In *just coping*, he is skimming the surface of his everyday coming and going; there is no depth or meaningfulness to what he does. Even going to the café or the dairy is simply a different way to try to fill in time. His routine lacks meaning. Archie is occupied, but bored. This is a type of boredom where it is not clear what is boring, but that one is bored (Freeman & Elpidorou, 2020) and left feeling empty, not truly present in what one is doing. There is an emptiness or *solitude* (Harman, 2007). Archie's existence is one of being alone. Even around others in the dairy or café, he is alone. His everyday routine covers over the aloneness and the loneliness. Ontologically, Archie experiences being-not-at-home amid his familiar routines. Waiting for the occupational therapist shows how carrying on both covers over and uncovers the uncanny feeling of being not-at-home.

Dwelling in ennui

To dwell in ennui[29] is to no longer be at-home in the world, no longer experiencing a sense of fulfilment and satisfaction. Rather, when the everyday familiarity of one's world falls away, the feelings of emptiness and meaninglessness can cause a person to feel helpless and apathetic, and surrender tiredly to a state of indifference (Shatz, 2022). As meaningful occupations and familiar routines fall away, one may come to experience a sense of unhomeliness. In contrast to Archie who is carrying on, Russell's meaningful occupations and routines have fallen away. He describes his days as being empty of things to do. His fear of falling immobilises him. Furthermore, the changes occurring within his body take away activities that once filled his day. As Russell focuses on his wait for the occupational therapist, it brings to light how diminished his world has become in waiting. He is no longer partaking in occupations that would usually occupy him, and give him a sense of fulfillment. Russell is not-at-home with this diminished world, and experiences an existential boredom, that is, ennui.

> *Just boring days. I get up, take a load of pills, sit, have coffee, sit. Every day is much the same, just sitting around. I used to pick the kids up in the afternoon from school. I would go a bit early and have a coffee and then go and pick them up. But then I had a fall. I cracked the pelvic bone. After that I was pretty much immobilised and didn't drive for quite a long time…. I watch TV mostly, read, but not a lot, that's about it. Not being able to use my hands means I can't pop out and do a bit of gardening or anything because my hands are useless. The rheumatoid arthritis has got worse and worse and worse and I couldn't even handle pulling out a weed now. That used to occupy quite a lot of my time. When you're messing around in the garden or cutting the lawns or something. I used to get on the ride on mower and go round and mow all the lawns. I had gardens down there, growing stuff. It was good then, but this last couple of years it hasn't been very good. The rheumatoid arthritis is the killer for me, that's what's really slowed me up, and of course, that's why I'm not very good on my legs. That's why getting in and out the bath is dodgy. (Russell, 75)*

Russell is stuck inside, bored and unoccupied. There is little to keep him engaged and interested. Watching television and reading do not provide meaning compared to the activities that he previously enjoyed and can no longer perform. The fall has been life changing. Even though he recovered, he does not regain his former strength and rejoin in

[29] Ennui – pronounced ahn-wee – translated as "a feeling of listlessness and general dissatisfaction resulting from a lack of activity or excitement" (Dictionary.com, n.d.-a).

his life from where he left off. He can no longer live his usual life. The rheumatoid arthritis, which was already there but hardly noticeable, suddenly becomes apparent. The fall brings the arthritis into focus as the accumulating changes in his body, which are getting *worse and worse and worse* changes his way of being in the world. Prior to the fall, Russell was absorbed in his everyday, doing the things that mattered to him. But in lacking occupation that matters, his way of being on earth falls away. He is not at-home with nothing to do. His sense of self and self-worth are diminished, as he can no longer be actively involved in doing things for and with his family. He no longer experiences the fulfillment of participating in those occupations that once gave meaning and structure to his life. The contentedness he previously experienced within his physical and natural worlds are lost. Russell feels useless. Russell dwells in ennui.

Russell is bored. His days are *boring*. Everything is *boring*. This mood of boredom is described by Heidegger as 'finitude' where the entire unified structure of being-in-the-world leaves one empty (Harman, 2007) and everything loses its meaning. Russell is not used to being unoccupied. He is not used to feeling useless. This unhomelike state holds him in limbo. He experiences an existential boredom. There is a profound emptiness in his Being. Life is dull. Russell no longer experiences the satisfaction of doing things. He carries on each day, but there is no sense of purpose, nothing carries any future prospect (Freeman & Elpidorou, 2020), he merely exists from day to day in the wait. In waiting for occupational therapy, Russell *sits*, thinks, and dwells on his difficulties. As he speaks about what is lost to him, he comes back to *the dodgy bath*. The bath is something that can be fixed, and fixing it will restore some sense of at-homeness.

Heidegger's notion of 'everydayness' (Heidegger, 1927/1962) seen through Archie and Russell's lived experience of waiting for occupational therapy show how they are existing in the average, inconspicuous way in which Dasein maintains itself in its every day. "Just living along [Das Dahinleben] in a way which 'lets' everything 'be' as it is, is based on forgetting and abandoning oneself to one's thrownness" (Heidegger, 1927/1962, p. 396). They are simply being. For the most part, Archie and Russell carry on in their world, each day one and the same, "like yesterday, so today and tomorrow" (p. 423). However, moods can reveal things that one is usually unaware of and illuminate what the everyday does not (Inwood, 2019). Archie and Russell carry on in their average everydayness but their stories capture the mood of boredom that underlies their indifference. As they go through

their daily routines, there is a lack or loss of meaningful things to do. They experience the uncanny feeling of being-not-at-home at home as they wait for the occupational therapist.

Summary

In this final findings chapter, waiting reveals the discomfort of a changing body and doing, or not doing, everyday occupations such as showering oneself or sharing a meal. Healthy people are largely oblivious to their physical condition and are able to participate in all the activities that their body is capable of (Todres & Galvin, 2010), thus maintaining a state of at-homeness. Heidegger's notion of being-at-home helps make it possible to understand 'the not at-homeness of waiting'. The existential unhomelike being-in-the-world experienced through bodily changes associated with ageing or ill health is brought to light through the stories. Participants no longer feel at-home in their bodies. In waiting for occupational therapy, they become aware of their bodies as they are deprived of the ease and familiarity of performing everyday occupations in their usual ways. Instead of daily life simply happening, being at home is hard going, and the participants come to experience home as "not being right" (Wright-St Clair & Smythe, 2012, p. 33).

Waiting for occupational therapy exposes a body that can no longer be relied upon. 'It' is no longer strong or capable of doing all that it should or could once do. This fragility brings to light the feeling of being-not-at-home in their bodies. In these moments of discomfort, the participants think about ways to carry on and will themselves to keep going, but their bodies are no longer engaging seamlessly with the world. Waiting for occupational therapy brings to light a physical world filled with entities that are no longer ready-to-hand, which requires people to actively seek out new ways of doing things. The effort affects the participants' sense of comfort and familiarity at home. As their familiar life at home falls away, they are no longer at-home in their homes. Home comes to be experienced as uncomfortable and unfamiliar. This disconcerting experience brings forth the confronting possibility of not being able to continue in their usual ways at home, and the possibility of not being able to continue living in their homes. Whilst participants do not speak of not being able to stay at home, it is there. The participants are determinedly carrying on at home, as they try to keep the ever present not at-homeness from becoming perceptible. In waiting for occupational therapy, the participants are devoid of the comfort of being-at-home. The 'not at-homeness of waiting' shows waiting as exhausting, as

strange, as tenuous, as precarious, as overlooked social worlds, as lost pleasures, and profound boredom. It also shows waiting as ingenuity, and as a call to action.

The participants wait in the anticipation of being seen and helped by the occupational therapist who they believe has the skills, knowledge, and resources to help restore their sense of at-homeness and their ability to do the things that matter. The ‘not at-homeness of waiting’ uncovers a way of being in the everyday that is changing. Left unsaid, but there, is the question: Will the occupational therapist arrive in time to help?

CHAPTER NINE: DOING WAITING WORK

I realized today that I have stopped living life.
I'm literally just trying to get to the next day,
just living in the thought of tomorrow.
I'm not living.
I'm waiting.
And the trouble is, I don't know what I'm exactly waiting for.
I'm kind of scared for what it might be.

(Unknown, n.d.)

Introduction

In this study, I set out to understand the lived experience of community-dwelling older adults waiting for community occupational therapy. Waiting is a very familiar phenomenon, and is deeply entrenched within healthcare culture (Rittenmeyer et al., 2012). Although waiting for healthcare has become normalised, the significance of what it means for older adults to be waiting for community occupational therapy has remained covered over. The preceding findings chapters, built upon the participants' stories, each bring to light an aspect of the experience of waiting. However, when read together they form a cohesive understanding of what it means to be waiting. This new understanding is not absolute. Gadamer (1975/2004) reminds us that "meanings represent a fluid multiplicity of possibilities" (p. 271); that there can never be one 'truth', and, therefore, that hermeneutic phenomenological studies can never be considered complete (Crowther & Thomson, 2020). This final chapter expresses my interpretation of the experience of waiting for community occupational therapy.

This chapter opens with a summary of the findings, followed by a discussion on the experience of waiting for community occupational therapy as lived by older adults residing in Northland. Here, the notion of waiting for community occupational therapy, as doing waiting work, is introduced. The essence of waiting for community occupational therapy is seen in the physical, mental and emotional effort of doing waiting work, and the subsequent way in which it insidiously depletes a person's way of being in the world. Waiting in this context leads to a diminishing of doing and being; it deprives older persons of a meaningful life.

The implications of my findings for practice is then addressed, as are the strengths and limitations of this study. My conclusion provides suggestions for further research to make meaningful inroads into the issue of waiting for community occupational therapy.

Summary of the findings

The first findings chapter, *The Uneasiness of Waiting*, captures the struggle and uncertainty of waiting. The effort of enduring the fear, invisibility and suspension in time discloses the uneasiness that comes from waiting. The participants anticipate returning to the occupations they are prevented from doing while waiting for the occupational therapist. This burden of waiting depletes their abilities to do what matters, in addition to their 'being' as occupational beings in the world. Inability to engage in their occupations in the same way, leads to a loss of purpose and agency – as meaningful occupations are replaced, modified, or lost. The second findings chapter, *Waiting as Being With*, reveals waiting as occurring in the world with others. In waiting for occupational therapy, the participants' relationships with other people are either enhanced or diminished by their decision to let others help them, or not. Some participants willingly accept the help of others, some determinedly hang on to their occupations, whilst others choose to release control over their occupations and the way in which these occupations are carried out. Even though the occupational therapist is 'with' the participants in their thoughts, their physical absence means the participants persevere with their daily occupations. The third findings chapter, *The Not at-Homeness of Waiting*, discloses the comfort and familiarity of being at home falling away. Physical changes to the participants' bodies, whether caused by ageing or disablement because of ill health, gives rise to a state of being not-at-home in their bodies, in their homes. However, waiting for occupational therapy is more than the not at-homeness of their body and home; it is a way of being in the everyday that affects their engagement in meaningful occupations of living and how these occupations are performed and experienced. The findings show that in this waiting, people are active as they do what they need to do, to keep going.

UNDERSTANDING THE LIVED EXPERIENCE OF WAITING FOR COMMUNITY OCCUPATIONAL THERAPY

They waited quietly, with a wild patience,
practicing patienthood,
actively practicing the skills of silence.
(Tim Diamond cited in D. E. Smith, 2003)

The experience of waiting for community occupational therapy is concealed within the ordinary everyday ways of doing and being. People spend their lives constantly engaged in 'doing' purposeful things, some of which are done out of necessity and others are done

out of desire (Wilcock, 1998). 'Being' is determined by one's engagement in what one does, how one feels about what they do (Hitch, Pépin, & Stagnitti, 2014), and is linked to the roles people choose, their skills and abilities (Hitch & Pepin, 2020), and their individual agency and choice (Hitch et al., 2014). Applying Heidegger's philosophical notions have extended our understandings of how older adults experience waiting for community occupational therapy. Being-in-the-world is doing. As occupational beings, we are always doing something. However, in waiting for community occupational therapy, we come to see a depletion of people's doing and in their being. This depletion is not of their making, but rather a consequence of the burden of waiting. During waiting, the participants have a strong desire to be, and stay, at home, and through the stories, we come to see a form of doing that would otherwise remain unseen.

This study shines a light on 'waiting' in a new way. It offers an insight we are generally not afforded. Many of the participants express their struggles persevering with daily occupations while waiting for community occupational therapy. This is captured in their language, such as: *it's a hassle, its hard work,* and *I'm hanging in there.* These stories show how waiting for community occupational therapy involves more than just the physical exertion of undertaking necessary, daily occupations. 'Doing waiting' is hard work in and of itself; waiting involves physical, mental and emotional effort, and is embedded in, and occurs alongside, the demands of everyday life. These older adults are self-managing their health conditions, i.e. doing patient work (Corbin & Strauss, 1985), attending to a changing body that is interfering with their ability to do what matters, and managing the effort forced onto them by the community occupational therapy service waitlist. Waiting for community occupational therapy is an additional burden imposed upon them by the very system that is designed to help them. In the absence of occupational therapy help, many of these adults find themselves being a "patient". Every time they go to do something they can no longer do, they are reminded that they are an occupational therapy "patient" in need of help. Being on a community occupational therapy waitlist reveals waiting is hard work.

Suggesting that waiting for community occupational therapy is active and effortful, is a new way of thinking about 'waiting'. I am suggesting that waiting for community occupational therapy is 'doing waiting work'. Doing waiting work shows the deliberate and methodical ways that older adults carry out difficult occupations, organise

themselves, and interact with others to keep on going at home. Contrary to the notion of the patient as 'a passive individual' (McColl, 2019), this study reveals that these older adults waiting for community occupational therapy are far from passive. Considering 'doing waiting work' as a way of waiting for community occupational therapy offers us a different way of thinking about what these people do, who is involved, and why they do it.

Waiting work involves tasks. Tasks are a set of actions with specific outcomes (Polatajko, Davis, et al., 2013); they form the foundation of work. 'Work' can be defined as "[being] engaged in physical or mental activity in order to achieve a result" (Dictionary.com, n.d.-d). In occupational science and therapy, work is a type of occupation (Molineux, 2017). As such, work is productive and structures daily time (Wilcock & Hocking, 2015). Work can also connect people, directly or indirectly, but not all work is visible (D. E. Smith, 2003). Doing waiting work involves physical and/or mental tasks. This entails planning, organising, predicting and managing risks, initiating mental coping strategies, sitting, thinking and ruminating about the situation. Additionally, new requirements extend to changing the environment, changing or re-organising how familiar tasks should now be performed, and how home activities, once taken for granted, require assistive devices and/or assistance from others. In this study, waiting work is effortful, but invisible. It involves others, and affects routines, and in some instances, provides small successes only. The study's findings highlight the burden of doing waiting work. They further elucidate the harmful and unhealthy impacts that result from the unproductive nature of doing waiting work.

Doing waiting work is effortful

Doing waiting work is effortful and demands physical, mental and emotional stamina. The findings show that waiting for community occupational therapy disrupts the everyday and is more than simply carrying on. As the participants *do* waiting, the work of waiting is brought to light. Waiting comes to dominate and it is *hard* work. This study shows how doing waiting work comes to occupy the participants' time and space, taking over their usual activities and valued occupations. Although each person experiences the effort of waiting uniquely, they all experience waiting as physically, mentally and emotionally demanding in varying degrees. Even for those like Betty, who had forgotten she was waiting, it was still effortful, and she made decisions about whether to go out. Or Archie,

who busied himself by keeping to his routine, despite the increasing difficulty moving about. The effort and 'activeness' of doing waiting work is comparable to the findings of a study undertaken by A. A. Lee, James, and Hunleth (2020), who identified the work patients do when waiting for health and social care. Lee and colleagues discuss the concept of 'active waiting' as a process that people manage through employing a 'variety of tactics'. That is, people find and create ways to respond to waiting in an attempt to reduce, avoid or endure the wait. Their cohort, mostly middle-aged adults identifying as Black or African American, and living in poverty, is dissimilar to the demographics of this study population. However, their concept of 'active waiting' resonates with the physical, mental and emotional effort expended by older adults in response to the demands imposed on them by the community occupational therapy waitlist. Similarly, Hage (2009a) argues that although waiting involves a large degree of passivity, "agency oozes out of waiting" (p. 2), and he puts forward that waiting is a 'passive activity'; waiting is something we do. In my study, the 'tactics' that older people employ are ways of doing waiting work, which may include changing their habits, changing the environment, changing how they do things, and/or finding ways to distract themselves. Anticipating a call from the occupational therapist announcing help is at hand, gives them a reason to keep making the effort.

The effort of doing waiting work is unseen. Doing waiting work becomes part of people's everyday experience – it is just what they do. In the ordinariness of doing what they do to keep going, the "work" is hidden from others, and also from themselves. Maintaining a routine and doing habitual activities and occupations streamline the day, and lowers the physical and mental effort of doing things. Habits and routines evolve from prolonged and consistent engagement in occupations (Polatajko, Davis, et al., 2013). However, when habits and routines are disturbed, it can take more effort to do things. Doing waiting work is seen to disrupt some people's routines. Consider Maurice, who was forced to live in the lounge, upsetting his usual routines, thus increasing the effort to do previously taken-for-granted activities. Whilst doing waiting work is disruptive, it becomes, nevertheless, woven into people's everyday lives and insidiously alters the routines and way that occupations are performed. Other occupations are subsumed, and the scope of occupations narrows. Molly, for example, sits and waits; waiting monopolises her day as her other occupations fall away. For many people, doing the same, narrowed range of activities is tedious and unsatisfying. Yet, for the sake of being at home, people persevere.

This perseverance is congruous with a study undertaken by Gramstad et al. (2013) exploring older adults' unmet assistive device needs. The researchers found that older adults living at home experiencing difficulties doing activities "strove to be satisfied with their situations and make the best of it with the means available", without complaint (p. 290). People endured in silence. They took pride in not complaining, downplayed their difficulties, and did not consider their needs unmet because they changed the way they did things. In my study, the participants are seen to be carrying on, but the sustained effort of doing waiting work changes their ability to participate in their previous, meaningful occupations. Rather than complain, occupations that formed part of life before waiting fade away, but not without struggle. Other occupations are consciously 'let go' because they are no longer manageable or experienced in the same way. Participation change in occupations parallels results from a study exploring the phenomenon of older people living with long-term health conditions that influence daily living (Aberg, Gillsjö, Hallgren, & Berglund, 2020). It was found that meaningful activities ceased when they could no longer be experienced in the same way, diminishing the fullness of the person's life. And yet, the need to engage, and the benefit of engaging in occupations is deeply-rooted in the occupational therapy profession because of the "positive potential of occupation to transform people's lives" (Hooper & Wood, 2019, p. 47). In my study, doing waiting work becomes inconspicuously embedded into people's lives. People are seen to be carrying on; they are enduring. Doing waiting work means that they can keep going; they do not complain. Doing waiting work consumes energy and insidiously alters the participants' way of being at home; they are doing less.

The concept of 'work' portrays people as active and physically doing things (D. E. Smith, 2003). Waiting work also involves mental doing (Molineux, 2017) or cognitive work (Yin et al., 2020); the unseen effort. Despite an external passiveness, internally, there can be strong inner activity (Fujita, 2002) associated with waiting and the expectation of being helped. In this study, the unremitting, invisible effort of doing waiting work is portrayed in the way participants think about ways to wait, the consequences of not being helped, whether they had been forgotten, or whether to contact the occupational therapist. In a similar manner to patients who are constantly thinking about ways to manage their health conditions (Yin et al., 2020), the mental waiting work is pervasive, unseen, and unrecognised by others and the older adults themselves. Despite the energy used, the work was often not productive in improving the person's situation.

Nevertheless, doing waiting work has a purpose. Older adults attach great importance to staying at home (Fjordside & Morville, 2016). Existing literature discusses how older adults proactively take steps to change their environment or personal circumstances to maintain their residential comfort and mastery zones (Golant, 2015) through implementing various forms of coping strategies (Golant, 2015; Levasseur & Couture, 2015; Schulz, Heckhausen, & O'Brien, 1994; Stafford, 2017). However, literature indicates that the most common type of strategy implemented by older adults, to remain at home, involves the use of assistive devices (Stafford, 2017), which are largely provided by community occupational therapists. In this present study, people are waiting for community occupational therapy assistance to provide the assistive devices they need to remain doing at home. Consequently, they work harder, physically and mentally, to maintain the sense of comfort, mastery and control denied to them by the waitlist. Congruent with the literature encompassing coping strategies, the participants determinedly find ways to retain the feeling of being-at-home, and persevere to stay at home. To exert control and maintain a sense of mastery, doing waiting work is seen in the way that people buy things, build things, recruit others to do things, or find new ways of doing things. Some people seek out ways to fill in time or distract themselves, some people actively sit and wait, while others relinquish occupations that require too much effort. The physical and mental exertion inherent in doing waiting work, for the sake of staying at home, insidiously depletes their energy reserves, deleteriously affecting their way of being at home.

Doing waiting work is tiring, and the longer the participants wait, the more exhausting and demoralising it becomes. Waiting for community occupational therapy is experienced in the way that people ‘do’. My findings show that doing waiting work is unremitting, an extra demand placed upon these adults already doing everyday life work and patient work, that is, the work patients do to self-manage chronic illness, which includes medical management, emotional management and role management (Corbin & Strauss, 1985; Yin et al., 2020). Living with chronic health problems, which fluctuate in intensity from day-to-day and throughout the day, affects daily life and daily activities (Aberg et al., 2020). Similarly, managing patient work consumes resources, such as time and physical energy, to maintain one’s state of health (Yin et al., 2020). In much the same way, the intensity of doing waiting work ebbs and flows alongside doing daily activities. It uses up personal resources in effortful ways that depletes people’s morale. Take for example Bruce, and

the effort to keep himself clean and the extra work this created for him each morning, or Bob who was persevering with a tortuously painful chair so that he could share a meal with his family. Doing waiting work is determinedly carrying out difficult occupations, but for many, the effortful nature of doing waiting work is wearisome, and sometimes injurious.

Doing waiting work is emotionally onerous. Lee and colleagues' (2020) findings draw attention to the labour of managing one's emotions whilst doing waiting activities. This labour may be experienced when responding to waiting with patience and endurance or with anger and confrontation, and shows waiting as effortful and active, something to be both managed and endured (A. A. Lee et al., 2020). Similarly, in my study, people waiting for community occupational therapy also actively manage their emotions. Many people demonstrate their patience, enduring the wait, while others are frustrated and upset. As people vacillate between moods of hope and hopelessness, it affects their sense of comfort and peace at home. The fear, despair, aloneness, and boredom, embodied in waiting work, saps their energy, adversely affecting their participation in valued occupations, and further influencing their health and well-being. As if the effort of doing waiting work is not enough, the literature highlights that older adults do not want to be a burden or a problem to others (Aberg et al., 2020; Lloyd et al., 2014). Consequently, people may work harder to keep the exertion of doing waiting work hidden from others. For the sake of not causing upset, but more so to stay at home, they may endure the work required to conceal the emotional and physical labour.

Doing waiting work is trying to maintain a sense of agency whilst living in the shadow of a system that offers no opportunity for people to assert agency. Waiting for community occupational therapy means not getting the help that is needed to maintain a sense of mastery and control. Literature points out that older adults (under 85 years), in a financial position to pay for healthcare, to avoid waiting, will pay (Werntoft et al., 2007), thus exerting agency over their situation. This is similarly seen in my study as two people thought about, and purchased what they needed, thus exercising some agency over their situation. However, most people in my study are waiting for community occupational therapy because they are devoid of options. As a result, they are stuck waiting, a state characterised by invisibility, immobility and uncertainty (Bandak & Janeja, 2018). In my study, being stuck is not only being physically stuck inside, but the participants are 'stuck'

by their inability to effect change; and so, they endure the wait. This endurance is congruous with the findings in Lee et al's. (2020) study, where waiting was seen as "something to be endured … that required an ability to 'tough it out'" (p. 5). Similarly, Hage (2009b) speaks of being able to 'wait out stuckedness'. This notion of endurance implies "asserting some agency over the very fact that one has no agency by not succumbing and becoming a mere victim" (p. 101). The findings from my study show people doing physical and mental waiting work; this reflects a way of asserting their agency and not giving up. However, despite their perseverance, the findings show that when people lack the resources they need, their capacity to exert control over their situation weakens. Subsequently, they experience a loss of agency and a deterioration in their being.

Doing waiting work is relational

Doing waiting work involves others. Waiting for community occupational therapy shows the relationships with others who are there to help because the participants do not have what they need to manage their daily occupations. The literature identifies the significance of other people, such as family, friends, and carers, as playing an important role in supporting older adults to remain in their home, ensuring continuity of care, and enabling them to retain a sense of autonomy, control and mastery (Fjordside & Morville, 2016; Janssen et al., 2012; Lambotte et al., 2019). However, the same literature examining older people's sense of autonomy, control and mastery identifies that older adults grapple with being a burden and having to ask for support (Aberg et al., 2020), and deliberate about maintaining their autonomy and accepting help (Fjordside & Morville, 2016). In other words, the decision to agree to help is not easy and not always done willingly (Fjordside & Morville, 2016; Hillcoat-Nalletamby, 2014; Stafford, 2017). My findings are in keeping with this literature. Doing waiting work is seen in the way that some people actively hang onto doing their occupations, some people grapple with letting others help them, others come to accept the help, knowing it is a way to stay at home, and some people willingly agree to being helped. The findings also show that as doing waiting work increases, it provides an opening for family to become involved in ways that they may not have before. The relational nature of doing waiting work is comparable with other research, which shows that maintaining mastery in older age is a relational process (Janssen et al., 2012; Lambotte et al., 2019), and that for many older adults, these relationships enable them to direct their life with the support of others (Janssen et al.,

2012). In waiting for community occupational therapy, relationships with others can be experienced as supportive and helpful.

