Stories From a Hazardscape:

Living with chronic illness in Petone,

Aotearoa New Zealand

A thesis presented in partial fulfilment of the requirements for the degree of

Master of Science

with an endorsement in Health Psychology

at Massey University, Wellington

Aotearoa New Zealand

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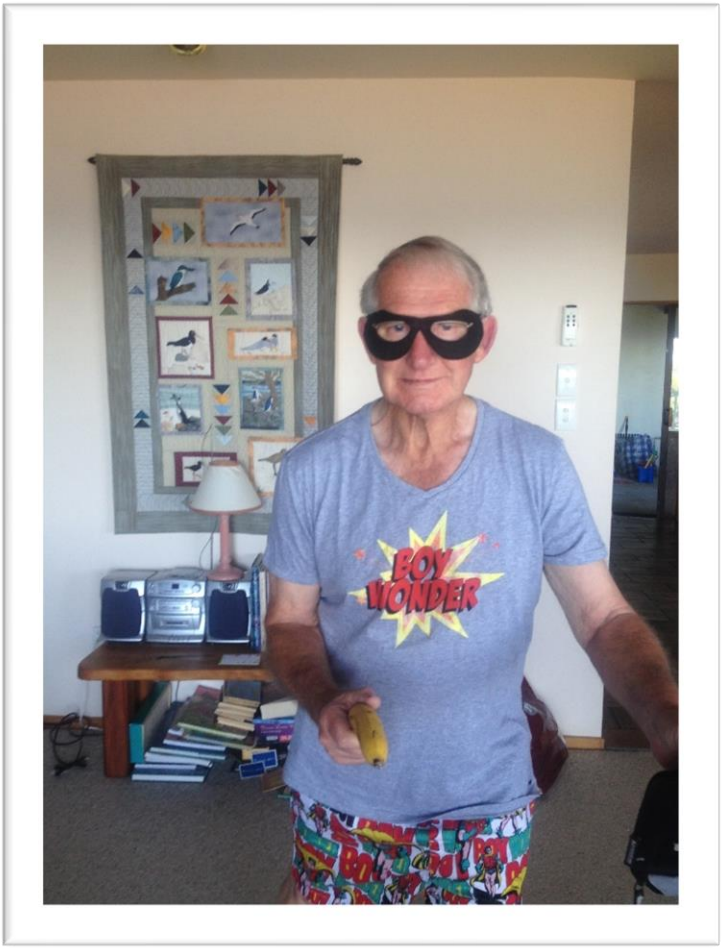
2022

Dedication

My Dad died during this process and it is to him that I also dedicate this thesis. My Dad was simply the best man that I ever knew. For those who were fortunate enough to know him, he embodied the good kiwi bloke who was always first to lend a hand and last to leave when the work was done. He loved his family more than anything and I hope we loved him back as much as he wanted and needed. Dad was not just the long list of chronic illnesses that took his life. He was Peter Robert Kearns, and we will love him always.

Peter Robert Kearns



Abstract

Natural hazards such as earthquakes, flooding, and landslides can disrupt routine medical treatment for people living with chronic illness including heart disease, diabetes, asthma, and renal failure, causing people's conditions to deteriorate (Miller & Arquilla, 2008). Studies of past events have shown that the chronically ill as a group face the greatest risk of adverse health outcomes from a natural hazard and require the most medical treatment after an event compared with other groups (Tomio & Sato, 2014). However, for a range of reasons, emergency management plans provide little or no specific planning for people with chronic illnesses, focussing instead on the needs of people critically injured by a natural hazard (Miller & Arquilla, 2008). In the event of a disaster, the lack of focussed planning for the chronically ill has resulted in people becoming acutely ill or dying because of lack of medication and other essential medical treatment (Tomio & Sato, 2014). This study set out to improve understanding of people's experience of living with a chronic illness in Petone, a hazard prone environment, and how this may matter to their ongoing health and wellbeing.

The narratives of eight people with a range of chronic illnesses and who had lived in Petone were analysed and interpreted through applying a critical narrative methodology as well as a Foucauldian lens to their stories. Semi-structured face-to-face narrative interviews were conducted, enabling people to share their stories of life in Petone with a chronic illness. Analysis of the eight people's stories was guided by the Narrative Orientated Inquiry model. The premise behind this model is that narratives function as a meaning making process that occur within social, psychological, and cultural contexts (Hiles, Cermák, & Chrz, 2009; E. G. Mishler, 1995; Riessman, 2008). The model incorporates this concept of narrative into each stage making it possible to carry out a deeper analysis of the contents of stories and exposing

the functioning of storytelling (e.g. social processes), which is important to how people structure and organise behaviour and experience (Hiles, Čermák, & Chrz, 2017).

With little research exploring the lived experience of people with chronic illness living in hazard prone areas, this narrative-based study benefits the health and emergency management sector by providing insight into the specific needs of the chronically ill. It also demonstrates the significance of the experience of the chronically ill with managing their illness generally, and suggests that this experience might be a valuable knowledge resource for emergency management planning.