Not all help is helpful. Older adults want to retain their autonomy for as long as possible, including being involved in daily life decisions (Fjordside & Morville, 2016). However, just as older people vacillate in deciding whether to accept care, there are polarised perspectives of how older people feel about the care being received. On one hand, the literature suggests that older people feel deprived of their autonomy when family takes over (Aberg et al., 2020), powerless when left out of making decisions (Lambotte et al., 2019), or dissatisfied when the relationship with the carer is rigid and unresponsive to their needs (Fjordside & Morville, 2016). On the other hand, when older people are involved in their own care, or when they are supported in a way that maintains their independence, their autonomy and sense of self is enhanced (Fjordside & Morville, 2016; Lambotte et al., 2019). These feelings are synonymous with the dominating care or supportive care experienced by people in my study. Consider Val who felt unheard by the Needs Assessor, or Betty who felt deprived of her independence when her neighbour brought in her mail, or Roger, who was involved in decision-making with his family and was able to maintain a sense of control. While the abovementioned research focuses on concepts of autonomy and mastery and how other people can influence older adults' sense of these, in my study, as others become involved, each person's waiting work shifts. Several people experience a lessening of the waiting-workload as the physical effort is reduced by others helping. However, for some, receiving this help increases their mental waiting work, as they think about the wait and the impact of this on their lives. Some people surrender their occupations, becoming passive observers as others take over, thus losing their physical abilities. Others experience the waiting-workload increase in the effort to hold on to valued occupations and maintain the feeling of being-at-home in their home. While having support from others facilitates independence in everyday life by compensating for lost abilities (Aberg et al., 2020), it does not eliminate the waiting work.

Doing waiting work is being socially connected. Relationships with others provides the means for older adults to see a way of continuing to be themselves and to maintain a social life in the context of a changing body (Lloyd et al., 2014). Relationships provide the older person with the possibility of staying at home. Allowing others to help is a way of being with others that lets social relationships develop through sharing the demands of

doing waiting work to accomplish daily occupations. More so, having others come and go provides a connection with the wider world. Remaining socially connected is identified as one of several determinants for ageing well in place (Associate Minister of Health, 2016). Loss of social occupations can lead to isolation and loneliness, which is harmful to one's mental health (Golden et al., 2009; Paredes et al., 2020). The harm experienced when waiting work is done alone is exemplified in some of the stories. The emotional distress Molly experienced doing waiting work alone was captured in her language: *it makes me quite alone, I feel lonely,* and [I feel] *depressed.* Similarly, Betty, who resisted letting others help, suffered the aloneness and lost connections – *I miss those fellas*. In contrast, for those people doing waiting work with others, social connections are maintained, which enhances health and well-being.

Engaging in waiting work can mean being or becoming invisible to others. The absence of occupational therapy help shows as the relationships with others is seen to disappear. Doing waiting work, that is, weighing up the risk or effort and then making the decision to no longer leave the house, means that people become disconnected from, and invisible to, others, as (social) occupations outside the home cease and relationships fade. Aberg et al. (2020) found that a changing body affects access to, and interaction with, the world, which contributes to both the risk of a sedentary lifestyle and a depleted social network, leading to further physical deterioration. The decline in outdoor occupations and/or social occupations, in conjunction with increasing physical inactivity is also evident in my study. In doing waiting work, those people who became increasingly housebound replaced active occupations like *going for a walk* or *swimming* with sitting, not only becoming less active but also less visible to others. In this study, people sit more and do less, leading to gradual depletion of their way of being in the world. Think about Val who stopped going shopping with the carer, and let the carer do the shopping for her. Research shows that disuse-induced functional decline as a result of physical inactivity, even short periods of only five days, can result in the loss of muscle mass and strength (Valenzuela et al., 2018), thus perpetuating physical inactivity. For those people who are unable to participate in occupations outside, literature also suggests that housebound older people benefit from having a view of the outside world (Musselwhite, 2018; Rowles, 1991) as a means of maintaining connections. A view of the outside world is important as it enables people to engage with nature and connect with society and culture through observing or watching the outside space (Musselwhite, 2018). This activity of 'watching' is mirrored

in my study, for some it is an active way of passing time, but not necessarily satisfying, and for others, it is a way of staying connected with, and visible to, the outside world, albeit, in a less physically demanding way.

Doing waiting work is harmful

The effort of doing waiting work is seen in the way that older adults' doing and their being diminishes. There is a high degree of physical, mental and emotional labour demanded of older adults to simply manage the natural changes occurring in their everyday lives (Lloyd et al., 2014). The additional burden of doing waiting work, which is both pervasive and largely unrecognised by those doing it, has harmful consequences to older adults' physical and mental health and well-being. Doing waiting work does not sustain their way of being in the world. Rather, there is a slow erosion of their ability to engage in meaningful occupations. While self-managing chronic illness is widely promoted and patients are supported by health professionals, literature suggests that many individuals still struggle to practise self-management effectively (Yin et al., 2018; Yin et al., 2020). When older adults find themselves waiting for community occupational therapy, there is no guidance provided by healthcare professionals or those managing the waitlist on how to do the waiting. Waiting for community occupational therapy is imposed onto people and requires them to draw on their own physical, mental, emotional, social and financial resources. Waiting drains these resources and shows as struggling, fearfulness, disconnectedness, aloneness, helplessness and powerlessness. As older adults are worn down by doing waiting, not only do they become socially disconnected, but they also become less able. The longer they wait, the greater the losses, and the less likely they are to regain these.

Existing literature establishes older adults' attachments to their homes. 'Home' is a place of safety and comfort where older adults usually have the ability to make their own decisions and choose how to act (Schofield et al., 2006). However, control theory suggests that when people are unable to exert control over their environment, as illuminated in this study, it can threaten their self-esteem, self-efficacy and mastery (Heckhausen & Schulz, 1995), consequently affecting their mental well-being. Furthermore, when people are unable to do what matters nor reach their potential, they tend toward a state of dysfunction, poor health and ill-being (Hooper & Wood, 2019). In this study, despite the participants' effort, they do not have the capacity nor resources to exercise agency or

maintain a sense of mastery. Contrary to the occupational therapy value that people have the need for, and right to, engage in meaningful occupations of their choice, and experience the well-being such occupations bring (Baum et al., 2013), waiting removes their sense of agency, their ability to do the things that matter, and the comfort of being at home. People become debilitated by (the lack of) the very service supposed to give this power and well-being back. The weakened ability to participate in valued roles and occupations that usually enhance one's sense of self and well-being, surreptitiously shapes their Being, and slowly erodes their way of life.

As doing waiting work comes to dominate, people are doing less of what matters to them. Waiting for community occupational therapy starts to take over – whether it is thinking about the waiting, sitting by the phone waiting for the occupational therapist's phone call, letting go of occupations, finding a way to fill in time, or distracting themselves until the occupational therapist arrives. This study points to what Hitch et al. (2014) describe as 'occupational imbalance', which is detrimental to healthy living (Polatajko, Backman, et al., 2013). While engaging in meaningful occupations provides the older person with a sense of achievement, and enhances their well-being (Green et al., 2005), doing waiting work does not offer the same sense of satisfaction and meaning as other occupations lost to the waiting. As occupational beings, the loss of valued occupations leaves a void that waiting work cannot fill.

The essence of what it means to be waiting is to be doing the work of waiting, which involves physical, emotional and social ways of being. Doing waiting work is hard work and it takes its toll. The effort of doing waiting work sees valued occupations fade away, cease, or lose their meaning or pleasure; people experience a diminishing way of being in the world. That is, their meaningful way of life is depleted in the wait. As the participants wait, it is not only about the fragility of the physical body, but also an experience that is 'deeply felt and lived through' (Heidegger, 1927/1962). This means that in doing what they need to do to keep going, people experience waiting as demoralising, they lose hope of being helped. The essence of Being is not widely discussed in the existing research. Other studies have typically focused on observable or measurable phenomena of occupational therapy intervention (Gitlin et al., 2006; Sheffield et al., 2013; Steultjens et al., 2004). Yet *being* is an integral quality of being human, and is a facet of occupation that leads to well-being (Wilcock & Hocking, 2015). Ontologically, Dasein is always

heading towards the future (Inwood, 2019). People are waiting for the occupational therapist in anticipation of being provided with what they need to return to their way of doing and being and live towards the future they had envisioned. The unceasing physical, mental and emotional waiting work restricts peoples' potentiality of their Being. In waiting, they are unable to realise their aspirations of growing old well. Doing waiting work shapes their quality of life. Rather than flourishing, people are simply surviving.

In this study, for the sake of being at home, each person is enduring and making every effort to do what they need to do to stay at home. The majority are not giving up, which mirrors existing research identifying older adults' perseverance (Gramstad et al., 2013; Lloyd et al., 2014). However, within the perseverance there is an existential fatigue, a weariness and exhaustion, which is similarly identified by Lloyd et al. (2014) in their study of older adults in the fourth age. In my study, people spoke of, or alluded to, the weariness, effort and exhaustion of waiting. Some had all but given up on being helped. Not able to sustain doing waiting work, but determined to stay at home, they relinquished valued occupations. However, long-term or unplanned loss of occupations and lack of choice or diversity of occupations is harmful. It can affect one's sense of self, and can deprive people of a sense of meaning required to thrive (Polatajko, Backman, et al., 2013), which can undermine one's health and well-being. People require occupation to survive, grow, thrive and belong (Hooper & Wood, 2019). The findings from this study show how waiting for community occupational therapy undermines people's ability to thrive; they work harder to stay at home, but do less, and this is counterproductive to healthy ageing.

This study of older people waiting for community occupational therapy adds to the wider discussion on 'the experience of waiting for healthcare'. The focus on older adults' experiences of waiting for community occupational therapy points to the detrimental effects that delayed community occupational therapy services has on their health and well-being. The insidious depletion of people's way of life leads to a state of dysfunction and ill-being. This study brings to light the experiences of older adults waiting for community occupational therapy; a cohort whose (lived) experiences of waiting for healthcare has not been widely researched. The importance of understanding the experience of waiting for community occupational therapy is understanding the way older adults draw on their own resources when they join the occupational therapy waitlist. But waiting drains their resources. Bringing forward the notion of 'doing waiting work' as a

way of understanding the experience of waiting for community occupational therapy, exposes how the continual exertion of doing the physical, mental and emotional work of waiting shapes the way occupations may be performed, experienced, or abandoned. It shows how waiting work leads to a reduced range of occupations, and how occupations are seen to lose their meaning and pleasure. Accordingly, in this study, people experience a depletion in their way of doing and in their being. This subsequently affects their feelings of safety and security at home, their way of being in the world, and their health and well-being. Waiting deprives older people of a meaningful life. This study shows how older adults are active in their waiting. In spite of this, there are repercussions of waiting for community occupational therapy, not only to the older adults themselves, but also to healthcare system and the various services that support older adults to age in place.

IMPLICATIONS FOR PRACTICE

This study illuminates the hard work that community-dwelling older adults undertake in waiting for community occupational therapy. The results of this study are of relevance to many people throughout the health, disability and social sectors who have an interest in the health and well-being of older people. The findings of my study suggest that the status quo – lengthy waitlists for community occupational therapy – is not okay. A change is needed to lessen the waitlist and lessen the waiting time to be seen by a community occupational therapist so that the needs of older adults are addressed in a timely manner. As a clinician, I am mindful that implementing change within well-established practice settings and entrenched ways of doing things is not always simple and often requires the support of Team Leaders, Service Managers and General Managers. Whilst clinicians can make changes to their practice, the onus of change should not lie solely with clinicians. I will therefore present the implications of this research at four levels, namely, clinical, service, organisational and governmental.

Clinical level: Doing clinical work well

As I interviewed participants and interpreted their stories, I found myself in a constant state of ethical tension. I knew that my practice had slipped into, as Wilcock (1998) described, ‘a rut’ – limiting work to what was essential – focusing on safety and personal independence, and not always looking towards enabling occupation. Undertaking this study has presented me with the privilege of sharing in the experience of older people waiting for our care and has reminded me of the importance of our uniqueness as

community occupational therapists, what we can offer, and why these people wait to see us.

Getting to know this person. Occupational therapists value being client-centred, that is, understanding and recognising that clients are experts regarding their own occupations and that clients must be active partners in the occupational therapy process (Townsend & Polatajko, 2013). Nonetheless, doing this well in practice is not always as simple as it sounds. In a review I undertook (Fryer et al., 2019), therapists identified the unremitting pressure to "see as many clients as possible; to deal with clients quickly; and to take on higher caseloads than is practical" (p. 17). Consequently, the relentless demand to work through the waitlist can impact on the ability to practice in a genuinely client-centred and caring way. Nonetheless, the person in front of the occupational therapist is not just 'another client' who cannot get down the steps or lift their leg over the side of the bath, but a person whose health and well-being has suffered from the wait inflicted by the system. This study shows how each person has worked hard waiting for community occupational therapy, and despite their best effort, may not have been able to sustain their participation in their valued occupations. Getting to know this person, who they are and what is important to them can help ensure a meaningful outcome.

To get to know the person is to listen to their story. "Listening is a mode of 'inviting.' … Listening is also a mode of 'showing'" (Wright-St Clair & Smythe, 2012, p. 35). Inviting the person to talk openly, and listening out for what is important to the person, invites conversation and shows that their experiences are heard and understood. Listening to what the person believes is the solution to their problem bridges their self-knowledge with the occupational therapist's knowledge when identifying occupational performance issues and carrying out corresponding therapy. This study brings to light how older people have already spent many months trying to find ways to adapt. Exploring what people have already tried is acknowledging their hard work in the waiting and recognises their expertise. Asking "tell me about how you have been managing …" or "What have you already tried?" allows the older person to tell their story. If they are not clear or able to articulate their situation you could ask "What do you mean by that?" or "help me to understand your situation". Listening involves silence (Wright-St Clair & Smythe, 2012), which gives people space to think and speak. Being curious helps to open the

conversation. Listening creates a space for the older person to share their learnings from doing waiting work and be an active partner in the occupational therapy process.

Doing occupational therapy well. Best practice for community occupational therapy is difficult to benchmark (Carrier et al., 2010), but as clinicians it is our responsibility to do a thorough first assessment and implement effective and timely intervention. Healthcare providers often concentrate on the acute or presenting problem, focusing on one problem at a time (Aberg et al., 2020) as this can be seen as time efficient. This narrowed approach to care means that an individual's needs may not be adequately addressed. Such was the case in this study, where one participant had received previous community occupational therapy intervention and as it was insufficient, had to wait over a year to be seen again. This caused unnecessary distress, which consequently affected his health and well-being.

This study illuminates the importance of showing care. It also points to why older adults wait for community occupational therapy intervention. They recognise the potential of our service, and anticipate that the occupational therapist will have access to what they need to remain at home. Applying our clinical knowledge, our 'knowing', in conjunction with understanding the meaning of the individual's occupations, makes it possible to consider the downstream implications of disease progression and the ageing process. By looking beyond the presenting problem, occupational therapists can 'leap ahead' to give back possibility and empower the person to do what matters to them.

According to Golant (2015) "even the most successful adaptations may not result in the older persons bouncing back or returning to their original equilibrium position" (p. 79). To me, this means that by the time we see the older person, they have already lost skills and abilities that they may not be able to recover even with our help. This infers that we need to be thorough and provide timely intervention to enable older adults to continue to be at home, doing the best they can, and prevent any further unnecessary functional decline or occupational loss. If we do not get this right, there is the potential for continued adverse changes to their way of being in the world, and worse, they may have to wait for help again.

Being attuned to the person's well-being. In this study, participants experienced a change or loss of occupations whilst waiting for community occupational therapy, and

many became disconnected from their social worlds. Several people experienced loneliness and social isolation, which is known to contribute to poor physical and mental health (Golden et al., 2009; Office for Senior Citizens, 2015). Each person experienced a degree of low or altered mood as their ability to participate in valued occupations was compromised as they waited for the community occupational therapist. Mental health is very much intertwined with physical health and well-being, which is key to occupational therapy practice. Similarly, the interconnection between taha hinengaro[30] (mental health) and taha tinana[31] (physical health), is illustrated in 'Te Whare Tapa Whā'[32], one of the models for understanding Māori health (Durie, 1998). However, in 'Te Whare Tapa Whā', there is also a strong interconnectedness with taha whānau (family) and taha wairua[33] (spiritual health). Together, these four dimensions of health are fundamental to well-being (Durie, 1998). When looking back at people's stories, we can see through the chapter – Waiting as Being With – how relationships and whānau were core to supporting people through the time of waiting. Thinking holistically about people's well-being, knowing that this can be affected by waiting, prompts us to attend to more than just physical health, but to people's broader well-being. As clinicians we need to be aware of, and acknowledge, the impact waiting may have had on the older person and their family or whānau. Giving our time, truly attending to the person, acknowledging loneliness and loss of doing, and asking questions about their mood, well-being and the whole of what matters, is relevant to our practice and shows our care.

Service level: Making the impact of waitlists visible

The lengthy waitlists overpower the individual occupational therapist's best intentions. Literature has shown that the pressure of long waitlists and organisational policies that help to structure occupational therapy services have an adverse effect on occupational therapists and their practice (Carrier et al., 2010; Fryer et al., 2019). Long waitlists can generate ethical tensions, which increase the risk of staff burnout, professional attrition (Raymond et al., 2020) and loss of job satisfaction (Fryer et al., 2019; McGill et al., 2020).

[30] Taha hinengaro – pronounced – ta-ha hee-neh-nah-raw
[31] Taha tinana – pronounced- ta-ha tee-nah-nah
[32] Te whare tapa whā – pronounced – te fah-ree tah-pah far
[33] Taha wairua – pronounced – ta-ha why-roo-ah

Delayed occupational therapy reduces the older person's ability to benefit from the service when it is eventually received (Raymond et al., 2020). Consequently, for those adults who have waited, not only may they not get the fullness of the service needed, but what help they get may be of reduced benefit to them. The significance of this, in addition to the new knowledge learnt from this study is worrisome. Does it mean that for many older people the service is too late? By understanding older adults' experience of waiting, the impact of waiting cannot be ignored or underestimated. The community occupational therapy waitlist needs to be made visible, and escalated within the organisation.

Possible ways of supporting people on the waitlist. In my study, the long and uncertain wait left many people feeling forgotten, disregarded and unimportant. After hearing these stories, I decided to implement a trial in our service. An occupational therapist would contact the clients on our waitlist. Most had been waiting 3 months or longer. Each person on the waitlist was contacted. They were pleased to hear from someone. It provided reassurance that they had not been forgotten. They were thankful for being contacted and assured the therapist that they were able to keep waiting. A small number of people said that they no longer required help as they had come to resolve their problem themselves. It was not possible to maintain this regular contact in the department due to increasing workload and lack of administrative help. Phone calls took up time, but kept the client connected to our service, and this appeared meaningful to them. This resonates with a study undertaken by Saywell and Taylor (2015) whose participants identified that receiving a phone call or text gave a sense of connection and made them feel important.

Implementing a system of contacting people (via phone, text or email) who are on the waitlist gives surety that they are still on the list and not forgotten. This provides the assurance of being helped and the opportunity to advise the service provider if their needs have changed. As seen in this study, older adults are unlikely to initiate contact with the service directly. In New Zealand, older people are adopting mobile technology, and mobile phones have been used successfully in the delivery of health programs (Saywell & Taylor, 2015). Therefore, it is possible that using mobile phones to keep connected with those on the waitlist by text messaging may be a potentially efficient and effective practical solution.

Alternatively, a clearly written letter advising they are on the waitlist, with information such as: how long the wait may be, when and how to contact the community occupational therapy department, private providers, and options of where to privately hire or purchase assistive devices. This information provides older adults with the tools they need to help make their own decisions. Making this information available may support older adults to maintain a sense of agency, and may also lessen the difficulty of trying to navigate in an unfamiliar and complex healthcare system.

Organisational level: Looking across services and allocating resources to less visible services

"'The hospital is full' is a more palpably demanding alarm bell than 'the community is full' – but both need adequate capacity for mutual effectiveness" (Young & Turnock, 2001, p. 254). This quote talks to the fact that community-based services, like occupational therapy, have low public visibility (Young & Turnock, 2001), and that the waitlists for these services are overshadowed by medical and surgical waitlists, which have ministerial priorities attached to them, and are monitored by the Ministry of Health (Ministry of Health, 2019a). Concentrating all resources into highly visible health services (such as elective surgery) can come at the cost of other equally important, but less visible services (Passalent et al., 2009), such as community occupational therapy. Several systematic reviews have convincingly demonstrated that occupational therapy intervention can make a difference to the lives of older people in the community (De Coninck et al., 2017; Gitlin et al., 2006; Sheffield et al., 2013; Stark et al., 2017; Steultjens et al., 2004). Additional research shows that early occupational therapy intervention can prevent disability, maintain independence (Raymond et al., 2020), maximise participation and quality of life (Levasseur & Couture, 2015), and reduce admission into hospital or premature entry into residential care (Raymond et al., 2013).

Waitlists are costly. The findings from this study shows how waitlists contribute to disability and social disconnection, and subsequent isolation. As mentioned above, social isolation and loneliness have been correlated with poor well-being, which contributes to poor physical and mental health (Golden et al., 2009). Further, waiting for community occupational therapy can result in not having the necessary tools to manage at home. Research has shown that the most frequent type of adaptation employed by older adults involved the use of assistive devices or technology (Stafford, 2017), and that people who

used assistive devices (provided by occupational therapists) required less personal assistance and had fewer unmet needs (Sheffield et al., 2013; Stark et al., 2017). Ministry of Health (2018) data shows that older adults use more health services, that spending on services for older adults is increasing faster than other expenses, and that rest home care is a substantial part of the budget. However, the literature argues that economically, it is less expensive to support older adults in their home than placing people into residential care (Sixsmith & Sixsmith, 2008), and for ageing in place to succeed, funding for community-based services needs to be prioritised above aged residential care (M. Parsons et al., 2014). From the aforementioned research, it can be extrapolated that well-timed community occupational therapy intervention could reduce the need for home support and delay admission into residential care; a potential cost-saving.

Investing in community occupational therapy services will improve health outcomes for older people (De Coninck et al., 2017) and maximise occupational performance and staying well at home. By adequately resourcing the services to improve triaging and waitlist management, as well as providing well-timed, thorough assessments and intervention, the demand on inpatient and other community services may be reduced. Moreover, it will improve or maintain older adults' health, well-being and quality of life, thus supporting them to age in place. It may also help to reduce recruitment costs if occupational therapists can be retained because they are less distressed and more satisfied with their job.

Government level: Overseeing and directing the health and disability system

"If wait times are considered 'acceptable' because they have always been there … there is little chance that energy will be invested in making a change" (Harding, Robertson, et al., 2018, p. 98). This quote speaks to what has driven this study. The waitlists for community occupational therapy services in Northland have been long-standing, and are also evident throughout New Zealand (Bishop & Brott, 2019; Fryer et al., 2019), but little seems to have changed; the waiting is 'just how it is'. It is time for change, and this has to come from the top. The existing literature has shown that older adults want to age in place. Likewise, Government strategies (Associate Minister of Health, 2016; Office for Seniors, 2019) support ageing in place and acknowledge that in order to do so successfully, older adults require the right supports at the right time. This small study showed that the ideology of Ageing in Place is not being achieved in the way that it has

been envisioned. Contrary to the intention of the Healthy Ageing Strategy (Associate Minister of Health, 2016) and Better Later Life 2019-2034 Strategy (Office for Seniors, 2019), the participants in this study were not ageing *well* in place. The waitlist prevented access to the community occupational therapy service when they needed it, and through their stories we heard how their health and well-being was adversely affected. Given that waitlists for community occupational therapy services exist nationally, it can be surmised that there are many older adults affected by these waitlists.

In 2017, a DHB occupational therapy workforce assessment report identified several trends impacting on occupational therapy services (Valentine et al., 2017). Key trends were: demand for community services were continually increasing, high priority clients were increasingly being triaged, and there had been an increase in unmet need for clients prioritised as medium and low. It is now 2023, and I would ask, what has been implemented to counter these trends? Community occupational therapists have told us that "staffing levels had not changed despite the rising numbers of older people and people with disability living in the community" (Fryer et al., 2019, p. 17). Services are ill-prepared for the growing, ageing population with increasingly complex needs. Community occupational therapy services are connected to the New Zealand Health Strategy goal of 'closer to home' (Valentine et al., 2017), and to Priority Three – keeping people well in their communities – of the Interim Government Policy Statement on Health (Ministry of Health, 2022b). Yet, inadequate community occupational therapy services means that older adults do not get the support they need to remain at home, or keep well in their community. Not receiving the support they need, may potentially jeopardise an older adults' safety, health and community participation. Furthermore, older adults are at risk of premature entry into residential care (Raymond et al., 2013).

Community occupational therapy services cannot be accessed when needed and subsequently do not work for their users. This study strongly supports the need for responsive services. The waitlists are unjust and contribute to greater inequality. Those people in a financial position to purchase what they need, rather than wait, can have their needs addressed without delay. However, options to purchase what is needed may not be available everywhere, and those who cannot afford to pay, the greater populace, have no choice but to wait, perpetuating inequity. In light of Priority Three in the Interim Government Policy Statement on Health (Ministry of Health, 2022b), caring for, and

keeping all older adults well in the community must be brought forward as a priority. The waitlists are not okay. If we are to make a genuine contribution to the lives of older adults, their health needs can no longer be pushed out to the fringes of the health system.

Continuing to underinvest in community occupational therapy services means that health outcomes for older adults, as illuminated in this study, will continue to worsen as their occupational needs remain unmet. Conversely, investing in community occupational therapy services to support the growing, ageing population who have increasingly complex health and disability needs, will enhance occupational performance and health outcomes. Undertaking a review of the ratio of therapists to the population, and understanding what the ratio should be by taking into account the regional socio-economic, geographical variations, population health, and population movements, may help to ensure that services are adequately resourced and prepared for the rising population.

Consideration of designing a national system that would enable an older or disabled person to obtain 'basic' equipment without an occupational therapy assessment would ensure their needs are addressed whilst lessening the demand on busy community occupational therapy services. For example, a person could go online and select what they need from a specific list of items, which could then be delivered directly to them. For those people who are unable to use computer-based services, Health Coaches working at GP practices could assist. This could potentially be a viable and economic solution for the healthcare system on several fronts: therapist's skills are utilised with clients who have complex needs and who require an occupational therapist, the risk of falls in the home is lessened as people have what they need, thus potentially leading to fewer ambulance call-outs for falls and subsequent hospitalisation, and, better health outcomes for clients. This type of system would demonstrate respect for the older person's autonomy, provide an immediate solution, and enable occupational therapists to respond to, and support, those people presenting with more complex occupational performance issues in a timelier manner.

STRENGTHS AND LIMITATIONS

The findings of this study have to be considered in light of its strengths and limitations, which are discussed in relation to the methodology, and the impact I have had on the research, as the primary researcher.

Methodology

As hermeneutic phenomenology aims to develop deeper understandings of the phenomenon, a cohort with a wide variation of lived experiences improves the possibility of rich and unique stories (Laverty, 2003). At the outset of my study, my intention was to recruit a diverse group of older adults. Whilst my cohort size of 12 is in keeping with the methodology, difficulty recruiting participants meant that I did not have a selection of participants to choose from. It was fortuitous that the cohort was diverse, which subsequently provided a range of 'waiting' experiences, thus enhancing the richness of the findings. Unfortunately, I did not succeed in recruiting any participants who lived in a very rural or remote area who may have added another dimension to the waiting experience.

At the outset of my study I decided not to include data from other people. However, as the study progressed it was evident that 'others' were part of the waiting experience. Choosing not include the voice of 'others' means that a dimension of the experience of waiting for community occupational therapy remains concealed.

A particular strength of this study is that it includes perspectives of both Māori and Pākehā; reflecting the population of Northland. As this study was undertaken in Northland, the findings are connected with this region. The aim of hermeneutic phenomenology is to throw a light on something already there so that one may be able to act more thoughtfully about a given situation and enable people to reflect on their practice. Although this study was undertaken in Northland, I believe that people reading this research, both in and beyond Northland, will be able to connect with the text in some way, and consider how the findings transfer to their situation.

I was learning and gaining an understanding of the philosophy and methodology at the same time I was doing hermeneutic phenomenology. My literature review is an example of this. It is more 'academic' in its execution rather than being wholly conducted in a manner consistent with hermeneutic phenomenology. What I mean is that I only focused

on published research to understand what was already known about the topic and to ascertain if there was a gap in the knowledge base. I did not consider other types of text exploring the phenomenon of waiting, such as newspaper articles, books, and poetry, which may have added another dimension to the literature review.

Interpreting the stories was challenging. Again, I was learning as I was doing. Knowing the hermeneutic circle in a theoretical sense was different to applying it. It required me to 'trust the process' as I moved between and across the participant stories and then make the 'interpretive leap' (Crowther & Thomson, 2020). Through an ongoing dialogue with my supervisors, I was able to reflect on, and develop my interpretations. Also, having the opportunity to present an example of my findings at a symposium led by Professor Susan Crowther and attended by Professors Liz Smythe and Deb Spence, provided an opportunity for others to hear how I made my interpretations, and provide feedback and assurance that I was on the right track.

Me, the researcher

The advantage of undertaking a hermeneutic phenomenology study has meant that I could engage with my own prejudices rather than try and keep these to one side. Drawing on one's forestructure of understanding is not perceived as a limitation, rather, it can aid in developing useful research (Lopez & Willis, 2004). However, to achieve useful research, it was my responsibility to keep a check on my understandings to maintain an openness towards the text. I engaged in an ongoing reflexive process throughout the study, and my prejudices were made explicit from the start so that the reader could determine their influence on the findings. Whilst being reflexive and reflective throughout the study enabled me to take a considered approach towards the phenomenon, I am cognisant that my supervisors, who provided their perspectives of the text, will have had an influence on my interpretation and presentation of the findings. It is possible that had other people been involved, the phenomenon may have been illuminated in another way.

Phenomenological interviewing required a different approach to the problem-based questioning and listening I use to complete clinical assessments. To elicit lived moments I used open-ended questions, such as "tell me about receiving the waitlist letter", and then had to get used to asking the closed questions, such as: "What happened then?" and "then what?" Mostly, I had to become comfortable with being silent and giving people space to

think and respond. Reviewing the first few transcripts with a supervisor helped me to recognise where I had missed opportunities to ask questions to draw out the lived moments in more depth. I became familiar and comfortable with this way of questioning and my interviewing improved. However, I recognise that there will be stories and moments that were not told, and this means that there will be nuances of the experience of waiting for community occupational therapy that may remain unknown.

A strength that I brought to this study was my ability to engage with, and build rapport with older adults. Several of the participants commented at the end of their interview that the information they had shared was not what they had planned to say. Likewise, having lived and worked in Northland for the past 23 years meant that I had a familiarity with, and understanding of, the region; a connection with the region and its people. My link with the region enhanced the research relationship as there was a mutual understanding of living in Northland; I understood the participants' stories within their context. On the other hand, my European background limited my depth of understanding of the stories shared by those participants who identified as Māori because of the different world views and experiences that we each brought to the interview. Hence, I engaged with the Takawaenga (Māori advisor) to discuss their stories. This deepened my understandings and subsequent interpretation of the stories, thus enriching the findings. That said, a limitation of this study is the ad-hoc engagement with the Takawaenga throughout the research process. Contrarily, a sustained collaboration with the Takawaenga from study design through to recruitment, data collection, analysis and reflecting on the study findings and subsequent discussion, may have added another dimension to, or deepened my understandings of, the experience of waiting for community occupational therapy. This would have likely resulted in interviews being conducted differently, and would have gathered different aspects of people's experiences. Analysis would have attended more to cultural domains of waiting, and may have illuminated a Māori perspective of waiting or doing waiting work.

POSSIBILITIES FOR FURTHER RESEARCH

As I analysed the text, wrote the discussion, spoke with colleagues and considered the strengths and limitations of this study, other questions arose.

How long is too long to wait? The reality is that there will always be waiting lists for health services. But at what point are we, as community occupational therapists, too late to prevent irreversible occupational loss? The findings show the cumulative impact of waiting on older adults' well-being, as well as on occupational participation. Using mixed methods to obtain data related to older adults' well-being and occupational participation when they join the waitlist and then obtain comparable data at regular intervals along the continuum of waiting may help to uncover how long older adults can safely wait for community occupational therapy before they experience permanent occupational loss. This information may help to inform MOH service specifications and resource allocation.

What is the lived experience of Māori waiting for community occupational therapy? This study took a whole of population approach rather than a Māori-centred approach and does not produce Māori knowledge; the unique experiences of Māori are subsumed within the data. Using kaupapa Māori[34] approaches to understand the experiences of Māori helps to ensure policy and service development that considers the needs of Māori in healthcare. That said, kaupapa Māori research is controlled and owned by Māori (Barnes, 2000), is for Māori and with Māori (Cunningham, 2000). Any such research needs to be of value to Māori, and led by Māori, with collaboration with Māori community members.

Is waiting in other regions experienced in the same way? This research was limited to Northland, which is largely rural. People living in cities may have different living arrangements that increase social connectedness (i.e. apartment blocks or townhouses), and access to alternate options, such as paying privately for an assessment or purchasing what they need from a local supplier, thus experiencing waiting differently. Understanding how city-dwellers experience waiting for community occupational therapy can help to extend our understandings of the phenomenon of waiting for community occupational therapy.

How do the family or whānau experience waiting? Waiting is occurring in the world with others. The findings show that others are part of the waiting experience. We

[34] Kaupapa Māori – pronounced ko-papa mow-ri – meaning "Māori customary practice, Māori institution, Māori agenda, Māori principles, Māori ideology - a philosophical doctrine, incorporating the knowledge, skills, attitudes and values of Māori society"(Te Aka Māori Dictionary, n.d.-e).

know little of how waiting impacts on their world. Understanding the experience of the family or whānau might allow us to develop resources that support the family or other people who are caring for older adults in the community.

How do younger adults experience waiting for community occupational therapy? As I read the literature, it became apparent that disabled younger adults have different priorities to older adults (Carr et al., 2017; Raymond et al., 2020). The participants in my study were resigned to wait, and their stories illuminated their frustration and despair as the waiting dragged on; they had expected to be helped. The participants worked hard to stay at home, and despite this, there was a gradual loss of participation in meaningful occupations. Some of these experiences may reflect their priorities and expectations as older people. However, younger adults may have different expectations and experiences. Using qualitative methodology to understand younger adults' experience of waiting and then comparing and contrasting this with older adults' experience of waiting may help to facilitate a change in how services are resourced, and how to direct those resources.

How do we improve service delivery to minimise people's wait time for community occupational therapy intervention? The findings indicate that early occupational therapy intervention would minimise occupational loss and support older people to stay well at home. Overseas studies have explored clinicians' caseload management behaviours (Kolehmainen et al., 2010) as well as service factors (Harding, Robertson, et al., 2018) that contribute to wait times for occupational therapy intervention. Identifying factors that contribute to lengthening waitlists for community occupational therapy services in New Zealand, such as disruptions to the service or processes that impact on work flow, and identifying which of these factors are modifiable, may help to initiate changes that can improve service delivery and subsequently lessen wait times.

What are the costs – human and economic – of waiting lists? Making good use of limited health dollars is essential. Undertaking health utilisation studies could determine what costs are incurred due to community occupational therapy waitlists (i.e. referrals to other services or admission to residential care or hospital), and whether these costs could be off-set through timely occupational therapy intervention. In addition, measuring quality-adjusted life years to determine the value and benefit of community occupational

therapy intervention and outcomes could provide a better understanding of where to direct resources.

Is the current MOH Risk Assessment Framework still relevant? The current framework is based on risk, with a strong focus on the loss of physical abilities, and does not consider a person's mental health and well-being nor their social or cultural circumstances. The findings show how many of these older adults became socially isolated as social occupations ceased. Replicating the study by Raymond et al. (2020) in New Zealand, using a larger sample size, to understand what matters to older adults and (younger) disabled people requiring community occupational therapy could help to inform service priorities and how referrals are triaged and prioritised.

Why invest in community occupational therapy? The findings indicate that early occupational therapy input could maximise occupational performance and staying well at home, thus reducing the burden on other (health) services. Undertaking a longitudinal study to measure health and quality of life outcomes of those that receive occupational therapy compared to those who remain on the waitlist could provide the evidence for investing in occupational therapy services to ensure earlier occupational therapy input.

FINAL THOUGHTS & LAST WORDS

Occupational therapists can, and do, make a difference to the lives of people we work with, yet the waitlists block too many people from accessing the service in a timely manner. When I started on this journey, I wanted to bring some humanness to the waitlist. That is, I wanted to make the waitlist about the people. I wanted to illuminate what it meant for older people to be waiting for community occupational therapy. I wanted to understand if waiting was of concern to older people or just our burden as therapists. I hoped that in doing this study it would alleviate the pressure therapists placed onto themselves. Mostly, by understanding, and drawing on the power of the stories about people waiting, I wanted to bring the waitlist, and what it means to be waiting, to the attention of those people with the power to effect change.

Using hermeneutic phenomenology enabled me to throw a light in a new way on something that has always been there, but remained unseen. Waiting announced itself in the way older people went about their ordinary everyday. Waiting was embedded within the context of the older person's daily life, but disrupted their everyday as it came to

subsume and shape the usual activities they might have engaged in. While the negative aspects of waiting dominated, we also came to see some positive elements. Waiting exposed the importance of the family and how the family were there, doing for and with, but not everyone had family to help. Waiting uncovered the ingenuity of older adults as they found ways to wait and hold on to the feeling of being-at-home, but many had limited or diminishing resources to do so. Resilience to persist through the daily struggle was evident in all the participants, but they were becoming exhausted. The positives were overshadowed by the occupational loss and disruption, and the consequent adverse effects on occupational balance and their well-being.

Understanding the experience of waiting for community occupational therapy has shown that doing waiting work is a way of being in the everyday that appears productive because it lets the older person continue living in their home while waiting for the community occupational therapist. However, the physical, mental and emotional impacts of doing waiting work insidiously shape people's engagement in meaningful occupations of living. Some occupations are substituted for less fulfilling ones. Some occupations are modified and lose their meaningfulness. Some occupations are lost. Unable to do the things they need to do at home, or like to do, they are not able to realise their aspirations of growing old well, and instead, move toward a state of dysfunction and ill-being. For this reason, the health system must be collectively concerned about the waitlists. As clinicians, we cannot shoulder the waitlists alone. For those who oversee the services that promote the health and well-being of older people, the impact of waiting for community occupational therapy must not be ignored or underestimated.

Whilst doing waiting work lets older people be at home, it drains their resources and is exhausting and demoralising. The essence of waiting for community occupational therapy *is* the insidious depletion of the older person's meaningful life.

REFERENCES

Aberg, C., Gillsjö, C., Hallgren, J., & Berglund, M. (2020). "It is like living in a diminishing world": Older persons' experiences of living with long-term health problems - prior to the STRENGTH intervention. *International Journal of Qualitative Studies on Health and Well-being, 15*(1), 1-12. https://doi.org/10.1080/17482631.2020.1747251

American Psychological Association. (2010). *Concise rules of APA style* (6th ed.). Washington, DC: American Psychological Association.

Associate Minister of Health. (2016). *Healthy Ageing Strategy*. Wellington: Ministry of Health. Retrieved from https://www.health.govt.nz/system/files/documents/publications/healthy-ageing-strategy_june_2017.pdf

Auckland University of Technology. (n.d.). *Applying for ethics approval: Guidelines and procedures*. Retrieved October 1, 2022, from https://www.aut.ac.nz/research/researchethics/guidelines-and-procedures#23

Bandak, A., & Janeja, M. K. (2018). Introduction: Worth the wait. In M. Janeja & A. Bandak (Eds.), *Ethnographies of waiting : Doubt, hope and uncertainty* (pp. 1-39). London, United Kingdom: Taylor and Francis. Retrieved from http://ebookcentral.proquest.com/lib/aut/detail.action?docID=5185041

Barnes, H. (2000). Kaupapa maori: Explaining the ordinary. *Pacific Health Dialog, 7*(1), 13-16.

Baum, C., Carey, L., & Polatajko, H. (2013). Occupational Therapy. In M. D. Gellman & J. R. Turner (Eds.), *Encyclopedia of Behavioral Medicine* (pp. 1371-1373). New York, NY: Springer.

Baum, C., Christiansen, C. H., & Bass, J. D. (2015). The person-environment-occupation-performance (PEOP) model. In C. H. Christiansen, C. Baum, & J. D. Bass (Eds.),

Occupational therapy: Performance, participation and well-being (4 ed., pp. 49-56). Thorofare, NJ: SLACK Incorporated.

Berghan, G., Came, H., Coupe, N., Doole, C., Fay, J., McCreanor, T., & Simpson, T. (2017). *Te Tiriti o Waitangi-based practice in health promotion*. Retrieved from https://trc.org.nz/treaty-waitangi-based-practice-health-promotion

Bien, B., McKee, K., Dohner, H., Triantafillou, J., Lamura, G., Doroszkiewicz, H., . . . Kofahl, C. (2013). Disabled older people's use of health and social care services and their unmet care needs in six European countries. *European Journal of Public Health, 23*(6), 1032-1038. https://doi.org/10.1093/eurpub/cks190

Birch, L., & Adams, J. (2008). Carers' perceptions of community occupational therapy: Short Report. *British Journal of Occupational Therapy, 71*(5), 205-208.

Biringer, E., Sundfor, B., Davidson, L., Hartveit, M., & Borg, M. (2015). Life on a waiting list: How do people experience and cope with delayed access to a community mental health center? *Scandinavian Psychologist, 2*(e6). https://doi.org/10.15714/scandpsychol.2.e6

Bishop, A., & Brott, T. (2019). Why the wait? A new approach to community occupational therapy waiting list management. *New Zealand Journal of Occupational Therapy, 66*(1), 19-23.

Board, M., & McCormack, B. (2018). Exploring the meaning of home and its implications for the care of older poeple. *Journal of Clinical Nursing*. https://doi.org/10.1111/jocn.14495

Bollnow, O. F. (1961). Lived-space. *Philosophy Today, 5*, 31-39.

Brewer, K. (2017). *Clinical insights from research with New Zealand Māori*. Retrieved from www.dropbox.com/s/36rfaocuaydvqi3/Brewer%202017%20Clinical%20insights%20from%20research%20with%20NZ%20Maori.pdf?dl=0

Brooke, J. (2019). Equity of people with dementia in research, why does this issue remain? *Journal of Clinical Nursing, 28,* 3723-3724. https://doi.org/10.1111/jocn.14957

Butcher, E., & Breheny, M. (2016). Dependence on place: A source of autonomy in later life for older Maori. *Journal of Aging Studies, 37,* 48-58. https://doi.org/10.1016/j.jaging.2016.02.004

Caelli, K. (2001). Engaging with phenomenology: Is it more of a challenge than it needs to be? *Qualitative Health Research, 11*(2), 273-281. https://doi.org/10.1177/104973201129118993

Came, H. A. (2013). Doing research in Aotearoa: a Pākehā exemplar of applying Te Ara Tika ethical framework. *Kotuitui: New Zealand Journal of Social Sciences Online*. https://doi.org/10.1080/1177083X.2013.841265

Canvin, K., MacLeod, C., Windle, G., & Sacker, A. (2018). Seeking assistance in later life: How do older people evaluate their need for assistance? *Age and Ageing, 7*, 466-473. https://doi.org/10.1093/ageing/afx189

Carr, T., Teucher, U., & Casson, A. (2017). Waiting for scheduled surgery: A complex patient experience. *Journal of Health Psychology, 22*(3), 290-301. https://doi.org/10.1177/1359105315603464

Carrier, A., Levasseur, M., & Mullins, G. (2010). Accessibility of occupational therapy community services: A legal, ethical, and clinical analysis. *Occupational Therapy in Health Care, 24*(4), 360-376. https://doi.org/10.3109/07380577.2010.510170

Cestari, V., Moreira, T., Pessoa, V., Florencio, R., Silva, M., & Torres, R. (2017). The essence of care in health vulnerability: A Heideggerian construction. *Rev Bras Enferm, 70*(5), 1112-1116. https://doi.org/10.1590/0034-7167-2016-0570

Collins English Dictionary. (n.d.). Waitlist. In *Collins English dictionary*. Retrieved May 22, 2022, from https://www.collinsdictionary.com/dictionary/english/waitlist

Corbin, J., & Strauss, A. (1985). Managing chronic illness at home: Three lines of work. *Qualitative Sociology, 8*(3), 224-247. https://doi.org/10.1007/BF00989485

Critchley, S. (2009). Being and Time part 7: Conscience. *The Guardian*. Retrieved from https://www.theguardian.com/commentisfree/belief/2009/jul/20/heidegger-being-time-critchley

Crowther, S., Ironside, P., Spence, D., & Smythe, L. (2017). Crafting stories in hermeneutic phenomenology research: A methodological device. *Qualitative Health Research, 27*(6), 826-835. https://doi.org/10.1177/104973231665661

Crowther, S., Smythe, E., & Spence, D. (2014). The joy at birth: An interpretive hermeneutic literature review. *Midwifery, 30*(4), e157-e165. https://doi.org/10.1016/j.midw.2014.01.004

Crowther, S., & Thomson, G. (2020). From description to interpretive leap: Using philosophical notions to unpack and surface meaning in hermeneutic phenomenology research. *International Journal of Qualitative Methods, 19*, 1-11. https://doi.org/10.1177/1609406920969264

Cunningham, C. (2000). A framework for addressing Māori knowledge in research, science and technology. *Pacific Health Dialog, 7*(1), 62-69.

Curtin, M. (2010). Enabling skills and strategies. In M. Curtin, M. Molineux, & J. Supyk-Mellson (Eds.), *Occupational therapy and physical dysfunction: Enabling occupation*. London: Elsevier Ltd.

De Coninck, L., Bekkering, G., Bouckaert, L., Declercq, A., Graff, M., & Aertgeerts, B. (2017). Home- and community-based occupational therapy improves functioning in frail older people: A systematic review. *J Am Geriatr Soc, 65*(8), 1863-1869. https://doi.org/10.1111/jgs.14889

de Witt, L., & Ploeg, J. (2006). Critical appraisal of rigour in interpretive phenomenological nursing research. *Journal of Advanced Nursing, 55*(2), 215-229. https://doi.org/10.1111/j.1365-2648.2006.03898.x

Dekkers, W. (2011). Dwelling, house and home: Towards a home-led perspective on dementia care. *Medical Health Care and Philosophy, 14*, 291-300. https://doi.org/10.1007/s11019-011-9307-2

Dickie, V. (2009). What is occupation? In E. B. Crepeau, E. S. Cohn, & B. A. B. Schell (Eds.), *Willard and Spackman's occupational therapy* (11 ed., pp. 15-21). Philadelphia: Lippincott Williams & Wilkins.

Dictionary.com. (n.d.-a). Ennui. In *Dictionary.com*. Retrieved September 24, 2022, from https://www.dictionary.com/browse/ennui

Dictionary.com. (n.d.-b). Limbo. In *Dictionary.com*. Retrieved October 25, 2022, from https://www.dictionary.com/browse/limbo

Dictionary.com. (n.d.-c). Unease. In *Dictionary.com*. Retrieved January 10, 2023, from https://www.dictionary.com/browse/unease

Dictionary.com. (n.d.-d). Work. In *Dictionary.com*. Retrieved September, 24, 2022, from https://www.dictionary.com/browse/work

Donne, J. (n.d.). *No man is an island*. Retrieved June 17, 2022, from https://web.cs.dal.ca/~johnston/poetry/island.html

Duggal, M. (2014). Health services for older people: The role of district health boards. In K. Diesfeld & I. McIntosh (Eds.), *Elder law in New Zealand* (pp. 199-216). Wellington, New Zealand: Thomson Reuters.

Durie, M. (1998). *Whaiora: Maori health development* (2 ed.). Australia: Oxford University Press.

English Oxford Living Dictionaries. (n.d.). Waiting. In *English Oxford Living Dictionaries*. Retrieved March 31, 2018, from https://en.oxforddictionaries.com/definition/waiting

Escudero, J. A. (2013). Heidegger: Being and Time and the care for the self. *Open Journal of Philosophy, 3*(2), 302-307. https://doi.org/10.4236/ojpp.2013.32047

Finlay, L. (2006). The body's disclosure in phenomenological research. *Qualitative Research in Psychology, 3*(1), 19-30. https://doi.org/10.1191/1478088706qp051oa

Fjelland, R., & Gjengedal, E. (1994). A theoretical foundation for nursing as a science. In P. Benner (Ed.), *Interpretive phenomenology: Embodiment, caring, and ethics in health and illness* (pp. 3-25). Thousand Oaks, CA: Sage.

Fjordside, S., & Morville, A. (2016). Factors influencing older people's experiences of participation in autonomous decisions concerning their daily care in their own homes: A review of the literature. *International Journal of Older People Nursing, 11*, 284-297. https://doi.org/10.1111/opn.12116

Fogarty, C., & Cronin, P. (2008). Waiting for healthcare: a concept analysis. *Journal of Advanced Nursing, 61*(4), 463-471. https://doi.org/10.1111/j.1365-2648.2007.04507.x

Freeman, L. (2014). Toward a phenomenology of mood. *Southern Journal of Philosophy, 52*(4), 445-476. https://doi.org/10.1111/sjp.12089

Freeman, L., & Elpidorou, A. (2020). Fear, anxiety, and boredom. In T. Szanto & H. Landweer (Eds.), *The Routledge handbook of phenomenology of emotions*. Retrieved from https://philpapers.org/archive/FREFAA-3.pdf

Fryer, V., Wright-St Clair, V., & Bright, F. (2019). Waiting for community occupational therapy services: A review. *New Zealand Journal of Occupational Therapy, 66*(3), 15-21.