Acknowledgments

Unexpectedly, creating this thesis has meant a great deal of trauma processing as it triggered past traumatic events in my life. While this has been most inconvenient, I have managed to come out the other side stronger and with a completed thesis. This is thanks to the following people (in no particular order):

Gavan, the other man in my life, has been everything a person doing a thesis could want and need. Without him there would be no thesis. Thank you for always being there to prop me up, sit with me, and celebrate. I am very grateful for you.

Mum has had a lot to deal with during this process but she never forgot to make sure I was OK. She is my Wonder Woman as she always stands up for what she believes, no matter the cost and always with respect and kindness.

Denise, your guidance and support have meant a great deal. I wish the journey had not been so rough and I am grateful that despite that you remained by my side. You are an inspiration, thank you.

Kendra, you have been there for me each week and thanks to you I was able start again and carry on through to the end. You provided me with reassurance and positivity when I needed it the most, as well as a good old chat. You helped me always and I am so grateful.

Karen, thank you for always helping me to shift focus and gain clarity when the frontal lobes had flipped.

Jane, Amigo, Cody, and Cameron, thank you for accepting me as part of the herd.

Thank you, QuakeCoRE for the scholarship and patience.

Thank you, tellers, sharing your stories has been a great privilege.

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Chapter One: Introduction

Figure 1 *People at Petone beach, Lower Hutt (Smith, 1924)*

This thesis aims to better understand how living in an area prone to natural hazard events might impact on people's health, by delving into the narratives of eight chronically ill people who have lived in Petone, Lower Hutt, Aotearoa New Zealand. Narratives are how people make sense of themselves, others, and the world (Sarbin, 1986). Using a narrative based analysis of the eight people's stories provides understanding of how they make sense out of conditions such as chronic illness and hazard events, and how these shape their lives (Lyons & Chamberlain, 2006; Stephens, 2011). It is hoped that exploration of these people's stories of life in Petone with chronic illness will provide knowledge about what it means to have a chronic illness within a disaster context. This focus is important because there is

limited research in this area, which can restrict the emergency management sector's ability to address the preparedness and recovery needs for this group.

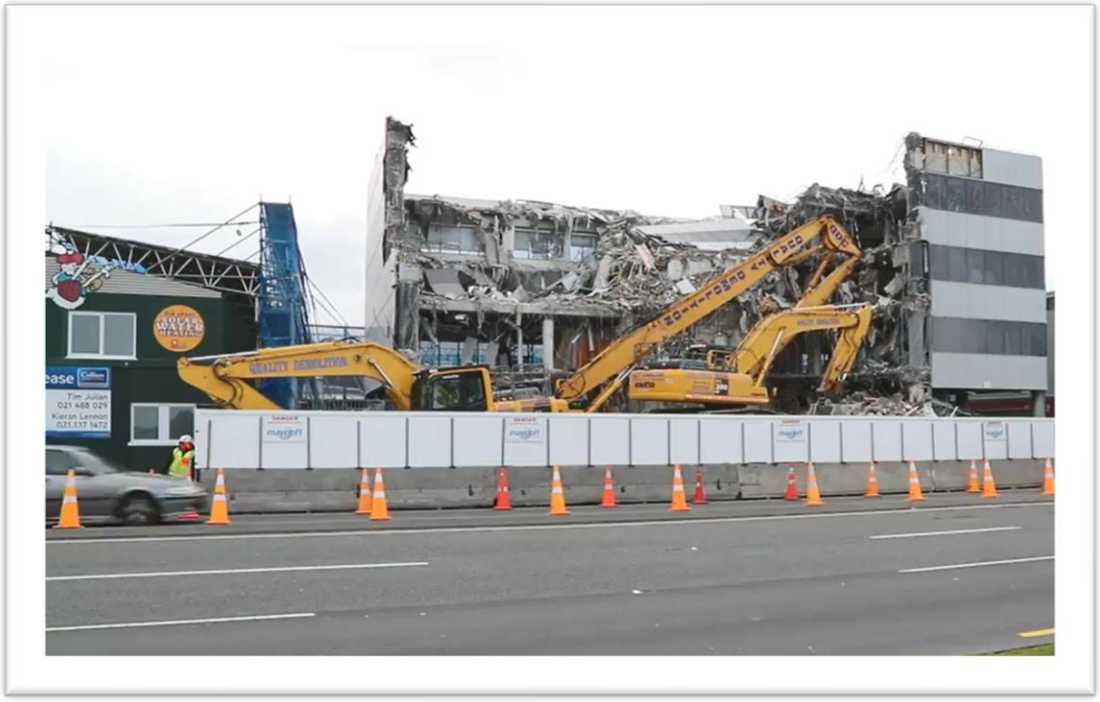
Figure 2 *Petone from the air (Hutt City Council, 2020)*

Petone, a popular coastal suburb as demonstrated in Figure two above, is prone to disasters as it is located on reclaimed land and a floodplain, making it susceptible to flooding, erosion, and slips (Grant, Guard, & Wall, 2005; Saunders & Beban, 2014). Indeed the first Europeans who tried to settle in Petone were flooded out, and it was more than forty years later before the development of a town occurred (Butterworth, 1988). Petone is also susceptible to earthquakes, liquefaction, and tsunamis because it lies near the Wellington earthquake fault line (Blake, Johnston, McLaren, Leonard, & Becker, 2018; Grant et al., 2005). Living on an active fault line means that most Petone residents have experienced an earthquake, and are always at risk of harm from significant earthquakes.