Fujita, M. (2002). Ambiguous experiences. In M. Van Manen (Ed.), *Writing in the dark: Phenomenological studies in interpretive inquiry*. Ontario, Canada: Althouse Press.

Gabriel, Z., & Bowling, A. N. N. (2004). Quality of life from the perspectives of older people. *Ageing and Society*, *24*(5), 675-691. https://doi.org/10.1017/S0144686X03001582

Gadamer, H.-G. (2004). *Truth and method* (J. Weinsheimer & D. G. Marshall, Trans., 2 ed.). London: Continuum. (Original work published 1975)

Gadamer, H.-G. (2016). *The beginning of philosophy* (R. Coltman, Trans.). London: Bloomsbury Revelations. (Original work published 1996)

Gallego, G., Dew, A., Lincoln, M., Bundy, A., Chedid, R. J., Bulkeley, K., . . . Veitch, C. (2017). Access to therapy services for people with disability in rural Australia: A carers' perspective. *Health & Social Care in the Community*, *25*(3), 1000-1010. https://doi.org/10.1111/hsc.12399

Gitlin, L., Hauck, W., Winter, L., Dennis, M., & Schulz, R. (2006). Effect of an in-home occupational and physical therapy intervention on reducing mortality in functionally vulnerable older people: Preliminary findings. *Journal American Geriatric Soc*, *54*(6), 950-955. https://doi.org/10.1111/j.1532-5415.2006.00733.x

Gledhill, K. (2014). Rights of access to health care and older people. In K. Diesfeld & I. McIntosh (Eds.), *Elder law in New Zealand* (pp. 147-177). Wellington, New Zealand: Thomson Reuters.

Golant, S. (2015). Residential normalcy and the enriched coping repertoires of successfully aging older adults. *The Gerontologist*, *55*(1), 70-82. https://doi.org/10.1093/geront/gnu036

Golden, J., Controy, R. M., Bruce, I., Denihan, A., Greene, E., Kirby, M., & Lawlor, B. A. (2009). Loneliness, social support networks, mood and wellbeing in

community-dwelling elderly. *International Journal of Geriatric Psychiatry, 24*, 694-700. https://doi.org/10.1002/gps.2181

Gramstad, A., Storli, S. L., & Hamran, T. (2013). 'Do I need it? Do I really need it?' Elderly peoples experiences of unmet assistive technology device needs. *Disability & Rehabilitation: Assistive Technology, 8*(4), 287-293. https://doi.org/10.3109/17483107.2012.699993

Grant, M., & Booth, A. (2009). A typology of reviews: An analysis of 14 review types and associated methodologies. *Health Information and Libraries Journal, 26*, 91-108. https://doi.org/10.1111/j.1471-1842.2009.00848.x

Green, S., Sixsmith, J., Ivanoff, S., & Sixsmith, A. (2005). Influence of occupation and home environment on the wellbeing of European elders. *International Journal of Therapy and Rehabilitation, 12*(11), 505-509. https://doi.org/10.12968/ijtr.2005.12.11.20061

Grime, H. (1990). Receiving referrals: Decision making by the community occupational therapist. *British Journal of Occupational Therapy, 53*(2), 53-56. https://doi.org/10.1177/030802269005300204

Hage, G. (2009a). Introduction. In G. Hage (Ed.), *Waiting* (pp. 1-12). Retrieved from https://search-informit-com-au.ezproxy.aut.ac.nz/documentSummary;dn=076793142359197;res=IELHSS>

Hage, G. (2009b). Waiting out the crisis: On stuckedness and governmentality. In G. Hage (Ed.), *Waiting* (pp. 97-106). Retrieved from https://search-informit-com-au.ezproxy.aut.ac.nz/documentSummary;dn=077538461209525;res=IELHSS

Harding, K. E., Lewis, A. K., Snowdon, D. A., Taylor, N. F., & STAT Research Group. (2018). *Specific and timely appointments for triage (STAT) handbook*. Melbourne, Victoria: Eastern Health & La Trobe University.

Harding, K. E., Robertson, N., Snowdon, D. A., Watts, J. J., Karimi, L., O'Reilly, M., . . . Taylor, N. F. (2018). Are wait lists inevitable in subacute ambulatory and community health services? A qualitative analysis. *Australian Health Review, 42*(1), 93-99. https://doi.org/10.1071/AH16145

Harman, G. (2007). *Heidegger explained: From phenomenon to thing*. Illinois: Open Court Publishing Company.

Health and Disability System Review. (2020). *Health and disability system review: Executive overview*. Wellington: HDSR. Retrieved from https://systemreview.health.govt.nz/assets/Uploads/hdsr/health-disability-system-review-final-report-executive-overview.pdf

Heckhausen, J., & Schulz, R. (1995). A life-span theory of control. *Psychological Review, 102*(2), 284-304. Retrieved from http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=ovftb&NEWS=N&AN=00006832-199504000-00005

Heidegger, M. (1962). *Being and Time* (J. Macquarrie & E. Robinson, Trans., 7 ed.). New York, NY: Harper & Row. (Original work published 1927)

Heidegger, M. (1971). Building Dwelling Thinking (A. Hofstadter, Trans.). In *Poetry, Language, Thought*. Retrieved from http://frontdeskapparatus.com/wp/wp-content/uploads/2012/10/Building-Dwelling-Thinking.pdf

Higgins, R., & Meredith, P. (n.d.). Kaumātua – Māori elders - Kaumātua and their role. In *Te Ara - the Encyclopedia of New Zealand*. Retrieved August 6, 2023, from https://teara.govt.nz/en/kaumatua-maori-elders/page-1

Hillcoat-Nalletamby, S. (2014). The meaning of "independence" for older people in different residential settings. *Journals of Gerontology, Series B: Psychological Sciences and Social Sciences, 69*(3), 419-430. https://doi.org/10.1093/geronb/gbu008

Hitch, D., & Pepin, G. (2020). Doing, being, becoming and belonging at the heart of occupational therapy: An analysis of theoretical ways of knowing. *Scandinavian Journal of Occupational Therapy*, 1-13. https://doi.org/10.1080/11038128.2020.1726454

Hitch, D., Pépin, G., & Stagnitti, K. (2014). In the footsteps of Wilcock, part one: The evolution of doing, being, becoming, and belonging. *Occupational Therapy in Health Care, 28*(3), 231-246. https://doi.org/10.3109/07380577.2014.898114

Ho, J. W., Kuluski, K., & Im, J. (2017). "It's a fight to get anything you need" - Accessing care in the community from the perspectives of people with multimorbidity. *Health Expect, 20*, 1311-1319. https://doi.org/10.1111/hex.12571

Hocking, C. (2013). Occupational Science. In M. D. Gellman & J. R. Turner (Eds.), *Encyclopedia of Behavioral Medicine* (pp. 1365-1370). New York, NY: Springer.

Hooper, B., & Wood, W. (2019). The philosophy of occupational therapy. In B. A. B. Schell & G. Gillen (Eds.), *Willard and Spackman's occupational therapy* (13 ed., pp. 42-55). Philadelphia, PA: Wolters Kluwer.

HOP Management Team. (2016). *Assessment Services: Operational manual*: Northland District Health Board.

Horrigan-Kelly, M., Millar, M., & Dowling, M. (2016). Understanding the key tenets of Heidegger's philosophy for interpretive phenomenological research. *International Journal of Qualitative Methods*, 1-8. https://doi.org/10.1177/1609406916680634

Human Rights Commission. (2010). *Human rights in New Zealand: Summary*. Retrieved from https://www.hrc.co.nz/files/8414/2388/0549/Human_Rights_Review_2010_Summary.pdf

Inwood, M. (1997). *Heidegger: A very short introduction*. New York: Oxford University Press.

Inwood, M. (2019). *Heidegger: A very short introduction* (2 ed.). United Kingdom: Oxford University Press.

Jane Austen quote. (n.d.). Retrieved December, 15, 2022, from https://www.brainyquote.com/citation/quotes/jane_austen_163803

Janssen, B., Abma, T., & van Regenmortel, T. (2012). Maintaining mastery despite age related losses. The resilience narratives of two older women in need of long-term community care. *Journal of Aging Studies, 26*, 343-354. https://doi.org/10.1016/j.jaging.2012.03.03

Jarrett, C. (2021). *Why does time seem to go slower when we're bored?* Retrieved July 25, 2021, from https://www.sciencefocus.com/the-human-body/why-does-time-seem-to-go-slower-when-were-bored/

Johnson, W. W. (n.d.). *Great inspirational quotes*. Retrieved May 16, 2022, from https://www.pinterest.ca/pin/329466528976800439/

Kielhofner, G. (1985). *A model of human occupation: Theory and application*. Baltimore: Williams & Wilkins.

Koch, T. (1996). Implementation of a hermeneutic inquiry in nursing: philosophy, rigour and representation. *Journal of Advanced Nursing, 24*, 174-184. https://doi.org/10.1046/j.1365-2648.1996.17224.x

Koch, T. (1999). An interpretive research process: revisiting phenomenological and hermeneutical approaches. *Nurse Researcher, 6*(3), 20-34. https://doi.org/10.7748/nr1999.04.6.3.20.c6085

Kolehmainen, N., MacLennan, G., Francis, J., & Duncan, E. A. (2010). Clinicians' caseload management behaviours as explanatory factors in patients' length of time on caseloads: A predictive multilevel study in paediatric community occupational therapy. *BMC Health Services Research, 10*(249). https://doi.org/10.1186/1472-6963-10-249

Lacey, A. (2010). The research process. In K. Gerrish & A. Lacey (Eds.), *The research process in nursing* (6 ed., pp. 13-26). Oxford, UK: Wiley-Blackwell.

Lambotte, D., Kardol, M., Schoenmakers, B., Fret, B., Smetcoren, A.-S., De Roeck, E. E., . . . D-SCOPE Consortium. (2019). Relational aspects of mastery for frail, older adults: The role of informal caregivers in the care process. *Health & Social Care in the Community, 27*, 632-641. https://doi.org/10.1111/hsc.12676

Laverty, S. M. (2003). Hermeneutic phenomenology and phenomenology: A comparison of historical and methodological considerations. *International Journal of Qualitative Methods, 2*(3), 21-35. https://doi.org/10.1177/160940690300200303

Lee, A. A., James, A. S., & Hunleth, J. M. (2020). Waiting for care: Chronic illness and health system uncertainties in the United States. *Social Science & Medicine, 264*, 1-8. https://doi.org/10.1016/j.socscimed.2020.113296

Lee, W.-J., Chen, L.-K., Peng, L.-N., & Chiou, S.-T. (2016). Personal mastery attenuates the adverse effect of frailty on declines in physical function of older people: A 6-year population-based cohort study. *Medicine, 95*(34), 1-7. https://doi.org/10.1097/MD.0000000000004661

Leonard, V. W. (1994). A Heideggerian phenomenological perspective on the concept of person. In P. Benner (Ed.), *Interpretive phenomenology: Embodiment, caring, and ethics in health and illness* (pp. 43-63). Thousand Oaks, CA: Sage.

Levasseur, M., & Couture, M. (2015). Coping strategies associated with participation and quality of life in older adults. *Canadian Journal of Occupational Therapy, 82*(1), 44-53. https://doi.org/10.1177/0008417414552188

Lloyd, L., Calnan, M., Cameron, A., Seymour, J., & Smith, R. (2014). Identity in the fourth age: Perseverance, adaptation and maintaining dignity. *Ageing and Society, 34*, 1-19. https://doi.org/10.1017/S0144686X12000761

Lopez, K., & Willis, D. G. (2004). Descriptive versus interpretive phenomenology: Their contributions to nursing knowledge. *Qualitative Health Research, 14*(5), 726-735. https://doi.org/10.1177/1049732304263638

Mackay, H. (n.d.). *Time is precious quotes*. Retrieved June 8, 2021, from https://www.google.com/search?q=time+is+precious+quotes&safe=active&rlz=1C1CHZL_enNZ840NZ840&biw=1254&bih=620&sxsrf=ALeKk01sfXNBCCONOfKIc4QDY45v8-r9Yw:1623146180051&tbm=isch&source=iu&ictx=1&fir=2rWp1yuE7x-2-M%252CG_vOl5bW36udEM%252C_&vet=1&usg=AI4_-kSY4qLRlTRYcrEzp09YEp6sHKEVAQ&sa=X&ved=2ahUKEwjXyevb4ofxAhVjyzgGHVYPC58Q_h16BAgSEAE#imgrc=2rWp1yuE7x-2-M

Madeira, L., Leal, B., Filipe, T., Rodrigues, M., & Figueira, M. (2019). The uncanny of the illness experience: Can phenomenology help? *Psychopathology, 52,* 275-282. https://doi.org/10.1159/000504141

Malpas, J. (2022). *Hans-Georg Gadamer* (Winter 2022 ed.). Retrieved from https://plato.stanford.edu/archives/win2022/entries/gadamer/

Malterud, K., Siersma, V. D., & Guassora, A. D. (2016). Sample size in qualitative interview studies: Guided by information power. *Qualitative Health Research, 26*(13), 1753-1760. https://doi.org/10.1177/1049732315617444

Matuska, K., & Barrett, K. (2019). Patterns of occupation. In B. A. B. Schell & G. Gillen (Eds.), *Willard and Spackman's occupational therapy* (13 ed., pp. 212-222). Philadelphia, PA: Wolters Kluwer.

McColl, M. (2019). *Should I say 'disabled person' or 'person with a disability'?*. Retrieved September 22, 2022, from https://theconversation.com/should-i-say-disabled-person-or-person-with-a-disability-113618#:~:text=Many%20disabled%20people%2C%20however%2C%20say,are%20a%20person%20either%20way

McGill, N., Crowe, K., & McLeod, S. (2020). "Many wasted months": Stakeholders' perspectives about waiting for speech-language pathology services. *International Journal of Speech-Language Pathology*, 1-14. https://doi.org/10.1080/17549507.2020.1747541

McKinstry, C., Brown, T., & Gustafsson, L. (2014). Scoping reviews in occupational therapy: The what, why, and how to. *Australian Occupational Therapy Journal, 61*, 58-66. https://doi.org/10.1111/1440-1630.12080

McManus Holroyd, A. E. (2007). Interpretive hermeneutic phenomenology: Clarifying understanding. *Indo-Pacific Journal of Phenomenology, 7*(2), 1-12. https://doi.org/10.1080/20797222.2007.11433946

Merriam-Webster. (n.d.-a). In limbo. In *Merriam-webster.com dictionary*. Retrieved November 20, 2022, from https://www.merriam-webster.com/dictionary/in%20limbo

Merriam-Webster. (n.d.-b). Patient. In *Merriam-Webster.com dictionary*. Retrieved October, 18, 2022, from https://www.merriam-webster.com/dictionary/patient#:~:text=1%20%3A%20bearing%20pains%20or%20trials,despite%20opposition%2C%20difficulty%2C%20or%20adversity

Merriam-Webster. (n.d.-c). Wait. In *Merriam-Webster.com dictionary*. Retrieved March 31, 2018, from https://www.merriam-webster.com/dictionary/waiting

Merriam-Webster. (n.d.-d). Wait-list. In *Merriam-Webster.com dictionary*. Retrieved May 22, 2022, from https://www.merriam-webster.com/dictionary/wait-list

Merriam-Webster. (n.d.-e). Waiting list. In *Merriam-Webster.com dictionary*. Retrieved May 22, 2022, from https://www.merriam-webster.com/dictionary/waiting%20list

Minister of Health. (2016). *New Zealand Health Strategy: Future direction* Wellington: Ministry of Health. Retrieved from

https://www.health.govt.nz/system/files/documents/publications/new-zealand-health-strategy-futuredirection-2016-apr16.pdf

Ministry for Culture and Heritage. (2017). *The Treaty in brief*. Retrieved May 9, 2019, from https://nzhistory.govt.nz/politics/treaty/the-treaty-in-brief

Ministry of Health. (2015a). *Community health, transitional and support services - allied health services (non inpatient). Tier level two service specification*. Retrieved from https://nsfl.health.govt.nz/system/files/documents/specifications/t2alliedhealthservicesservicespecificationmarch2015.docx

Ministry of Health. (2015b). *Statement of intent 2015 to 2019: Ministry of Health*. Wellington: Ministry of Health. Retrieved from https://www.health.govt.nz

Ministry of Health. (2016). *Population of Northland DHB: 2016/17*. Retrieved July 7, 2018, from https://www.health.govt.nz/new-zealand-health-system/my-dhb/northland-dhb/population-northland-dhb#

Ministry of Health. (2017). *Statement of strategic intentions 2017 to 2021*. Wellington: Ministry of Health. Retrieved from https://www.health.govt.nz/publication/statement-strategic-intentions-2017-2021

Ministry of Health. (2018). *Older people's health data and stats*. Retrieved August 25, 2019, from https://www.health.govt.nz/nz-health-statistics/health-statistics-and-data-sets/older-peoples-health-data-and-stats

Ministry of Health. (2019a). *About elective services patient flow indicators*. Retrieved August 8, 2022, from https://www.health.govt.nz/our-work/hospitals-and-specialist-care/elective-services/elective-services-and-how-dhbs-are-performing/about-elective-services-patient-flow-indicators

Ministry of Health. (2019b). *Northland DHB*. Retrieved August 3, 2019, from https://www.health.govt.nz/new-zealand-health-system/my-dhb/northland-dhb

Ministry of Health. (2019c). *Population of Northland DHB*. Retrieved August 25, 2019, from https://www.health.govt.nz/new-zealand-health-system/my-dhb/northland-dhb/population-northland-dhb

Ministry of Health. (2022a). *Ao Mai te Rā | The Anti-Racism Kaupapa*. Retrieved December 1, 2022, from https://www.health.govt.nz/our-work/populations/maori-health/ao-mai-te-ra-anti-racism-kaupapa?utm_source=OTBNZ+Register&utm_campaign=8e7191ba60-EMAIL_CAMPAIGN_2021_04_06_01_34_COPY_01&utm_medium=email&utm_term=0_35202f7421-8e7191ba60-401232304

Ministry of Health. (2022b). *Interim government policy statement on health 2022-2024*. Wellington: Ministry of Health. Retrieved from https://www.health.govt.nz

Ministry of Social Development. (2016). *New Zealand Disability Strategy 2016 - 2026*. Wellington: Ministry of Social Development. Retrieved from https://www.odi.govt.nz/assets/New-Zealand-Disability-Strategy-files/pdf-nz-disability-strategy-2016.pdf

Molineux, M. (2010). The nature of occupation. In M. Curtin, M. Molineux, & J. Supyk-Mellson (Eds.), *Occupational therapy and physical dysfunction: Enabling occupation* (6 ed., pp. 17-26). London: Elsevier Ltd.

Molineux, M. (2017). Occupation. In *Dictionary of occupational science and occupational therapy*. https://doi.org/10.1093/acref/9780191773624.001.0001

Moya, P. (2014). Habit and embodiment in Merleau-Ponty. *Frontiers in human neuroscience, 8*, 1-3. https://doi.org/10.3389/fnhum.2014.00542

Munday, R. (2009). *Glossary of terms in Being and Time*. Retrieved 25 January 2022, from http://www.visual-memory.co.uk/b_resources/b_and_t_glossary.html#a

Musselwhite, C. (2018). The importance of a room with a view for older people with limited mobility. *Quality in Ageing and Older Adults*. https://doi.org/10.1108/QAOA-01-2018-0003

Nelms, T. (2014). Phenomenological philosophy and research In M. De Chesnay (Ed.), *Nursing research using phenomenology: Qualitative designs and methods in nursing* (pp. 1-24). New York: Springer Publishing Company. Retrieved from http://ezproxy.aut.ac.nz/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=nlebk&AN=910078&site=eds-live

Nenon, T. J. (2015). Horizonality. In N. Keane & C. Lawn (Eds.), *A companion to hermeneutics* (pp. 248-252). https://doi.org/10.1002/9781118529812.ch27

Nielsen, C. (2013). Hearing the other's voice: How Gadamer's fusion of horizons and open-ended understanding respects the other and puts oneself in question. *Otherness: Essays and Studies, September*, 1-25. https://doi.org/https://www.otherness.dk/fileadmin/www.othernessandthearts.org/Publications/Journal_Otherness/Otherness-_Essays_and_Studies_4.1/Gadamer_on_Hearing_the_Other_s_Voice.pdf

Northland District Health Board. (2012). *Northland health services plan: 2012-2017*. Retrieved from https://www.northlanddhb.org.nz/assets/about/NHSP-2012-2017-Full-Version-min.pdf

Novek, S., & Wilkinson, H. (2019). Safe and inclusive research practices for qualitative research involving people with dementia: A review of key issues and strategies. *Dementia, 18*(3), 1042-1059. https://doi.org/10.1177/1471301217701274

Occupational Therapy New Zealand Whakaora Ngangahau Aotearoa. (2002). *Role of Community OT working in Physical Health*. Retrieved from https://www.otnzwna.co.nz/download/27/position-statements/724/the-role-of-a-Community-OT-working-with-Physical-Health-Position-Statement.pdf

Occupational Therapy New Zealand Whakaora Ngangahau Aotearoa. (n.d.). *What is Occupational Therapy?* Retrieved October 12, 2022, from https://www.otnzwna.co.nz/occupational-therapy/what-is-occupational-therapy/

Office for Senior Citizens. (2015). *2014 Report on the Positive Ageing Strategy*. Wellington: Office for Senior Citizens. Retrieved from https://www.msd.govt.nz/documents/about-msd-and-our-work/publications-resources/planning-strategy/positive-ageing/action-plan-and-annual-report/msd-17470-2014-ageing-strategy-report-final.pdf

Office for Seniors. (2019). *Better Later Life He Oranga Kaumatua 2019-2034: A strategy for making the future better for New Zealanders as we age*. Wellington, New Zealand: Office for Seniors. Retrieved from http://superseniors.msd.govt.nz/documents/better-later-life/better-later-life-strategy.pdf

Online Etymology Dictionary. (n.d.-a). Inconspicuous. In Douglas Harper (Ed.), *Online Etymology Dictionary*. Retrieved August 7, 2021, from https://www.etymonline.com/search?q=inconspicuous

Online Etymology Dictionary. (n.d.-b). Wait. In Douglas Harper (Ed.), *Online Etymology Dictionary*. Retrieved March 31, 2018, from https://www.etymonline.com/search?q=wait

Orange, C. (n.d.). Northland Region. In *Te Ara-The Encyclopedia of New Zealand*. Retrieved October 20, 2022, from https://teara.govt.nz/en/northland-region

Pani-Harreman, K., Bours, G., Zander, I., Kempen, G., & van Duren, J. (2021). Definitions, key themes and aspects of 'ageing in place': a scoping review. *Ageing and Society, 41*, 2026-2059. https://doi.org/10.1017/S0144686X20000094

Paredes, A. M., Lee, E. E., Chik, L., Gupta, S., Palmer, B. W., Palinkas, L. A., . . . Jeste, D. V. (2020). Qualitative study of loneliness in a senior housing community: The

importance of wisdom and other coping strategies. *Aging and Mental Health, 25*(3), 1-8. https://doi.org/10.1080/13607863.2019.1699022

Parsons, K. (2010). Exploring how Heideggerian philosophy underpins phenomenological research. *Nurse Researcher, 17*(4), 60-68. https://doi.org/10.7748/nr2010.07.17.4.60.c7925

Parsons, M., Parsons, J., & Jacobs, S. (2014). The genesis and impact of the "ageing-in-place" policy. In K. Diesfeld & I. McIntosh (Eds.), *Elder law in New Zealand* (pp. 33-58). Wellington, New Zealand: Thomson Reuters.

Passalent, L. A., Landry, M. D., & Cott, C. A. (2009). Wait times for publicly funded outpatient and community physiotherapy and occupational therapy services: Implications for the increasing number of persons with chronic conditions in Ontario, Canada. *Physiotherapy Canada, 61*(1), 5-14. https://doi.org/10.3138/physio.61.1.5

Peoples, K. (2021). *How to write a phenomenological dissertation: A step-by-step guide*. Thousand Oaks, CA: Sage.

Plager, K. (1994). Hermeneutic phenomenology: A methodology for family health and health promotion study in nursing. In P. Benner (Ed.), *Interpretive phenomenology: Embodiment, caring, and ethics in health and illness* (pp. 65-83). Thousand Oaks, CA: Sage.

Polatajko, H., Backman, C., Baptiste, S., Davis, J., Eftekhar, P., Harvey, A., . . . Connor-Schisler, A. (2013). Human occupation in context. In E. Townsend & H. Polatajko (Eds.), *Enabling occupation II: Advancing an occupational therapy vision for health, well-being and justice through occupation* (2 ed., pp. 37-62). Ottawa, Ontario: CAOT Publications ACE.

Polatajko, H., Davis, J., Stewart, D., Cantin, N., Amoroso, B., Purdie, L., & Zimmerman, D. (2013). Specifying the domain of concern: Occupation as core. In E. Townsend & H. Polatajko (Eds.), *Enabling occupation II: Advancing an occupational*

therapy vision for health, well-being and justice through occupation (2 ed., pp. 13- 36). Ottawa, Ontario: CAOT Publications ACE.

Pool, I. (n.d.). Effects of colonisation on Maori. In *Te Ara-The Encyclopedia of New Zealand*. Retrieved October 20, 2022, from https://teara.govt.nz/en/death-rates-and-life-expectancy/page-4

Popova, M. (2018). *The art of waiting: Reclaiming the pleasures of durational being in an instant culture of ceaseless doing*. Retrieved 19 May 2022, from https://www.themarginalian.org/2018/12/17/jason-farman-delayed-response/?fbclid=IwAR126ZQcuwUyuoBXM8DkqTgyWpQPoh8sDJIMb1aHLtWVgvTSZfAPy8QEedg

Potter, B. (n.d.). Retrieved June 14, 2022, from https://www.goodreads.com/author/quotes/11593.Beatrix_Potter

Raymond, M.-H., Demers, L., & Feldman, D. (2018). Differences in waiting list prioritization preferences of occupational therapists, elderly people, and persons with disabilities: A discrete choice experiment. *Archives of Physical Medicine and Rehabilitation, 99*, 35-42. https://doi.org/10.1016/j.apmr.2017.06.031

Raymond, M.-H., Demers, L., & Feldman, D. E. (2016). Waiting list management practices for home-care occupational therapy in the province of Quebec, Canada. *Health & Social Care in the Community*, *24*(2), 154-164. https://doi.org/10.1111/hsc.12195

Raymond, M.-H., Feldman, D., & Demers, L. (2020). Referral prioritization in home care occupational therapy: A matter of perspective. *Canadian Journal of Occupational Therapy*, 1-10. https://doi.org/10.1177/0008417420917500

Raymond, M.-H., Feldman, D., Prud'homme, M., & Demers, L. (2013). Who's next? Referral prioritization criteria for home care occupational therapy. *International Journal of Therapy and Rehabilitation, 20*(12), 580-588. https://doi.org/104169710

Rechel, B., McKee, M., Haas, M., Marchildon, G., Bousquet, F., Blumel, M., . . . Nolte, E. (2016). Public reporting on quality, waiting times and patient experience in 11 high-income countries. *Health Policy, 120*, 377-383. https://doi.org/10.1016/j.healthpol.2016.02.008

Reich, W. T. (1995). *Classic article: History of the notion of care*. Retrieved from https://theology.georgetown.edu/research/historyofcare/classicarticle/

Rittenmeyer, L., Huffman, D., & Godfrey, C. (2012). The experiences of patients, families, and/or significant others of waiting when engaging with the healthcare system: A qualitative systematic review. *JBI Database of Systematic Reviews & Implementation Reports, 8*, 193-258. https://doi.org/10.11124/jbisrir-2014-1664

Rodgers, V., & Neville, S. (2007). Personal autonomy for older people living in residential care: An overview. *Nursing Praxis in New Zealand, 23*(1), 29-36.

Rowles, G. (1991). Beyond performance: Being in place as a component of occupational therapy. *American Journal of Occupational Therapy, 45*(3), 265-271.

Rowles, G. (2000). Habituation and being in place. *The Occupational Therapy Journal of Research, 20*(Supplement), 52s-67s. https://doi.org/pdf/10.1177/15394492000200S105

Rowles, G. (2009). The meaning of place. In E. B. Crepeau, E. S. Cohn, & B. A. B. Schell (Eds.), *Willard and Spackman's occupational therapy* (11 ed., pp. 80-89). Philadelphia: Lippincott Williams & Wilkins.

Sandelowski, M. (2000). Whatever happened to qualitative description? *Research in Nursing and Health, 23*, 334-340.

Saywell, N., & Taylor, D. (2015). Focus group insights assist trial design for stroke telerehabilitation: a qualitative study. *Physiotherapy Theory and Practice, 31*(3), 160-165. https://doi.org/10.3109/09593985.2014.982234

Schofield, V., Davey, J., Keeling, S., & Parsons, M. (2006). Ageing in Place. In J. Boston & J. Davey (Eds.), *Implications of population ageing: Opportunities & Risks* (pp. 275 - 306). Victoria University of Wellington: Institute for Policy Studies.

Schulz, R., Heckhausen, J., & O'Brien, A. (1994). Control and the disablement process in the elderly. *Journal of Social Behavior and Personality, 9*(5), 139-152.

Seamon, D. (2002). Physical comminglings: Body, habit and space transformed into place. *The Occupational Therapy Journal of Research, 22*(Supplement), 42s-51s. https://doi.org/10.1177/15394492020220S106

Shatz, I. (2022). *Ennui: How to overcome chronic boredom. In Effectiviology.* Retrieved February 14, 2022, from https://effectiviology.com/ennui/#:~:text=Ennui%20implies%20a%20judgment%20of,a%20response%20to%20the%20immediate%E2%80%9D.&text=Furthermore%2C%20ennui%20is%20often%20existential,major%20domain%20in%20one's%20life.

Sheffield, C., Smith, C. A., & Becker, M. (2013). Evaluation of an agency-based occupational therapy intervention to facilitate aging in place. *The Gerontologist, 53*(6), 907-918. https://doi.org/10.1093/geront/gns145

Shine. (n.d.). *Colonisation and family violence*. Retrieved October 20, 2022, from https://www.2shine.org.nz/resources/colonisation-and-family-violence/#:~:text=Colonisation%20meant%20the%20erosion%20of,for%20M%C4%81ori%20w%C4%81hine%20and%20tamariki.

Sixsmith, A., & Sixsmith, J. (2008). Ageing in Place in the United Kingdom. *Ageing International, 32*, 219-235. https://doi.org/10.1007/s12126-008-9019-y

Sloan, A., & Bowe, B. (2014). Phenomenology and hermeneutic phenomenology: The philosophy, the methodologies and using hermeneutic phenomenology to investigate lecturers' experiences of curriculum design. *Quality & Quantity, 48*(3), 1291-1303. https://doi.org/10.1007/s11135-013-9835-3

Smith, D. (2018). *Phenomenology* (Summer 2018 ed.). Retrieved from https://plato.stanford.edu/archives/sum2018/entries/phenomenology/

Smith, D. E. (2003). Making sense of what people do: A sociological perspective. *Journal of Occupational Science, 10*(1), 61-64. https://doi.org/10.1080/14427591.2003.9686512

Smythe, E. (2011). From beginning to end: How to do hermeneutic interpretive phenomenology. In G. Thomson, F. Dykes, & S. Downe (Eds.), *Qualitative research in midwifery and childbirth* (pp. 35-54). London, UK: Routledge.

Smythe, E. (2012). Discerning which qualitative approach fits best. *New Zealand College of Midwives Journal, 46*, 5-12.

Spence, D. (2017). Supervising for robust hermeneutic phenomenology: reflexive engagement within horizons of understanding. *Qualitative Health Research, 27*(6), 836-842. https://doi.org/10.1177/1049732316637824

Stafford, G. E. (2017). Maintaining residential normalcy through self-initiated assimilative and accommodative coping while aging-in-place. *Housing and Society, 44*(1-2), 22-40. https://doi.org/10.1080/08882746.2017.1389560

Stark, S., Keglovits, M., Arbesman, M., & Lieberman, D. (2017). Effect of home modification interventions on the participation of community-dwelling adults with health conditions: A systematic review. *American Journal of Occupational Therapy, 71*(2). https://doi.org/10.5014/ajot.2017.018887

Steultjens, E., Dekker, J., Bouter, L., Jellema, S., Bakker, E., & Van den Ende, C. (2004). Occupational therapy for community dwelling elderly people: A systematic review. *Age and Ageing, 33*, 453-460. https://doi.org/10.1093/ageing/afh174

Stones, D., & Gullifer, J. (2016). 'At home it's just so much easier to be yourself': Older adults' perceptions of ageing in place. *Ageing and Society, 36*, 449-481. https://doi.org/10.1017/S0144686X14001214

Sutton, D. (2008). *Recovery as the re-fabrication of everyday life* (Doctoral thesis). Auckland University of Technology, Auckland, New Zealand. Retrieved from https://openrepository.aut.ac.nz/handle/10292/662

Taylor, B., & de Vocht, H. (2011). Interviewing separately or as couples? Considerations of authenticity of method. *Qualitative Health Research, 21*(11), 1576-1587. https://doi.org/10.1177/1049732311415288

Te Aka Māori Dictionary. (n.d.-a). Hapū. In *Te Aka Māori Dictionary*. Retrieved December 11, 2022, from https://maoridictionary.co.nz/search?idiom=&phrase=&proverb=&loan=&histLoanWords=&keywords=hapu

Te Aka Māori Dictionary. (n.d.-b). Iwi. In *Te Aka Māori Dictionary*. Retrieved December 11, 2022, from https://maoridictionary.co.nz/search?idiom=&phrase=&proverb=&loan=&histLoanWords=&keywords=iwi

Te Aka Māori Dictionary. (n.d.-c). Kaumatua. In *Te Aka Māori Dictionary*. Retrieved July 30, 2023 from https://maoridictionary.co.nz/search?idiom=&phrase=&proverb=&loan=&histLoanWords=&keywords=kaumatua

Te Aka Māori Dictionary. (n.d.-d). Kaunihera. In *Te Aka Māori Dictionary*. Retrieved July 30, 2023, from https://maoridictionary.co.nz/search?idiom=&phrase=&proverb=&loan=&histLoanWords=&keywords=kaunihera

Te Aka Māori Dictionary. (n.d.-e). kaupapa Māori. In *Te Aka Māori Dictionary*. Retrieved August, 6, 2023, from https://maoridictionary.co.nz/search?idiom=&phrase=&proverb=&loan=&histLoanWords=&keywords=kaupapa+maori

Te Aka Māori Dictionary. (n.d.-f). Māori In *Te Aka Māori Dictionary*. Retrieved December 11, 2022, from https://maoridictionary.co.nz/search?idiom=&phrase=&proverb=&loan=&histLoanWords=&keywords=maori

Te Aka Māori Dictionary. (n.d.-g). Pākehā. In *Te Aka Māori Dictionary*. Retrieved May 17, 2022, from https://maoridictionary.co.nz/search?idiom=&phrase=&proverb=&loan=&histLoanWords=&keywords=pakeha

Te Aka Māori Dictionary. (n.d.-h). Takawaenga. In *Te Aka Māori Dictionary*. Retrieved March 7, 2022, from https://maoridictionary.co.nz/search?idiom=&phrase=&proverb=&loan=&histLoanWords=&keywords=takawaenga

Te Aka Māori Dictionary. (n.d.-i). Whakawhanaungatanga. In *Te Aka Māori Dictionary*. Retrieved January 15, 2023, from https://maoridictionary.co.nz/search?idiom=&phrase=&proverb=&loan=&histLoanWords=&keywords=whakawhanaungatanga

Te Aka Māori Dictionary. (n.d.-j). Whanau. In *Te Aka Māori Dictionary*. Retrieved November 24, 2021, from https://maoridictionary.co.nz/search?idiom=&phrase=&proverb=&loan=&histLoanWords=&keywords=whanau

Te Aka Māori Dictionary. (n.d.-k). Whanaungatanga. In *Te Aka Māori Dictionary*. Retrieved October 12, 2022, from https://maoridictionary.co.nz/word/10068

The Britannica Dictionary. (n.d.). Nouns ending in -ness. In *Encyclopedia Britannica*. Retrieved April 17, 2022, from https://www.britannica.com/dictionary/eb/qa/Nouns-ending-in-ness

The Open University. (2017). *The body: A phenomenological psychological perspective*. Retrieved April 24, 2021, from

https://www.open.edu/openlearn/ocw/mod/oucontent/view.php?id=4281&printable=1

Thorne, S. (2016). *Interpretive Description : Qualitative Research for Applied Practice*. London, UNITED KINGDOM: Taylor & Francis Group. Retrieved from http://ebookcentral.proquest.com/lib/aut/detail.action?docID=4511832

Todres, L., & Galvin, K. (2010). "Dwelling-mobility": An existential theory of well-being. *International Journal of Qualitative Studies on Health and Well-being, 5*(3), 5444-5449. https://doi.org/10.3402/qhw.v5i3.5444

Todres, L., & Holloway, I. (2010). Phenomenological research. In K. Gerrish & A. Lacey (Eds.), *The research process in nursing* (6 ed., pp. 177-187). Oxford, UK: Wiley-Blackwell.

Toles, M., & Barroso, J. (2014). Qualitative approaches to research. In G. LoBiondo-Wood & J. Haber (Eds.), *Nursing research: Methods and critical appraisal for evidence-based practice* (8 ed., pp. 109-131). St Louis, MO: Mosby, Elsevier.

Townsend, E., Beagan, B., Kumas-Tan, Z., Versnel, J., Iwama, M., Landry, J., . . . Brown, J. (2013). Enabling: Occupational therapy's core competency. In E. Townsend & H. Polatajko (Eds.), *Enabling occupation II: Advancing an occupational therapy vision for health, well-being and justice through occupation* (2 ed., pp. 87-134). Ottawa, Ontario: CAOT Publications ACE.

Townsend, E., & Polatajko, H. (2013). *Enabling occupation II: Advancing an occupational therapy vision for health, well-being and justice through occupation* (2 ed.). Ottawa, Ontario: CAOT Publications ACE.

Tuohy, D., Cooney, A., Dowling, M., Murphy, K., & Sixsmith, J. (2013). An overview of interpretive phenomenology as a research methodology. *Nurse Researcher, 20*(6), 17-20. https://doi.org/10.7748/nr2013.07.20.6.17.e315

Turcotte, P.-L., Larivière, N., Desrosiers, J., Voyer, P., Champoux, N., Carbonneau, H., . . . Levasseur, M. (2015). Participation needs of older adults having disabilities and receiving home care: Met needs mainly concern daily activities, while unmet needs mostly involve social activities. *BMC Geriatrics, 15*(1), 1. https://doi.org/10.1186/s12877-015-0077-1

Unknown. (n.d.). Retrieved May 16, 2022, from https://www.pinterest.nz/pin/631770653965927751/

Valentine, S., McLean, S., & Rahiman, F. (2017). *Strategic workforce services: Occupational therapy workforce assessment*. Wellington, New Zealand: Central Region Technical Advisory Services Limited.

Valenzuela, P. L., Morales, J. S., Pareja-Galeano, H., Izquierdo, M., Emanuele, E., de la Villa, P., & Lucia, A. (2018). Physical strategies to prevent disuse-induced functional decline in the elderly. *Ageing Research Reviews, 47*, 80-88. https://doi.org/10.1016/j.arr.2018.07.003

van Manen, M. (1997). From meaning to method. *Qualitative Health Research, 7*(3), 345-369. https://doi.org/10.1177/104973239700700303

van Manen, M. (2007). Phenomenology of practice. *Phenomenology & Practice, 1*, 11-30. https://doi.org/10.29173/pandpr19803

van Manen, M. (2014). *Phenomenology of practice: Meaning-giving methods in phenomenological research and writing*. New York, NY: Routledge.

van Manen, M. (2016). *Researching lived experience: Human science for an action sensitive pedagogy* (2 ed.). New York, NY: Routledge.

van Manen, M. (2017). Phenomenology in its original sense. *Qualitative Health Research, 27*(6), 810-825. https://doi.org/10.1177/1049732317699381

van Manen, M., Higgins, I., & van der Riet, P. (2018). A conversation with Max van Manen on phenomenology in is original sense. *Nursing and Health Sciences, 18*(1), 4-7. https://doi.org/10.1111/nhs.12274

Verbrugge, L., & Jette, A. (1994). The disablement process. *Social Science & Medicine, 38*(1), 1-14. https://doi.org/10.1016/0277-9536(94)90294-1

Viberg, N., Forsberg, B., Borowitz, M., & Molin, R. (2013). International comparisons of waiting times in health care - Limitations and prospects. *Health Policy, 112*, 53-61. https://doi.org/10.1016/j.healthpol.2013.06.013

Walker, J. (2009). Waiting in line for health care. *Canadian Nurse, 105*(7), 26-30.

Werntoft, E., Hallberg, I., & Edberg, A. (2007). Older people's reasoning about age-related prioritization in health care. *Nursing Ethics, 14*(3), 399-412. https://doi.org/10.1177/0969733007075887

Whalley Hammell, K. (2013). Client-centred occupational therapy in Canada: Refocusing on core values. *Canadian Journal of Occupational Therapy, 80*(3), 141-149. https://doi.org/10.1177/0008417413497906

Wheeler, M. (2020). *Martin Heidegger* (Fall 2020 ed.). Retrieved from https://plato.stanford.edu/archives/fall2020/entries/heidegger/

Whitehead, L. (2004). Enhancing the quality of hermeneutic research: decision trail. *Journal of Advanced Nursing, 45*(5), 512-518. https://doi.org/10.1046/j.1365-2648.2003.02934.x

Wilcock, A. A. (1998). Reflections on doing, being and becoming. *Canadian Journal of Occupational Therapy, 65*(5), 248-256. https://doi.org/10.1177/000841749806500501

Wilcock, A. A., & Hocking, C. (2015). *An occupational perspective of health* (3rd ed.). Thorofare, NJ: Slack.

Withy, K. (2014). Situation and limitation: Making sense of Heidegger on thrownness. *European Journal of Philosophy, 22*(1), 61-81. https://doi.org/10.1111/j.1468-0378.2011.00471.x

Wordhippo. (n.d.). Uneasiness. In *Wordhippo Thesaurus*. Retrieved January 8, 2023, from https://www.wordhippo.com/what-is/another-word-for/uneasiness.html

World Health Organization. (2016). *Global strategy and action plan on ageing and health (2016 - 2020): A framework for coordinated global action by the World Health Organization, member states, and partners across the sustainable development goals*: World Health Organization. https://doi.org/www.who.int/ageing/GSAP-Summary-EN.pdf

Wrathall, M. (2005). *How to read Heidegger*. London: Granta Books.

Wright-St Clair, V. (2008). *'Being aged' in the everyday: Uncovering the meaning through elders' stories* (Doctoral thesis). University of Auckland, Auckland, New Zealand. Retrieved from http://hdl.handle.net/2292/3080

Wright-St Clair, V. (2015). Doing (interpretive) phenomenology. In S. Nayar & M. Stanley (Eds.), *Qualitative research methodologies for occupational science and therapy* (pp. 53-69). New York, NY: Routledge.

Wright-St Clair, V., & Smythe, E. (2012). Being occupied in the everyday. In M. P. Cutchin & V. Dickie (Eds.), *Transactional perspectives on occupation* (pp. 25-37). Retrieved from http://ebookcentral.proquest.com/lib/aut/detail.action?docID=971995

Yin, K., Harms, T., Ho, K., Rapport, F., Vagholkar, S., Laranjo, L., . . . Lau, A. (2018). Patient work from a context and time use perspective: A mixed methods study protocol. *BMJ Open, 8 :e022163*. https://doi.org/10.1136/bmjopen-2018-022163

Yin, K., Jung, J., Coiera, E., Laranjo, L., Blandford, A., Khoja, A., . . . Lau, A. (2020). Patient work and their contexts: Scoping review. *Journal of Medical Internet Research*, *22*(6). https://doi.org/10.2196/16656

Young, J., & Turnock, S. (2001). Community care waiting lists and older people. *BMJ, 322*, 254. https://doi.org/10.1136/bmj.322.7281.254

GLOSSARY

Hapū – sub-tribe

Iwi – tribe

Kaumātua – Māori elder; a person of status

Kaunihera Kaumātua – Council of elders

Māori – indigenous people of Aotearoa New Zealand

Pākehā – New Zealanders of European descent

Taha hinengaro – mental health

Taha tinana – physical health

Taha wairua – spiritual health

Taha whānau – family health

Takawaenga – Māori advisor or support person

Te Aka Whai Ora – Māori Health Authority

Te reo – Māori language

Te Tai Tokerau – Northland

Te Tiriti O Waitangi – Māori text of Treaty of Waitangi

Te Whare Tapa Whā – model for understanding Māori health and well-being

Te Whatu Ora – Health New Zealand

Whakawhanaungatanga – process of establishing relationships

Whakaora ngangahau – occupational therapy

Whānau – extended family

Whanaungatanga – a relationship through shared experience

APPENDICES

APPENDIX A: MINISTRY OF HEALTH FRAMEWORK

Risk Assessment Framework

HIGH RISK	MEDIUM RISK	LOW RISK
Failure to provide the service may result in the Service User:	**Failure to provide the service may result in the Service User:**	**Failure to provide the service may result in the Service User:**
• being admitted as an in-patient for symptom control or as the result of injury • experiencing irreversible and fast deterioration of their health or functional status • no longer being able to safely stay in their own residence (for want of targeted service delivery or appropriate environmental adaptation) • unable to be discharged from an inpatient environment in a timely and appropriate manner.	• being unable to undertake activities of daily living in a safe manner, and there is no help readily available • continuing with compromised functional status which is not life-threatening but if left permanently unmanaged would lead to more extensive and/or additional problems • losing functional skills to a degree that places significant pressure on the family / caregiver which may cause their health status to be compromised • being admitted to short-term care to provide respite for the caregiver while awaiting services.	• living with a limited degree of compromised health status which is not in any way life threatening but intervention would enable them to return to optimal health status or to function as independently as possible.

(Ministry of Health, 2015a)

Response time to referrals

Urgency for initiation of Service provision according to risk level assessed from referral	Allied Health Professional response to assessed risk for provision of the Service
High or excessive level of risk	within 2 working days of receipt of referral, according to assessed need.
Medium risk	within 15 working days of receipt of referral, according to assessed need.
Low risk	within 3 months of receipt of referral according to assessed need.

(Ministry of Health, 2015a)

APPENDIX B: DETAILS OF ARTICLES

Author	Study design	Context	Aim/Purpose	Relevance to the review
Bien et al. (2013)	Cross-sectional questionnaire-based survey	Six European countries (Greece, Italy, Poland, UK, Germany, Sweden) Family carers who provided >4hours of unpaid care to an older relative with high levels of disability, living in the community or in an institutional setting. n = 2629 participants	Examine the range of health and social care services used by older people and their unmet care needs.	Older people use a number of services. In countries where higher number of services are used there are fewer areas of unmet need. Poor service provision affects quality of life and ability to stay at home. Did not discuss the impact of delayed service provision.
Birch and Adams (2008)	Qualitative approach using semi-structured interviews	United Kingdom (England) Carer of person with a disability who had received occupational therapy input. n = 6 participants	Explore the views and experiences of informal carers where occupational therapy had been provided for a family member.	Findings highlighted that services were not available when needed. Identified the need for timely occupational therapy services, which were valued once received.
Biringer et al. (2015)	Hermeneutic Phenomenology	Norway Adults referred to a community mental health center. n = 9 participants	Explore how individuals with mental health problems experience waiting for community mental health treatment.	People found waiting challenging and experienced hardship in their everyday life. Some people developed active coping strategies but this did not alleviate the need for services.
Bishop and Brott (2019)	Report on a quality improvement initiative	New Zealand (Auckland) Community occupational therapy service.	Review the provision of services and establish more effective utilisation of community occupational therapy resources to ensure a sustainable service with better outcomes for clients and well-	Waitlist for community occupational therapy growing year on year. Provides information about factors that can lead to waiting lists and offers ways to reduce these. Focused on improving

Author	Study design	Context	Aim/Purpose	Relevance to the review
			being of occupational therapists.	services rather than adults' experiences of waiting.
Canvin et al. (2018)	'Modified' grounded theory	United Kingdom (Northwest England & North Wales) Older adults living in their own homes. n = 40 participants aged 68 – 95 years	Explore older adults' experience of seeking assistance in later life.	Older people make adaptations to meet their needs to avoid assistance. They do not present to services for minor issues; public services are considered a last resort. As such, services need to be responsive to older adults' needs when they do eventually ask for help.
Carr et al. (2017)	Interpretive Phenomenological Analysis (IPA)	Canada Adults and older adults waiting for scheduled orthopaedic or cardiac surgery. n = 32 participants aged 43 – 89 years	Explore patients' experience of the effect of waiting for surgery.	Waiting is a complex and individual process. Many people were resigned to waiting and accepted that waiting is a reality of the healthcare system. Relates to the experience of waiting for healthcare.
De Coninck et al. (2017)	Systematic review and meta-analysis	Belgium Randomised controlled trials reporting on occupational therapy as intervention or part of a multidisciplinary approach for older adults living in the community. n = 9 studies	Assess the effectiveness of occupational therapy to improve performance in daily activities in community-dwelling physically frail older people.	Strong evidence that community occupational therapy improves functioning in community-dwelling physically frail older people. Older people prefer to remain in their homes. Does not address timeliness of service provision.
Fogarty and Cronin (2008)	Concept Analysis	United Kingdom (Ireland) PubMed and CINAHL databases were searched using	Conduct an analysis of the concept of waiting for health	Waiting for healthcare is an unspecified yet measurable period of time. The

Author	Study design	Context	Aim/Purpose	Relevance to the review
		the keywords 'health care' and 'waiting'.	care from the client's perspective	consequent stress and frustration of waiting may contribute to a worsening of symptoms. Focuses on studies addressing medical/surgical services; allied health services overlooked.
Gallego et al. (2017)	Cross-sectional study using online and paper surveys	Australia (New South Wales) Carers of people with disability accessing allied health services in rural/remote areas. n = 166 participants	Examine issues involved in the delivery of therapy services to people with disability in rural and remote areas in order to develop, implement and evaluate new models of service delivery.	Access to allied health services is limited and this becomes more restricted when people with disability transition into adulthood. Carer's recognised that timely interventions prevented the development of more severe conditions. Relates to the research topic of delayed community occupational therapy for older adults.
Gitlin et al. (2006)	Randomised control trial	United States (Philadelphia) Community- dwelling older adults aged 70 years and older followed for 14 months. Intervention group No-treatment control group. n = 319 participants in total	Evaluate the intervention effect of a multicomponent intervention on mortality and the role of control-oriented strategy use as the change mechanism.	Intervention (occupational and physical therapy) enhances control over daily life and reduces mortality risk in older adults. Even a small change can have a significant impact in supporting function. No discussion regarding timeliness of intervention.
Golant (2015)	Discussion paper	United States This paper focuses on older people who no longer in their residential comfort and/or mastery zones.	To outline a theoretical model that predicts why older occupants of incongruent residential environments cope	When older people are no longer in their residential comfort and/or mastery zones, they initiate coping strategies. However, even the most

Author	Study design	Context	Aim/Purpose	Relevance to the review
			differently with their unmet needs and goals.	successful adaptations may not result in the older person returning to their previous state/level of function. Implies that timely service is beneficial to minimising functional loss and maintaining residential comfort/mastery.
Gramstad et al. (2013)	Hermeneutic phenomenology	Norway Home-dwelling older adults over 67 years assessed by health professional and waiting for assistive technology. n = 9 participants aged 69 – 90 years	Investigate the unmet need experiences of older adults who have applied for assistive technology devices.	Older adults endure their situation by adjusting their expectations and activities. This enabled people to maintain meaningful activities but hid their unmet needs. Intervening at the right time, i.e. when the person acknowledges the need, is important to improve their difficult situation.
Grime (1990)	Discussion paper	United Kingdom (England) Author's workplace – factors influencing decision-making by community occupational therapists.	Exploring the factors that influence decision-making when receiving referrals.	Discussion about how therapists determine referral priority and placement on the waitlist. Demonstrates that waitlists for community occupational therapy services have existed for decades. Waiting for community occupational therapy is a longstanding phenomenon.
Harding, Robertson, et al. (2018)	Qualitative analysis using semi-structured interviews	Australia	Explore managers' perceptions of factors that contribute to wait times.	Demand for community health services (such as community occupational therapy) is high

Author	Study design	Context	Aim/Purpose	Relevance to the review
		Ambulatory and community health services in a large health network. n = 26 managers / team leaders		and likely to grow as care shifts from hospital to community. High demand for services contributes to long wait lists. There are modifiable service factors that contribute to wait times. Relates to the topic of waiting.
Heckhausen and Schulz (1995)	Discussion paper	This paper presents a life-span theory of development based on the concept of primary and secondary control.	To provide a conceptual framework regarding control-related behaviours and apply it to development across the lifespan.	Provides an understanding how older adults respond to challenges in their life in order to improve function and maintain control. Sheds light on how older adults may respond to lost function and why referral made to community occupational therapy services.
Ho et al. (2017)	Secondary analysis of qualitative data. Exploratory interpretive analysis to identify themes	Canada (Toronto) Adults with multi-morbidity accessing community services. n = 116 adults	Understand the needs and experiences of patients with complex chronic diseases accessing care in the community, and how they deal with these challenges.	Patients experience considerable difficulty navigating the health system to access care. Each service has its own entry criteria and waiting list. No discussion about accessing community occupational therapy services.
Kolehmainen et al. (2010)	Retrospective survey of discharged cases	United Kingdom (Scotland) Community occupational therapy services for children. n = 26 therapists working in children's therapy services n = 154 cases reviewed	Explore the extent to which therapists' caseload management behaviours affects children's length of time on caseloads.	Illustrates high service demand and subsequent wait times for paediatric occupational therapy services. Waitlists for occupational therapy are not unique to adult services.

Author	Study design	Context	Aim/Purpose	Relevance to the review
Levasseur and Couture (2015)	Cross-sectional design	Canada (Quebec) French-speaking older adults living in the community with ageing limitations or health problems. n = 82 participants aged 65 years and older	Examine the association between coping strategies used to deal with ageing limitations and participation and quality of life.	Older adults draw on various coping strategies when facing limitations. Some coping strategies are associated with lower participation and quality of life. The longer the wait for occupational therapy, the longer older adults have to rely on their own coping skills; possibly to their detriment.
McGill et al. (2020)	Qualitative analysis of written documents	Australia Stakeholders who submitted written documents to an Australian Government Senate Inquiry. n = 133 documents	Explore in greater depth the long waiting lists for speech-language pathology.	This research identifies the negative consequences of waiting, which has far-reaching effects. Waiting was more frequently raised as an issue for children in comparison to adults. Waitlists are not confined to occupational therapy services.
Passalent et al. (2009)	Quantitative approach – self-administered questionnaire	Canada (Ontario) Publicly funded sites across Ontario (urban/rural) that deliver outpatient or community occupational therapy and physiotherapy services. n = 214 sites	Examine wait lists and wait times for publicly funded outpatient and community occupational therapy and physiotherapy services.	Demand for service exceeds supply. People waiting for occupational therapy experience longer wait times for community occupational therapy services compared to outpatient occupational therapy services. No guidelines to define acceptable wait times.

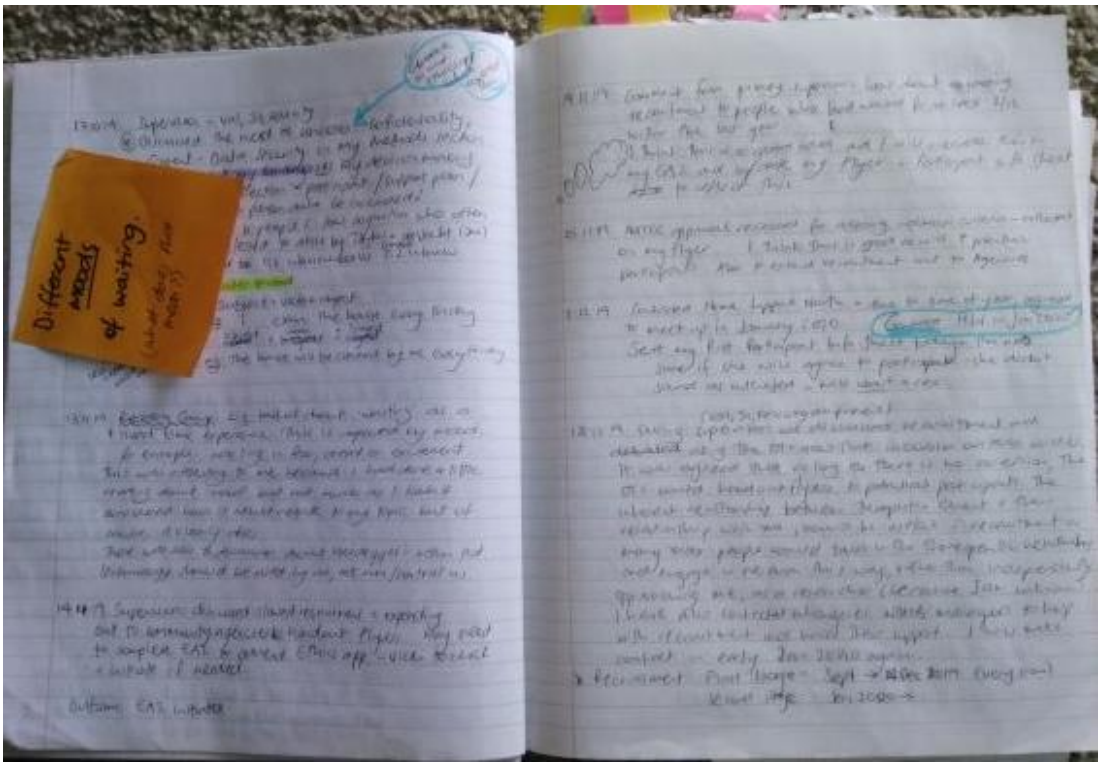
Author	Study design	Context	Aim/Purpose	Relevance to the review
Raymond et al. (2013)	Quantitative approach – survey.	Canada (Quebec) Home care programmes across all Health and Social Services Centres in the province. n = 55 participants; those who manage the waitlist	Identify prioritisation criteria in home-based occupational therapy services.	Low priority clients may wait many months or years. Confirms the existence of wait lists for community occupational therapy services. Focused on waitlist management rather than the experience of those waiting.
Raymond et al. (2016)	Cross-sectional study	Canada (Quebec) Home care programmes across all Health and Social Services Centres in the province. n = 55 participants; those who manage the waitlist	Describe waiting list management practices targeting low-priority referrals.	Low priority clients may never get seen if no management strategies are in place. Focused on waitlist management rather than the experience of those waiting.
Raymond et al. (2020)	Qualitative approach using in-depth interviews	Canada (Montreal) Participants were asked to prioritise referral scenarios. n = 11 occupational therapists working in homecare n = 10 older adults n = 9 adults with disabilities	Explore views of occupational therapists, older adults and adults with disabilities on waiting list priorities.	Each group placed a different value on what was important, which affected how they would prioritise a referral. Understanding what is important to older adults provides useful background to the topic of waiting for occupational therapy.
Rechel et al. (2016)	Quantitative approach – questionnaire-base survey	European Observatory on Health Systems and Policies n = 11 high-income countries	Provide a comparative analysis of public sector approaches towards the collection and publication of provider performance data.	Most common information made available to public is on waiting times for hospital treatment, particularly elective procedures. No data collected about community services.

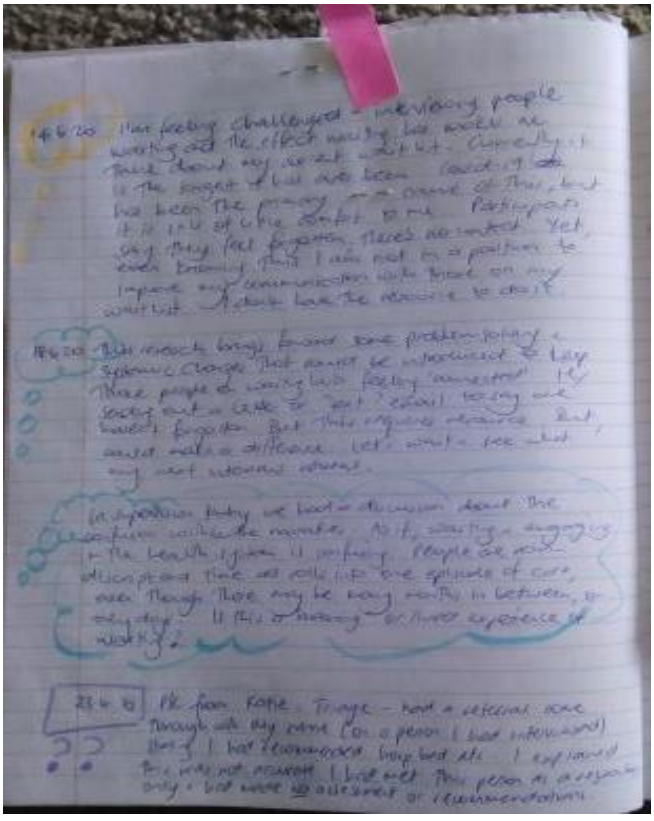
Author	Study design	Context	Aim/Purpose	Relevance to the review
Rittenmeyer et al. (2012)	Qualitative systematic review	Studies that focused on qualitative data were included in the review. These studies captured the experience of waiting for healthcare as experienced by patients, family members and/or significant others of any age. n = 39 studies	Systematically examine scientific literature in order to identify the phenomenon of waiting in healthcare.	The experience of waiting is a fearful and turbulent experience. The studies reviewed were based on people waiting for diagnostic, medical and surgical services. No studies were included that focused on community nor allied health services nor specific to older adults.
Sheffield et al. (2013)	Randomised control trial	United States Community-dwelling older adults aged 65 years and older. The intervention group received immediate intervention following evaluation and the control group received an initial evaluation but intervention was delayed for 3 months. n = 31 (intervention group) n = 29 (control group)	Evaluate a restorative occupational therapy intervention relative to 'usual care'.	Sample size was too small to determine the impact of delayed therapy. This would be helpful in determining how long older adults could safely wait for therapy. The occupational therapy intervention provided resulted in a 39% reduction in recommended personal care.
Stafford (2017)	Grounded-theory	United States (Iowa, Minnesota, New Jersey, Rhode Island) Older adults living alone in their family home. n = 10	Develop a deeper understanding of the phenomenon of ageing-in-place from the perspective of the oldest-old.	Older adults initiate coping strategies in response to declining abilities. The most frequent type of adaptation involves the use of assistive devices or technology. Waitlist delays occupational therapy intervention and subsequent provision of these devices.

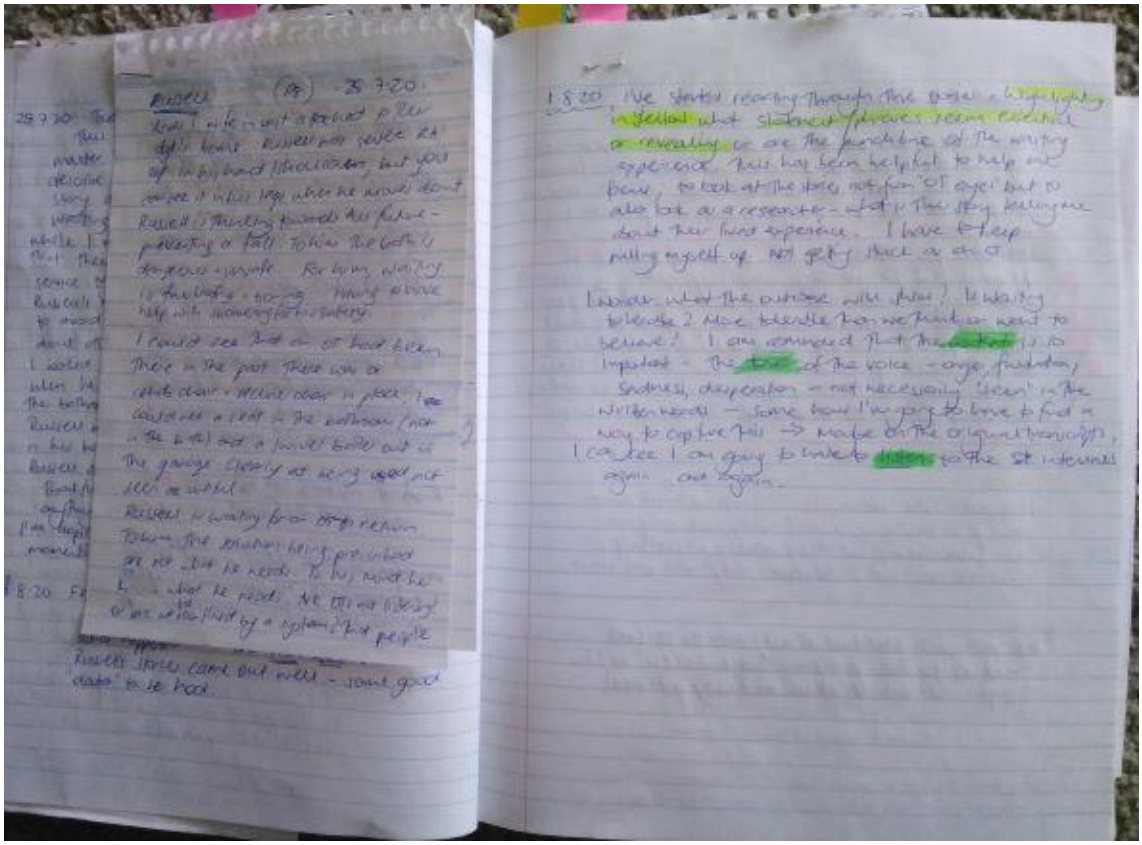
Author	Study design	Context	Aim/Purpose	Relevance to the review
Stark et al. (2017)	Systematic review	United States Studies included studied community-dwelling people aged 18 years and older with health conditions affecting performance of daily activities and intervention included home modifications. n = 36 studies	Investigate the role of home modification interventions to improve participation outcomes for community-living adults and older adults.	Strong evidence was found for home modification to improve function and reduce risk of falls. Data suggests that occupational therapists are more effective than other health professionals in delivering these interventions. Hence people being referred to occupational therapy.
Verbrugge and Jette (1994)	Discussion paper	This paper presents a socio-medical model of disability called The Disablement Process.	Present a conceptual scheme for disability that has broad utility in social science, medicine and public health.	Authors compare the disablement experiences of people who acquire chronic conditions early in life and those who acquire these conditions in later life. Older adults expend energy to restore their capabilities.
Viberg et al. (2013)	Unclear	Sweden Information was collected through scientific articles, documents and web pages. n = 23 OECD countries	Describe how countries measure waiting times and to assess whether waiting times can be compared internationally.	Significant difference in how waiting times are measured. The main focus of data collection is on elective surgery. Data for community services are not reported on.
Walker (2009)	Phenomenology	Canada People who have endured long waits for medical care. n = 50	Examine the experiences of those who are unable to access care.	When people are unable to access timely care they endure significant pain, anxiety and suffering. This study provides information about the experience of waiting for medical care. Allied health services are not included.

Author	Study design	Context	Aim/Purpose	Relevance to the review
Werntoft et al. (2007)	Qualitative approach using interviews	Sweden Healthy adults and adults receiving continuous care and services in the public sector. n = 446 participants aged 60 years and older	Describe the reasoning of older people about prioritisation of health care with regard to age and willingness to pay.	Older people would be willing to pay for health care if in a financial position to do so. Polarised perspectives regarding prioritisation of healthcare. People have different values and expectations. Provides an insight into how older people rationalise waiting for health care.
Young and Turnock (2001)	Editorial	United Kingdom		Community care has low public visibility and the waitlists remain invisible to those who allocate resources.

APPENDIX C: JOURNAL ENTRIES



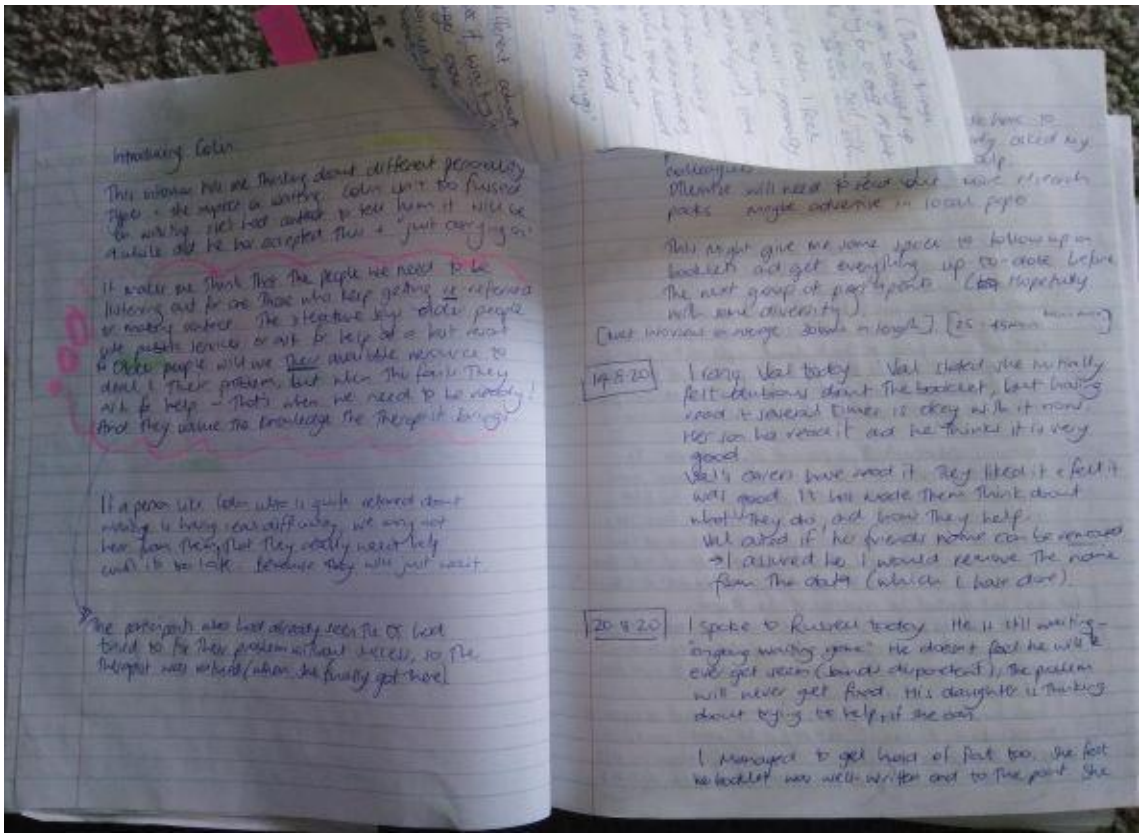




Russell (RS) 25.7.20.

1.8.20 I've started reading through these & highlighting in yellow what statements/phrases seem essential or revealing or are the punchline of the writing experience. This has been helpful to help me focus, to look at the data not for 'OT ego' but to also look at it as research - what is this story telling me about their lived experience. I have to keep pulling myself up. Not going back as an OT.

I wonder what the outcome will show? Is writing bibliotherapy? More bibliotherapy than we thought or want to believe? I am reminded that the voice is so important - the tone of the voice - anger, frustration, sadness, desperation - not necessarily 'seen' in the written words - some how I've got to have to find a way to capture this → maybe on the original transcripts. I can see I am going to have to listen to the SI interviews again - and again.



Introducing Colin

This woman has me thinking about different personality types - she wrote a warning Colin isn't to Russell to writing. Not had contact to you him it will be a while as he has accepted this + "just carry on".

It makes me think that the people we need to be listening out for are those who keep getting re-referred or making contact. The creative key data people or making contact. The creative key data people use public services or ask for help a lot but most other people will use their available resources to deal with their problems but when they finally ask for help - that's when we need to be ready! And they value the knowledge the therapist brings.

If a person like Colin who is quite informed about mental ill health, can't access support, how can those people who are more vulnerable access support? Especially if they are not ready to be ready?

The participants also had already seen the OT but failed to fix their problem without success, so the therapist was valuable when she finally got involved.

collaborate.
Ultimately will need to have this more in-depth parts maybe extensive in local paper.

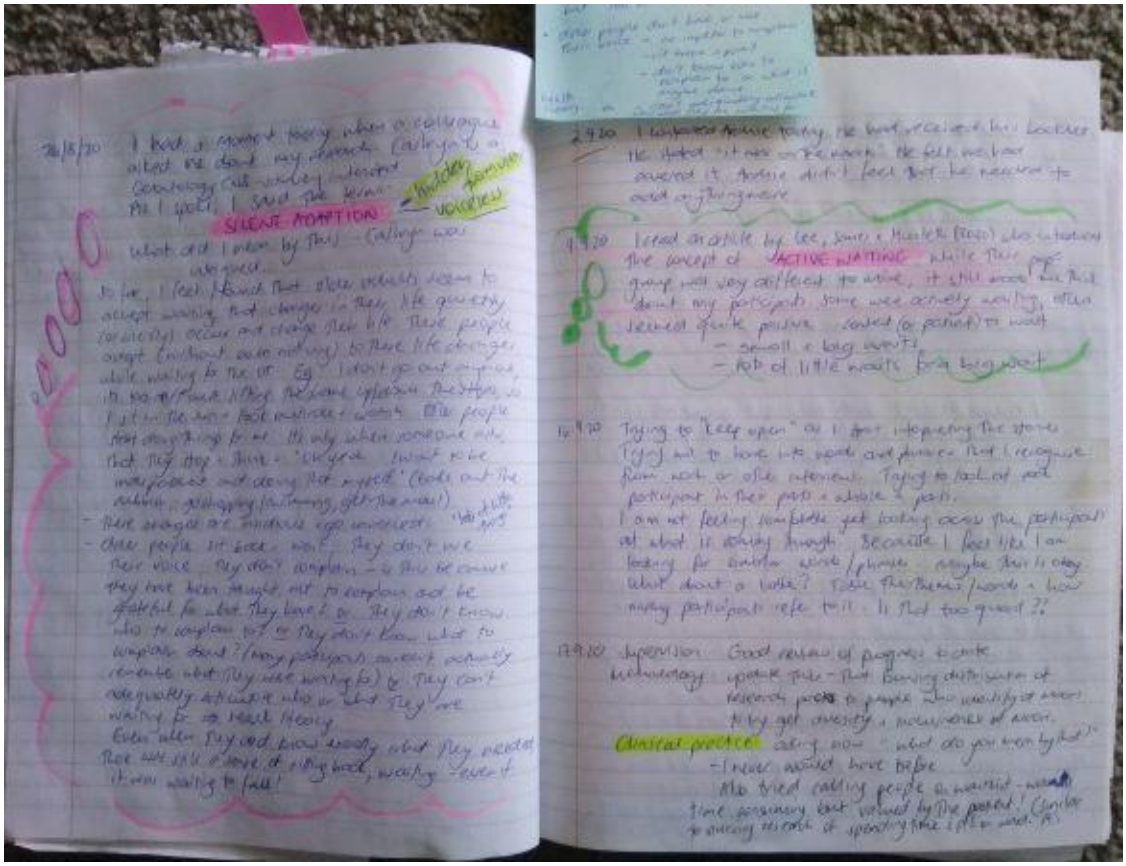
This might give me some space to follow up on booklets and get everything up to date before the next group of participants. Hopefully with some diversity.

[Next interview on average 30 mins in length] [25 - 45 mins]

14.8.20 I rang Neil today. Neil thinks we've really felt ambivalent about the booklet, but having read it several times is okay with it now. Her son has read it and he thinks it is very good.
Neil's carers have read it. They liked it & felt it was good. It has made them think about what they do, and how they help.
We asked if he friends name can be removed → I assured he I would remove the name from the data (which I have done).

20.8.20 I spoke to Russell today. He is still waiting - "ongoing waiting game". He doesn't feel he will be ever get seen (sounds disportant). The problem will never get fixed. His daughter is thinking about trying to help put the cost.

I managed to get hold of Neil too. She felt the booklet was well written and to the point. She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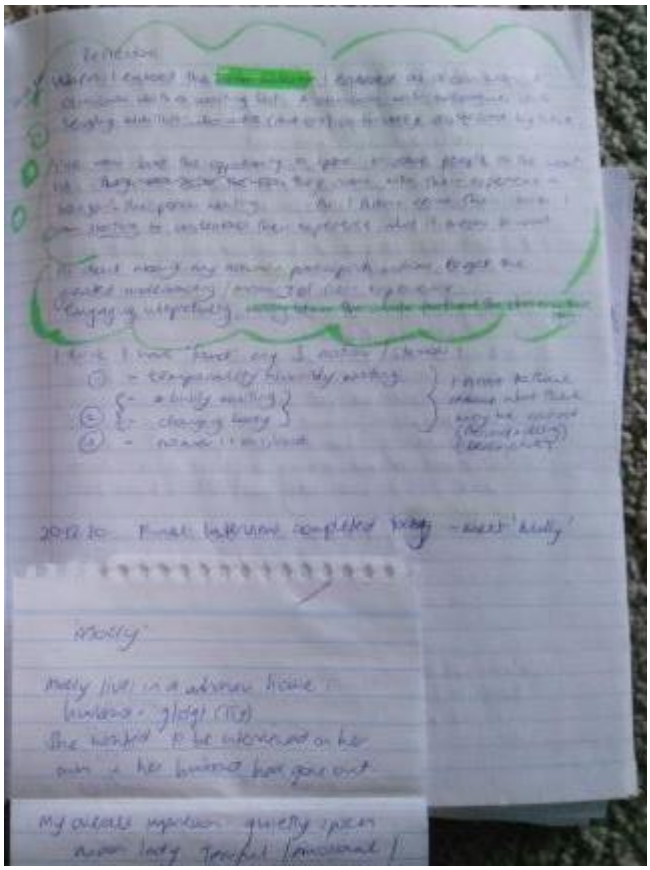

APPENDIX D: RECRUITMENT TOOLS

Recruitment flyer

AUT
TE WĀNANGA ARONUI O TĀMAKI MAKAU RAU

Are you **waiting** for an occupational therapist to visit you at home?

If you:

- ✓ are age 65 years and older; or 50 years and older and are Māori;
- ✓ are able to speak conversational English and talk about recent events and feelings;
- ✓ live in the region covered by Northland DHB services;
- ✓ have been referred to the community occupational therapy service for assessment;
- ✓ have been on the waiting list more than 3 months

then I would be interested in talking with you about your experience of waiting for the community occupational therapist to visit you.

My name is Vicki Fryer.
I am a researcher from AUT, completing my Doctorate degree

Please call (or text) or email me with your name and a contact number so that I can call you back. I will be happy to answer any questions you may have

You can contact me directly on: 021 0296 7361

Or if you prefer, you can email me: vicrub97@autuni.ac.nz

Expression of Interest & Eligibility Form

- ○ Yes, I would like to be contacted about participating in the research project: *'The experience of waiting for community occupational therapy services'*

- ○ Yes, I give the researcher permission to view the referral made to the occupational therapy service to check eligibility to participate in this study (i.e.: when the referral was made and the priority of the referral).

Name: _____

Contact phone number: _____

Alternative contact number: _____

Postal address: _____

Best contact time
- ☐ 8am - 12pm
- ☐ 12pm - 4pm
- ☐ 4pm - 6pm
- ☐ 6pm - 8pm

Please post this back to me in the envelope provided or phone me

I will then contact you in a few days to discuss and confirm your eligibility.

You are also welcome to contact me directly on 021 029 67361 or via email at vicrub97@autuni.ac.nz

Signature: _____

Approved by the Auckland University of Technology Ethics Committee on 13.08.2019
AUTEC Reference number 19/215

Participant Information Sheet

Date Information Sheet Produced:

22 June 2019

Project Title

Experiences of older people waiting for community occupational therapy

An Invitation

My name is Vicki Fryer. I am completing my doctorate degree at AUT.

I am interested in hearing about how waiting for the community occupational therapist has impacted on your daily life.

It is important for you to know that whether you choose to participate or not, this will neither advantage nor disadvantage you or your place on the waiting list, or your healthcare.

What is the purpose of this research?

Northland's population is significantly older than the national average. And as people age, an increased proportion will experience disabilities, which can restrict participation in daily and social activities, and effect quality of life, home safety and increase the risk of falls.

Occupational therapists have the skills to support older people to remain living in their home, and prevent hospitalisation and premature entry into residential care. Yet lengthy waiting lists restrict access to community occupational therapy services. Occupational therapists are concerned about the people waiting for assessment.

The aim of this research is to uncover what it means to wait. Find out the common themes and concerns, and the effect *waiting* has on being able to remain living in your home.

This may then help occupational therapists to better understand, and help to develop better ways of managing waiting lists.

The findings of this research may be used for academic publications and presentations.

How was I identified and why am I being invited to participate in this research?

You were handed a flyer about this research, and have since spoken to me, the researcher.

You have received this information sheet as you meet the inclusion criteria for my study.

The inclusion criteria are: age 65 years and older, or 50 years and older for Māori (to account for population longevity differences); able to speak conversational English; able to engage in a conversation about recent events and feelings; live within the region covered by Northland DHB services; have been referred to the community occupational therapy service for assessment; have been on the waiting list for community occupational therapy assessment for a minimum of 3 months; and, have been prioritised as high or medium risk on the referral.

*If you live in the Kaitaia/Far North region, you will not be able to be included. This is to avoid any potential conflict of interest, as I live and work in the Far North.

How do I agree to participate in this research?

Please complete the attached Consent Form and return it me in the envelope provided. By signing the form you are agreeing to be part of my study.

Your participation in this research is voluntary (it is your choice) and whether or not you choose to participate will neither advantage nor disadvantage you. You are able to withdraw from the study at any time. If you choose to withdraw from the study, then you will be offered the choice between having any data that is identifiable as belonging to you removed or allowing it to continue to be used. However, once the findings have been produced, removal of your data may not be possible.

What will happen in this research?

I will contact you by phone to arrange to meet with you. You are welcome to invite and have a support person with you.

I am happy to meet you at your home, or a location of your choice.

I will be asking you some questions about waiting for the occupational therapy service. This conversation will take about an hour. It will be recorded and then transcribed (typed).

I will then arrange to either come back to visit you to check through your transcript, to make sure it is correct; or send your transcript in the mail for you to read through, and then talk to you over the phone, to ensure it is correct.

What are the discomforts and risks?

You may experience some discomfort or distress recalling your experiences but you will not be put at risk in any way during the study.

How will these discomforts and risks be alleviated?

I will be asking you questions about your experiences.

You can decline to answer any questions that make you feel uncomfortable.

Your choice to have a support person present may assist you to feel comfortable during the interview.

What are the benefits?

Participation in the study provides an opportunity for you to share your experiences and the impact waiting has had on your life.

It will give me a better understanding about what waiting means to you, and these understandings can then be shared with occupational therapists and their managers.

Your participation will help me to achieve my qualification.

How will my privacy be protected?

To protect your privacy/confidentiality, you will have the choice to select a name that will be used, so that you cannot be identified.

What are the costs of participating in this research?

There are no direct costs, only your time, between 1-2 hours.

What opportunity do I have to consider this invitation?

If you are interested in taking part, then please return the consent form within 4 weeks.

Will I receive feedback on the results of this research?

Yes, a summary of the findings will be sent to you, if you tick the box on the consent form.

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 Valerie Wright-St Clair

valerie.wright-stclair@aut.ac.nz

09 921 9999 ext7736

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:	***Project Supervisor Contact Details:***
Vicki Fryer	Professor Valerie Wright-St Clair
vicrub97@autuni.ac.nz	valerie.wright-stclair@aut.ac.nz
02102967361	09 921 9999 ext 7736

Approved by the Auckland University of Technology Ethics Committee on 13.08.2019
AUTEC Reference number *19/215*

Consent form

Consent Form

Project title: ***Experiences of older people waiting for community occupational therapy***

Project Supervisor: ***Prof Valerie Wright-St Clair***

Researcher: ***Vicki Fryer***

- ○ I have read and understood the information provided about this research project in the Information Sheet dated 22 June 2019.
- ○ I have had an opportunity to ask questions and to have them answered.
- ○ I understand that notes may 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 (my choice) and that I may withdraw from the study at any time without being disadvantaged in any way.
- ○ I understand that if I withdraw from the study then I will be offered the choice between having any data that is identifiable as belonging to me removed or allowing it to continue to be used. However, once the findings have been produced, removal of my data may not be possible.
- ○ I agree to take part in this research.
- ○ I wish to have a support person with me during my interview: Yes○ No○
- ○ I wish to receive a summary of the research findings (please tick one): Yes○ No○
  If yes, please be sure to include your postal address below

Participant's signature: .....

Participant's name: .....

Participant's Contact Details (if appropriate):

.....

.....

.....

.....

Date:

Approved by the Auckland University of Technology Ethics Committee on 13.08.2019
AUTEC Reference number 19/215

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

Letter of introduction – Whangārei

13 March 2020

Dear Sir / Madam,

You are receiving this letter as you are currently on the waiting list for the community occupational therapy service to assess your needs. DHB approval has been obtained to send this letter of introduction.

I would like to introduce Vicki Fryer. She is an occupational therapist working in the Northland DHB with over 20 years of clinical experience.

She is currently completing her Doctorate through AUT, exploring the ***"Experience of waiting for community occupational therapy services".***
The purpose of her research is to gain an in-depth understanding of the impact waiting may be having on you at home.
The result of the study will inform the DHB of the significance of waiting, and may also aid with how we prioritise referrals.

There are no direct costs involved, only your time, between 1-2 hours. Your participation will involve an interview with her at your home or venue of your choice.

If you are interested and would like to talk about your experience of waiting, Vicki would be happy to hear from you.

You can contact her directly on:

021 0296 7361 - please leave a message with your name and phone number; this is checked each evening.

Or, you can email her at vicrub97@autuni.ac.nz

Or, you can complete and return the enclosed consent form. **Please provide your phone number** on the consent form so that she can contact you.

An information sheet, consent form and return envelope are attached.

Yours sincerely,

Sandie Kirkman
Manager of Whangarei Community Occupational Therapy Services.

Letter of introduction – Mid-north region

13 May 2020

Dear Sir / Madam,

You are receiving this letter as you are currently on the waiting list for the community occupational therapy service to assess your needs. DHB approval has been obtained to send this letter of introduction.

I would like to introduce Vicki Fryer. She is an occupational therapist working in the Northland DHB with over 20 years of clinical experience.

She is currently completing her Doctorate through AUT, exploring the ***"Experience of waiting for community occupational therapy services".***
The purpose of her research is to gain an in-depth understanding of the impact waiting may be having on you at home.
The result of the study will inform the DHB of the significance of waiting, and may also aid with how we prioritise referrals.

There are no direct costs involved, only your time, between 1-2 hours. Your participation will involve an interview with her at your home or venue of your choice.

If you are interested and would like to talk about your experience of waiting, Vicki would be happy to hear from you.

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Or, you can email her at vicrub97@autuni.ac.nz

Or, you can complete and return the enclosed consent form. **Please provide your phone number** on the consent form so that she can contact you.

An information sheet, consent form and return envelope are attached.

Yours sincerely,

Jen Thomas
Operational Manager
Kawakawa Hospital

APPENDIX E: DESCRIPTION OF RECRUITMENT PROCESS

Stage One (September – November 2019). My initial recruitment occurred within the mid-North region through three routes. First, I liaised with the Operational Manager of Kawakawa Hospital to gain her support and obtain her permission to liaise with DHB staff who had regular contact with older people in the community to assist with recruitment. I spoke with the district nurses, gerontology clinical nurse specialist and physiotherapist. Secondly, I met with the community health nurses based in the Hokianga who have close working relationships within their local communities and are well aware of who could be waiting for community occupational therapy. Thirdly, I contacted the Primary Health Enterprise (PHE) to discuss my research and enquire if they could send out my flyer and expression of interest form to all GP clinics in the mid-North region. This meant I could reach potential participants throughout the region who were visiting their GP but were not known to existing DHB community services. The PHE sent out the information flyer and eligibility forms to all GP practices to display. People interested in being part of the study could complete the form and return it to their community health professional to return to me, or could contact me directly by email or cellphone. If I was contacted directly by someone who had seen the information flyer, I had planned to check eligibility during the initial phone call.

Outcome from Stage One recruitment. I received three returned Interest and eligibility forms. Two people did not meet the eligibility criteria, and the third person chose not to participate.

Recruitment slowed and there was no further interest. I reviewed my inclusion criteria with my supervisors and amended them to also include those older people who had previously waited three months or more for a community occupational therapist within the past year. It was agreed that a person who had previously experienced the phenomenon of waiting would still be able to recall and recount their experience. An amendment was sent through to AUTEC on 22/11/19 and approval received on 25/11/19.

Stage Two (January – April 2020). I expanded my recruitment area to also include Whangārei. The amendment to my inclusion criteria enabled me to ask my occupational therapy colleagues to assist with recruitment, as many of their existing clients had previously been on the waiting list. I explained my inclusion criteria, assured them my

focus was purely on their client's experience of the wait and not about their practice and emphasised that the client/potential participant should not be coerced into participating.

I also met with local NGOs and community support providers. They showed an interest in my research and agreed to assist with recruitment by handing out my flyer and expression of interest form to those older adults under their care whom they knew were waiting for the community occupational therapist.

As recruitment continued to be slow, I contacted the Northland DHB ethics chairman (CMO) on the 27/02/20 to discuss an alternate recruitment stage. I proposed sending out a letter of introduction on DHB letterhead directly to those older people on the waiting list introducing me as a researcher and inviting them to contact me directly. He supported this and I completed a draft letter which he approved. Before contacting the occupational therapy service manager in Whangārei, approval from AUTEC was required.

AUTEC reviewed my application to amend recruitment and approved my application on the 19/03/20, with the condition that as the researcher, I did not have access to the existing referral system and that a third party sent out the letter of introduction. My letter of introduction was altered to reflect these conditions. Fifty 'Letter of Introduction packs'[35] were prepared and sent to the Service Manager in Whangārei to be addressed and sent out to potential participants.

Outcome from Stage Two recruitment. One participant was recruited in February 2020. Recruitment was interrupted on the week beginning 23rd March 2020 due to the Covid-19 pandemic and all ethics approvals were suspended until 14th May 2020 when AUTEC advised that data collection (i.e. participant interviews) could resume. Three more participants were subsequently recruited.

Stage Three (May – October 2020). Due to the impact of Covid-19, I submitted an amendment to AUTEC to expand my data collection method, that was, to offer participants the opportunity to complete their interview in-person, by phone or online. My preference was in-person interviews, but in light of the pandemic and resultant anxiety and uncertainty in the community, and vulnerability of my participants, I felt it

[35] This included: Letter of introduction, participant information sheet, consent form, pre-paid return addressed envelope

important that they have a choice. My Participant Information Sheet and Consent form were updated to reflect these changes. I received approval from AUTEC on 22/05/20.

I gained permission from the Operation Manager at Kawakawa hospital to send out my 'Letter of Introduction packs' in the mid-North region, and twenty packs were mailed out.

Recruitment slowed in July 2020. I re-focused on recruitment again in September 2020 and twenty more 'Letter of Introduction packs' were made up and sent out in the Whangārei region. I also requested, that at least sixteen of these packs were sent to older people who identified as Māori. Additionally, I spoke with the Communications Manager at Northland DHB, who posted information about my research onto the DHB social media site with an invitation to those older people who were waiting, or who had previously waited for community occupational therapy services, to contact me.

Outcome from Stage Three recruitment. Ten people responded to my recruitment strategy, and nine met the eligibility criteria for the study. One person agreed to be interviewed but was not home at the agreed time; she could not be contacted after this time.

APPENDIX F: INDICATIVE INTERVIEW QUESTIONS

Introduction: Good morning/afternoon/kia ora…

Thank you for agreeing to meet with me to be part of this study.

- Complete Consent forms [eligibility/participant/support person]; provide a copy
- TURN ON RECORDERs x2 then check consent so it is recorded

I am interested in your experience of waiting for the occupational therapist/ OT service. Advise that if they feel uncomfortable at any time they can decline to answer or ask for the recorder to be turned off. I may take some notes during the interview to remind me if I need to come back to anything.

Warm up: Tell me about your day so far. Is that how your days usually go?
Questions:

Tell me about receiving the letter saying that you are on a wait list.

What happened then?
What did you think at the time?
How did it feel? Tell me more about that…

Tell me about a good day waiting for you.

You mentioned …., tell me more about…., then what?

Tell me about a not so good day waiting.

What happened when…? And then?

What have you noticed about your day(s) since being on the waitlist?

Tell me more about….
Why do you think that is?

Tell me, what are the things/activities that you maybe do differently since you have been on the waiting list?

Can you share an example with me? Tell me more…

Tell me about the last time you attempted to (*use example from above question*)

Have you ever had a moment where you thought 'I just can't wait for this service (anymore)'?

Tell me about the situation/what happened?
What did you think at the time? How were you feeling?
Reflecting on what the participant has said:
What do you mean …? Tell me more about… Why do you think that is?

What does waiting mean to you?

What, if anything, is different about waiting in queue, such as at the shops/bank, compared to waiting for the occupational therapist?

Concluding:

Would you like to add anything else about your experience of waiting?

I really appreciate your time that you have given to me today.

- Select a pseudonym
- Give koha

Returning a copy of your story – I can post it to you and then give you a call about a week later to check in with you and ensure it is okay.

APPENDIX G: EXAMPLE OF A BOOKLET

We would do whatever it takes

LUCKIE'S EXPERIENCE OF WAITING

March 2020

CONTENTS

MY CROOK SHOULDER

I've got a crook left shoulder, but we made ourselves an apparatus on the bed before I got the bed that I've got now from the therapist. You don't know how long the waiting list is going to be. It got to the stage I just couldn't get out of bed easily and that's why my son made me a frame so I could get out of bed. I could grab on to this hook and on to that one, and pull myself up out of bed. No doubt about it, the bed that I've got in there now is streets ahead of what I had, because I haven't got the same pain in my shoulder, but I've still got it. But pulling on it didn't help it.

In the past I could get up out of bed and go and do what I had to do, just like that. I was a mechanical serviceman. It became quite difficult, because for example I might have a job in Dargaville, and I'd be fine when I left here but it would be a struggle to do my job when I got to Dargaville. I'd do my job and come home again. If I needed, I would sit down or lie down, that's what I did.

I changed from being a fit man to one that wasn't fit. I wasn't very happy and I'm still not very happy today 'cause I think, I wish I could go outside and do this and do that but you can't. I just got no get up and go. I'm an outside man, I wasn't an inside man. But I got used to it because I can't go out, even though I'd like to.

THE NEVER-ENDING WAIT

Waiting for the bed

Waiting for the bed felt never ending. It was a struggle getting out of bed at times. I think there were days when I didn't get up. I know I've become very lazy but I'm just helpless. I preferred to stay in bed, it's easier to lie in bed. Which is ridiculous for me as I used to get up with the sparrows and didn't go to bed till they went to bed either. I could go to Kaitaia, I could go to Dargaville, I could go down South. It was not an effort, but then things became an effort. Even getting out of bed in the morning was a real struggle. Waiting for the bed or waiting for what the next move was never ending. There's no doubt about it, the long wait didn't do much good. Waiting is frustrating, it's not easily done, you think oh yeah well they've gone away and forgotten about me. You've got to be patient. I know that you know you can't just say "I'd like this and I'd like that". But now the bed that's up there is excellent, absolutely excellent, it's paradise. I am I glad that I can sleep well too.

Good days

I have good days, I could wake up and in the morning and I feel real good about it. On another day I wake up and I feel really yuk. A good day was when I could swing myself around out of bed and get up and come down to breakfast. Other times that was a struggle too. I am still housebound. We get the odd good day where it's not too hot and 'mum' [wife] will say "get out" or we'll go up the road in the car. My wife was trying to help me. It was a bit tough on me, but it was tougher on the wife. You don't realise what goes on till it happens.

DID THEY FORGET?

Unfortunately the waiting is never ending; it's as if they've forgotten [about me]. That's what you think. It [the referral] sounded good but it's not happening. You think they've forgotten about you but the good lady hadn't forgotten about me, she was marvellous. You think something's changing. You think of the good side of it and when I got that bed or chair that I've got up there now well heavens above, when she rang me up after, and said "how do you like that?", it was the best thing since sliced bread.

Waiting in the bank is a bit annoying but you can see that person has done their transaction and moved out of your way so you're one step further forward all the time, one step further forward which is great. But when you're waiting for somebody like (the therapist) you don't know whether they're coming or whether they've gone away and forgotten about you. Or even thrown the paper [referral] in the wastepaper basket and forgotten about you. It is not their fault. The wheels have got to get turning where they've got to be.

SITTING AROUND WAITING

Sitting around waiting. It was such a long time [in between the referral and assessment]. During that time I haven't been getting any better, have I? I've been getting worse I reckon. But you know I had a good son that's very capable. If we haven't got it, we make it. We've got a son that's hands on, just like myself, I was a hands on too. We've got the gear and he made a very good frame that went in under the side of the bed. I could grab hold of this handle and that other one and stand up. But you can't beat the bed that's up there at the moment either.

THANK YOU

Thank You for your time and interest in my research.

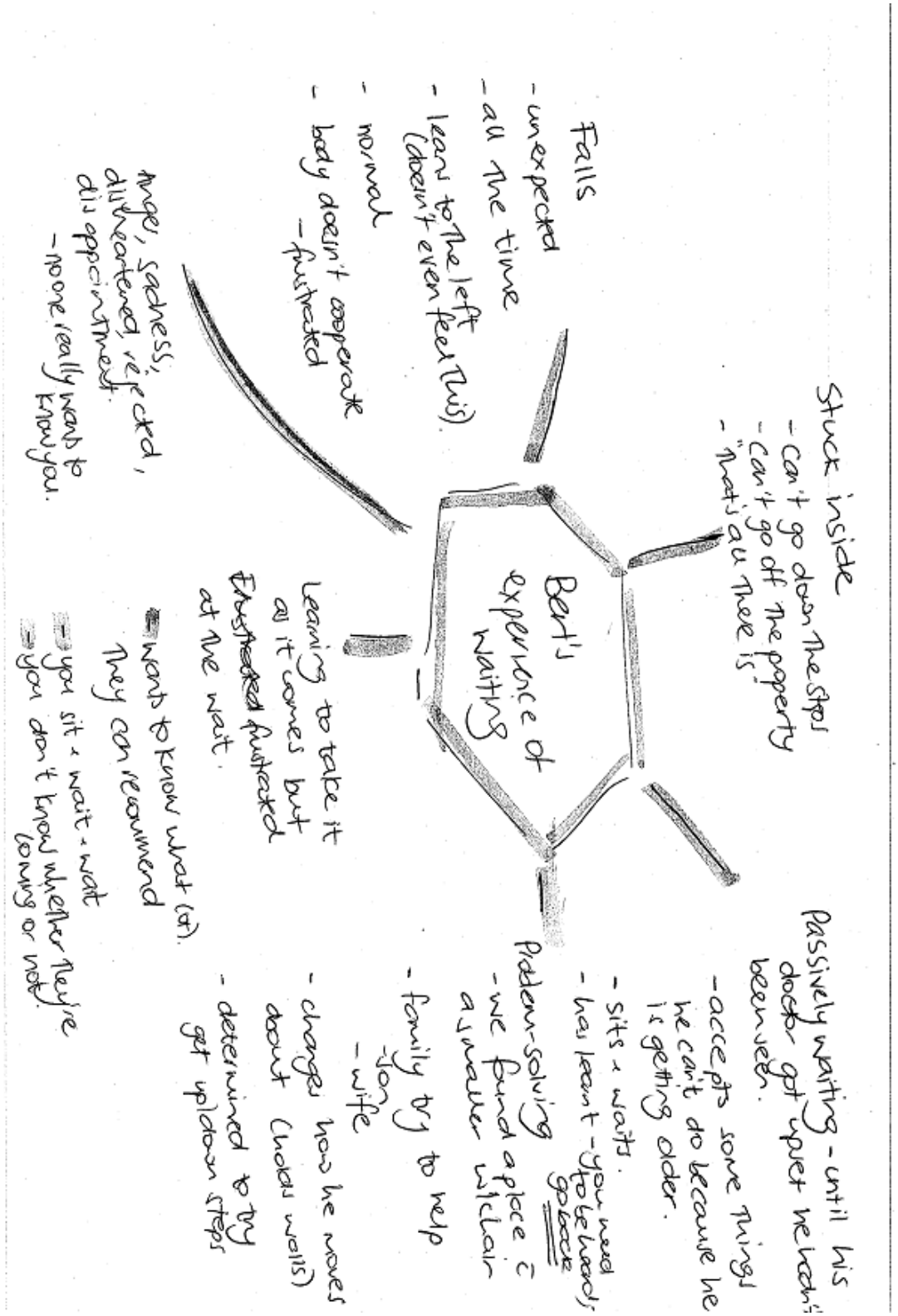
You can contact me at

- Postal: Po Box 256, Kaitaia
- Phone: 021 029 67361
- Email: vicrub97@autuni.ac.nz

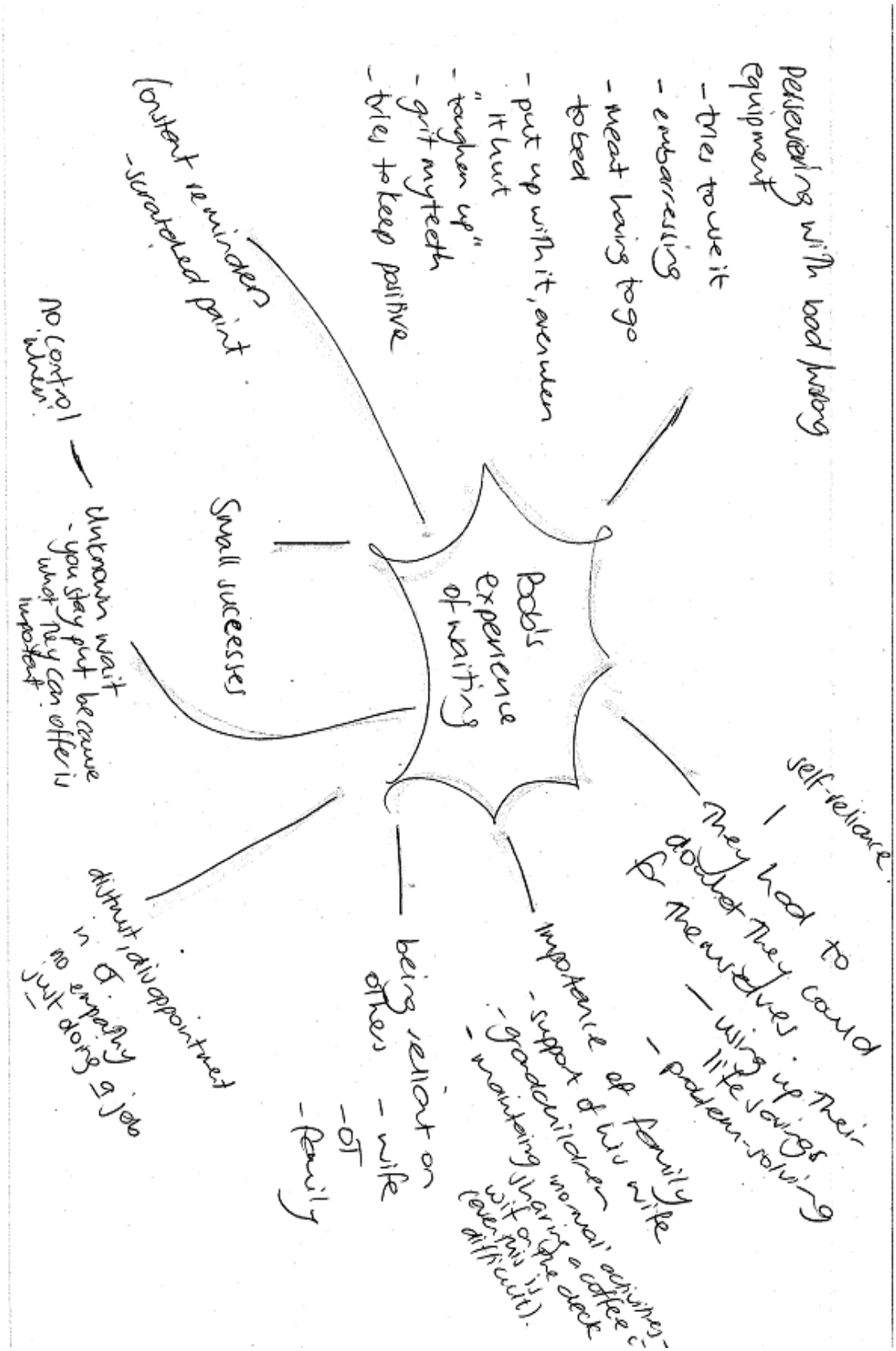
Vicki Fryer

APPENDIX H: INTERPRETING THE STORIES

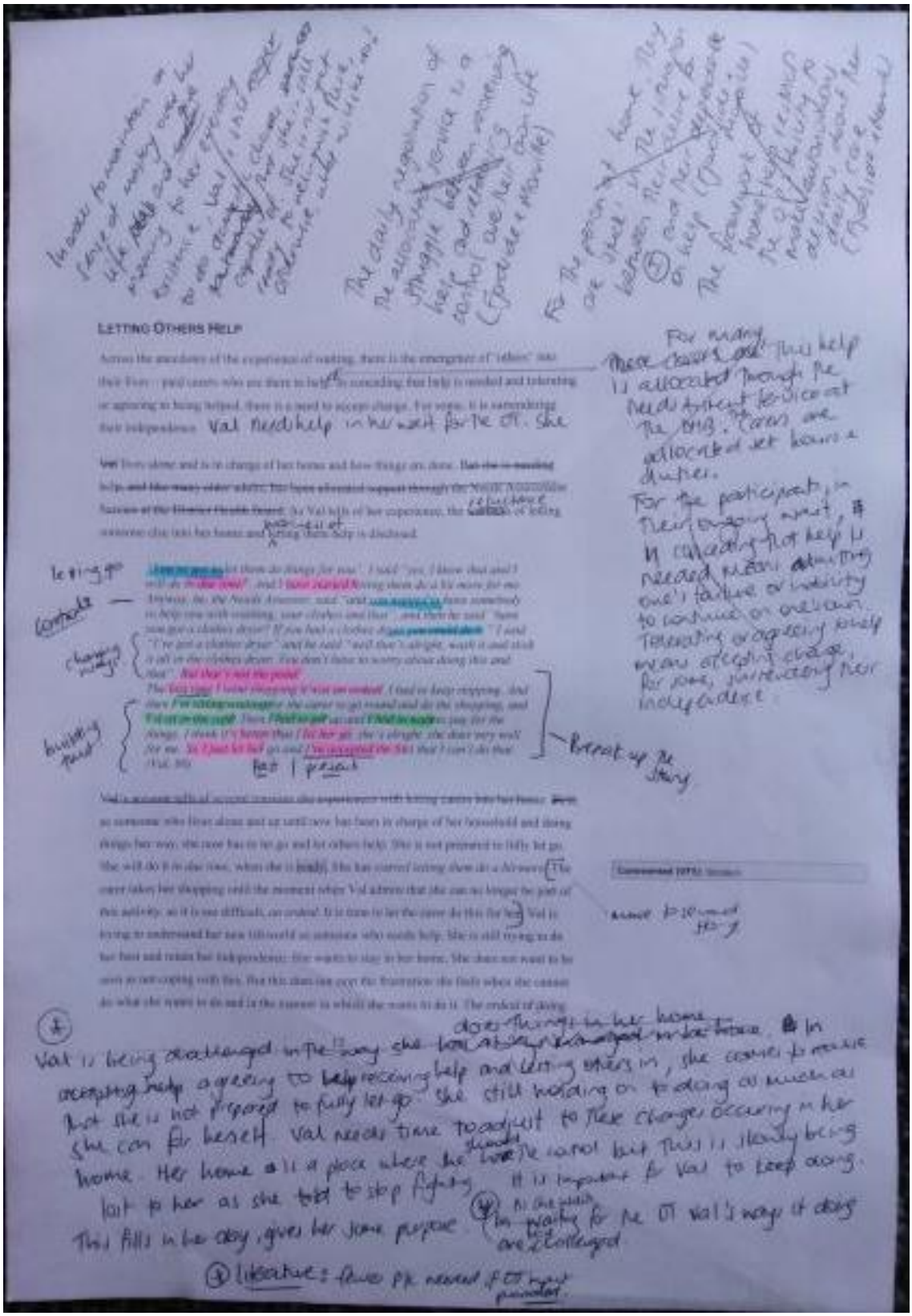
Mind-map: Bert



Mind-map: Bob


Persevering with bad history
equipment
- tries to use it
- embarrassing
- meant having to go to bed
- put up with it, even when it hurt
- "toughen up"
- grit my teeth
- tries to keep positive
Bob's experience of waiting
Small successes
(constant reminder
-structured point
No control when
Unknown wait
- you stay put because what they can offer is important
distrust, disappointment
lack of empathy
no empathy in just doing a job
self-reliance
- they had to could
- they could not rely on themselves
- using up their life savings
- problem-solving
Importance of family
- support of his wife
- grandchildren
- maintaining stigma with the clock
(except in difficult).
being reliant on others
- wife
- OT
- family

An example of interpreting a story



APPENDIX I: SUMMARY OF FINDINGS BOOKLET

The meaning of waiting: A summary of the findings

February 2022

CONTENTS

THE FINDINGS

There were three key findings that emerged from the stories shared by you and the 11 other participants.

I have called these findings:

Thrown into Waiting

Waiting as Being with

Waiting as Dwelling

Although they are written separately, they are very much interconnected. I will now go on to explain these.

The Participants[1] – those who took part in my study

The waiting is never ending; it's as if they've forgotten me (Luckie)

We had to walk around it, this bundle of wood that was meant to be a lift for my armchair. (Maurice)

I'm pissed off. I'd like them to be able to see me earlier. Because this is dragged out for over 6 months now and we're still waiting. (Bert)

There's always some hope that there'll be a knock at the door, but I've sort of given up lately and I'm just puttering on in my own little way. (Bruce)

I like to be independent. I'd rather do it myself. (Betty)

They take a long time to come. You could die and they wouldn't even know. (Bob)

One day I sat at the door and I looked at the sunshine, but I couldn't get down the steps. (Val)

When, when, when are they going to fix it? If I do go down and have a fall, I'll probably end up a lot worse off than I am now. (Russell)

Just keep on keeping on. (Archie)

If people don't complain about the system, it doesn't get improved (Roger)

You don't sort of go asking for these things if it's not needed. (Maryanne)

I'm bored just waiting. And I don't want to do anything but just wait. I've got that appointment coming to me. (Molly)

[1] Names used are pseudonyms chosen by each participant

THROWN INTO WAITING

'Thrown into Waiting' explored what it means to be waiting for the occupational therapist to make contact. Waiting is a familiar phenomenon and much of the waiting we do is *for* something to happen. 'Thrown into Waiting' revealed what matters most: to be able to do the things that matter.

Waiting exposed the struggle of an indefinite and unknown wait. When waiting, things are not easy, they take effort, and help is needed now. However, people were being told there is no choice but to wait. Waiting also showed how older people can struggle to understand the system, who they are waiting for, and why they have to wait. Some stories alluded to waiting being unfair, that as an older person you were made to feel less important and that younger people were prioritised.

'Thrown into Waiting' also showed the various moods that people experienced. These were often not talked about in the interviews, but hidden in the words of the stories. Moods such as fear, despair, dread, and aloneness were revealed. But also hope. Hope of being seen in time and of being helped. To being able to return to doing things in order to be at home.

Invisibleness of Waiting

From the moment the waitlist letter is received, the person waiting is invisible to the occupational therapist, and also invisible from the occupational therapist. People described sitting and waiting for the phone call that signaled the end of the wait. The way that people's lives changed goes unseen as they waited in an invisible queue.

Although people are all used to queueing, queueing for the occupational therapist is different. Unlike the physical experience of queueing there is no visible line, or others standing there too, and no one at the front that can be seen and who can help. This line cannot be seen or felt. There is no knowing of one's place in the queue waiting for the occupational therapist. There is no knowing of how fast or slow the queue is moving. This invisibility gives rise to uncertainty of ever being helped; not knowing what lies ahead increases the angst of waiting.

The struggle to carry on has gone unseen. In the invisibleness many people felt discarded and helpless, their faith in the system tested as time passed by. In many ways, people were hanging on to doing the things they have always done, trying to find new ways to wait. There were some people who didn't worry about waiting as they knew their turn would come. There was one person who had forgotten they were waiting at all, it had been so long. However, one thing in common in all these stories was that people's worlds shrunk while they waited. Valued activities and occupations faded away as people focused on remaining at home.

Time

Time was felt differently in the wait. Time slowed down, stretched out, was lost, and was interrupted. Waiting, for some people, was thinking about their past and what they used to be able to do, and thinking about a future of retuning to doing these things again.

In waiting, people lived see-sawing between the hope that the occupational therapist would arrive in time, and the dread that they wouldn't.

WAITING AS BEING WITH

Waiting involved others. Waiting brought some people together, a shared journey, but for some lead to the loss of relationships, which made it a lonely journey. The ability to maintain one's independence was highly valued, but challenged as the need for assistance increased. Asking for help was often a last option for older adults, and because of the lengthy wait, participants came to rely on others, not always by their own choice.

Being with as Being Cared For

Being in the unfamiliar position of needing help with the ordinary everyday activities that one has always been able to do placed most people in the situation of needing help from others.

The significant role of family or whānau was revealed as they were there to provide care and support. Family provided hands-on support and assistance and some family members were able to build things that were helpful. As the family were there showing their care, this also highlighted how life had changed and what was now lost.

The role of paid carers was also highlighted. Most people grappled with holding onto their independence and simultaneously needing help. Letting others in meant having to do things differently. 'Home' was no longer a space of freedom and choice, but instead a place of losing one's autonomy. Help was accepted reluctantly by some. However, some people willingly accepted the help as it enabled them to keep on at home. Even for those who were reluctant to accept help, the solicitude (or care) shown by others provided the necessary support to remain at home.

Being with as Not Mattering

As the wait went on, people experienced ‘care’ as unresponsive from the healthcare system and lacking concern or interest in them. “You don’t ask for help unless it is needed” stated one person, so why must we wait? Waiting is unseen and unheard, and many had the sense that no one cared. While this mostly pointed at the occupational therapist, for some, their family or whānau where unable or did not want to help. In the seemingly unending wait, even when asking for help, no one seemed to care.

WAITING AS DWELLING

Dwelling is not only the way we live in our home but also the way in which we experience the world. Almost everyone told of the changes to their body, which came from ageing or the onset of health conditions. In waiting, the changing body no longer felt or behaved like '*my body*', disrupting how people engaged with and experienced their world.

As the body changed, the ability to do things at home also changed. Not only did 'my body' feel different, but so too did home. For some, home no longer felt like home. It no longer offered comfort, freedom and safety but rather came to be felt as unhomely and unfamiliar.

Possibility

The situation participants found themselves in shaped the choices that were made. For many, not giving up was important, but in trying to keep on, there was a sense of weariness as things became an effort. This effort was confronting as the ordinary everyday routines became more difficult, and the unfamiliar feeling of running out of energy was revealed. Although left unsaid, the possibility of not being able to continue at home was always there, lingering.

Action

Some people made changes to their home and their furniture, and some made changes to the way that they did things. Being called to action showed how some people tried to find their own solutions as they waited. It also showed how simple pleasures (such as simply stepping into the shower and feeling the water on the skin) were lost in the wait. Being called to action showed that even the ordinary taken-for-granted things that are usually no problem can suddenly become too much, which revealed the weariness in waiting for the occupational therapist.

Others

We live in a social world, with others. Social interaction and participating in daily life can be influenced by other people and by things. Waiting revealed how not having the right equipment could lead to being disconnected from others and therefore lead to an unfamiliar feeling of being alone. In waiting, as the focus turns to getting the things or equipment that are needed, it showed how one's social world can be easily overlooked.

Occupation Lacking

Human beings are always doing something. Being busy helped to bring a sense of familiarity and a structure to the day, although doing the same thing each day was not satisfying. Whereas for others, waiting resulted in a feeling of boredom as valued occupations faded away and there was nothing left to do.

'Doing' both hid and revealed waiting. Occupations and routines were sustaining and enabled some people to carry on whilst waiting, consequently hiding the wait, as they looked to be doing okay. For others, occupations lost their meaning or faded away, thus revealing the seemingly unending wait.

THANK YOU

I would like to take this opportunity to **'Thank You'** once again for your time and contribution towards my research. Without you and your willingness to share your experience of waiting for the occupational therapist, this research could not have been possible.

I would love to hear your thoughts and comments, and so I have enclosed a pre-paid envelope for you.

With my deepest thanks,

Vicki Fryer

APPENDIX J: ETHICS APPROVAL

Northland District Health Board

Locality Assessment No. 2019-24

Locality Assessment Sign Off

All research conducted in the Northland DHB must be conducted with the knowledge of the Northland DHB, and must meet all the requirements of the Health & Disability Ethics Committees (HDECs), though not all research will require HDEC review.

A locality assessment must be undertaken to review all research conducted at Northland District Health Board. Locality Assessments will consider resource implications, suitability of the local researcher and research environment, and cultural issues.

Part One: General

Full project title: (Working Title as this may change)	The meaning of waiting: the lived experience of older people waiting for community occupational therapy
Short project title:	The meaning of waiting: the lived experience of older people waiting for community occupational therapy
Locality to be assessed:	Northland
Brief outline of study:	Older people are known to be high users of health care services (Schofield, Davey, Keeling, & Parsons, 2006) and, as people age, an increased proportion will experience disabilities, which can restrict participation in daily and social activities, and effect quality of life, home safety and increase the risk of falls. Occupational therapists have the skills to support rehabilitation, recovery and restoration of function, and prevent hospitalisation or premature entry into residential care. Yet lengthy waiting lists restrict access to community occupational therapy services. Research question: What is the lived experience of older people waiting for community occupational therapy? Methodology: Hermeneutic phenomenology will be used to explore the phenomenon of waiting. The aim of hermeneutic phenomenology is to reveal the meaning of everyday human experiences (Horrigan-Kelly, Millar, & Dowling, 2016) which are usually hidden and difficult to describe (van Manen, 2016). This research will be guided by the philosophies of Heidegger and Gadamer. Participant recruitment: Northland District Health Board clinicians, community health nurses and GP clinics will be invited to assist with recruitment. A one-page flyer will be provided to the clinicians to hand out to older people on their caseloads who are known to be waiting for community occupational therapy assessment. Up to 16 participants who meet the inclusion criteria will be purposively selected to be interviewed. Data gathering: As understanding is revealed through dialogue and the telling of stories, data gathering will occur through semi-structured interviews to draw out examples and descriptions of the experiences. Participants will have the option of inviting their significant other (for example a spouse, child, carer) to be a support person at the interviews. Data analysis: These stories will be analysed using the methods described by Caelli (2001) to draw out the narratives from the

	transcript, and van Manen (2016) to conduct thematic analysis. The aim of analysis is to identify the commonalities and differences, concerns and meanings of waiting, and the significance of these for older people. Anticipated outcome: This study may help to guide best-practice for waitlist management by helping therapists recognise important cues when triaging referrals, and direct limited resources where needed, at the right time.
Principal investigator (for this locality):	Vicki Fryer
Contact details:	Vicki.fryer@northlanddhb.org.nz

Part Two: Locality Issues

Identify any local issues and specify how these issues will be addressed.

1.	**Suitability of local researcher** For example, are all roles for the investigator(s) at the local site appropriate (ie, has any conflict the investigator might have between her or his local roles in research and in patient care been adequately resolved)?	☑ Yes	☐ No
2.	**Suitability of the local research environment**		
	a) Are all the resources (other than funding that is conditional on ethical approval) and/or facilities that the study requires appropriate and available (for example, is staffing adequate? Is this site accessible for mobility-impaired people where necessary)?	☑ Yes	☐ No
	b) Have all potentially affected managers of resources such as clinical records or laboratory managers been notified?	☑ Yes	☐ No
3.	**Have issues such as cultural issues specific to this locality or to people being recruited at this locality been addressed?**	☑ Yes	☐ No
4.	**Have the local investigator contact details and other important contact details been provided to the locality organisation for checking?**	☑ Yes	☐ No
5.	**Has the local investigator been advised of the unacceptability of using personal hand-held devices to photograph identifiable patient information?**	☑ Yes	☐ No

Part Three: Declaration by locality organisation

I am authorised to complete locality approval on behalf of this locality organisation. I understand that I may withdraw locality approval if any significant local concerns arise. I agree to advise the principal investigator and then the relevant ethics committee should this occur.

I confirm the organisation has sufficient indemnity insurance to compensate participants for harm that does not qualify for compensation under the Injury Prevention, Rehabilitation and Compensation Act 2001.

Signature:	M. Roberts	Date:	28/2/19.
Name:	Dr Michael Roberts	Position:	Chief Medical Officer
Contact details:	Northland District Health Board, Private Bag 9742, Whangarei 0148		

NORTHLAND DISTRICT HEALTH BOARD
Te Poari Hauora Ā Rohe O Te Tai Tokerau

23 July 2019

To Whom it May Concern

Re: – The meaning of waiting: the lived experience of older people waiting for community occupational therapy, 2019-24

This letter is to confirm the Kaunihera Kaumatua have expressed approval through the Locality Assessment process for the above study.

This study was approved on 23 July 2019 under Reference No.2019-24.

Yours faithfully

Te Ihi Tito
Kaunihera Kaumatua

34287
Phone: (09) 430 4101 - Fax: (09) 470 0001 - DHB Office, Tohorā House, Hospital Road, Private Bag 9742, Whangarei 0148, New Zealand
www.northlanddhb.org.nz

Auckland University of Technology Ethics Committee

Auckland University of Technology Ethics Committee (AUTEC)
Auckland University of Technology
D-88, Private Bag 92006, Auckland 1142, NZ
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www.aut.ac.nz/researchethics

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E: ethics@aut.ac.nz
www.aut.ac.nz/researchethics

13 August 2019

Valerie Wright-St Clair
Faculty of Health and Environmental Sciences

Dear Valerie

Re Ethics Application: **19/215 The meaning of waiting: Experiences of older people waiting for community occupational therapy**

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 13 August 2022.

Standard Conditions of Approval

1. The research is to be undertaken in accordance with the Auckland University of Technology Code of Conduct for Research and as approved by AUTEC in this application.
2. A progress report is due annually on the anniversary of the approval date, using the EA2 form.
3. A final report is due at the expiration of the approval period, or, upon completion of project, using the EA3 form.
4. Any amendments to the project must be approved by AUTEC prior to being implemented. Amendments can be requested using the EA2 form.
5. Any serious or unexpected adverse events must be reported to AUTEC Secretariat as a matter of priority.
6. 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.
7. 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.

AUTEC grants ethical approval only. You are responsible for obtaining management approval for access for your research from any institution or organisation at which your research is being conducted. When the research is undertaken outside New Zealand, you need to meet all ethical, legal, and locality obligations or requirements for those jurisdictions.

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

For any enquiries please contact ethics@aut.ac.nz. The forms mentioned above are available online through http://www.aut.ac.nz/research/researchethics

Yours sincerely,

Kate O'Connor
Executive Manager
Auckland University of Technology Ethics Committee

Cc: dismalbog@gmail.com; vicki.fryer@northlanddhb.org.nz; felicity.bright@aut.ac.nz

APPENDIX K: CONFIDENTIALITY AGREEMENT

Confidentiality Agreement

Project title: *The Meaning of Waiting: Experiences of older people waiting for community occupational therapy*

Project Supervisor: ***Prof Valerie Wright-St Clair***

Researcher: ***Vicki Fryer***

- ○ I understand that all the material I will be asked to transcribe is confidential.
- ○ I understand that the contents of the tapes or recordings can only be discussed with the researchers.
- ○ I will not keep any copies of the transcripts nor allow third parties access to them.

Transcriber's signature: .....

Transcriber's name: .....

Transcriber's Contact Details (if appropriate):

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Date:

Project Supervisor's Contact Details (if appropriate):

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Approved by the Auckland University of Technology Ethics Committee on 13.08.2019
AUTEC Reference number 19/215

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