For instance, on 14 November 2016 Petone residents experienced a significant disruption when the Kaikōura magnitude 7.8 earthquake stuck, which resulted in a tsunami warning and evacuation, power outages, road closures, transport disruption, and infrastructure

damage (Becker, 2017; Blake et al., 2018). Due to confused messages via media about the threat of a tsunami, and the turning on of flood sirens, many Petone residents tried to evacuate but were unable to leave due to road congestion (Blake et al., 2018). Residents were then faced with more long-term disruption as businesses in the area were closed due to damage, with some buildings subsequently demolished, as depicted in Figure three below.

Figure 3 *An earthquake damaged building on Petone's Esplanade being demolished (Stuff.co.nz, 2016)*



People make sense of disasters, like the Kaikōura earthquake, based on their personal and social experiences, which are shaped by the social, economic, political, and environmental conditions they live in (Bolin & Kurtz, 2018; Rodríguez et al., 2007). Understanding this, means in this research disasters are considered a social phenomenon rather than a purely physical event (FitzGerald, Tarrant, Aitken, & Fredriksen, 2017; Perry, 2018). Disasters will effect some people, in communities like Petone, more severely than others because of pre-existing conditions and their personal and social contexts (Rodríguez,

Donner, & Trainor, 2018). Other elements are also implicated in how people experience chronic conditions and natural hazards, such as age, socio-economic status, and environment (Lyons & Chamberlain, 2006; Stephens, 2008a). For example, someone in good health who has strong social connections and disposable income will experience disruptions caused by a natural hazard disaster (for example loss of housing, jobs, access to amenities, and adverse health outcomes) differently from someone in poor health, living alone on government support (Bolin & Kurtz, 2018; FitzGerald et al., 2017). As such, the impacts experienced by someone less well-placed are likely to be more severe.

Research demonstrates that people with chronic illnesses are at greatest risk from harm and experience some of the highest morbidity and mortality rates in disasters (Miller & Arquilla, 2008; Tomio & Sato, 2014). So significant is their risk that member countries of the United Nations are encouraged via the Sendai Framework for Disaster Reduction 2015 (the Sendai Framework) to include the chronically ill in the design of disaster mitigation plans and policies (United Nations, 2015). Research had shown that previous approaches to disaster risk reduction have failed to meet the needs of the chronically ill, which was graphically illustrated by the poor health outcomes for the chronically ill in Hurricane Katrina in the USA and the Indian Ocean earthquake and tsunami (Jhung et al., 2007; Kessler, 2007; Tomio & Sato, 2014).

Most research (e.g. Carameli, Eisenman, Blevins, d'Angona, & Glik, 2013; Miller & Arquilla, 2008; Mokdad et al., 2005) concerned with the effects of disasters on the health and wellbeing of people with chronic illnesses focus on the numbers of chronically ill requiring medical care during a disaster. These forms of quantitative research focus on numbers and health status as only part of the story and can overlook the lived experience of people with chronic illness, denying them a voice. Such research can assume that the chronically ill are adversely affected because their health makes them vulnerable, further overlooking any

strengths-based characteristics (Carameli et al., 2013; Gignac, Cott, & Badley, 2003; Jhung et al., 2007; Miller & Arquilla, 2008; Owens & Martsolf, 2014; Tomio & Sato, 2014). Yet chronically ill groups who have been positioned as vulnerable do possess skills, competencies, and resilience as demonstrated through research that has analysed their stories of managing health and successfully navigating illness and natural hazard events (Tuohy, 2014; Tuohy, Johnston, & Stephens, 2015; Tuohy & Stephens, 2012, 2016).

With the growing number of high weather, natural hazard and human-generated disasters in Aotearoa New Zealand and globally, such as wild fires, flooding, volcanic eruption, drought, and the COVID 19 ("COVID") pandemic, it is important to better understand the health and disaster experiences of people living with chronic illnesses, and how personal and social vulnerabilities and attributes influence how people act in disaster events (Tuohy & Stephens, 2016). Therefore, this research asked how do people with chronic illness living in Petone, an area prone to natural hazards perceive and manage this risk and how does it matter to their health and wellbeing?

While this chapter presented a general overview of the research aims and context, the next chapter explores the literature relating to people with chronic illness and disasters to provide a comprehensive account of the research that informs this thesis. It begins by considering the concept of chronic illness in terms of a biographical story, an identity and social representation. It then looks at health and disaster concepts and research. Also discussed is the influence of personal, social, economic, and political conditions on people's experiences of health and disasters.

Chapter Two: Literature Review

Figure 4 *People on Petone foreshore (National Emergency Management Agency).*

Introduction

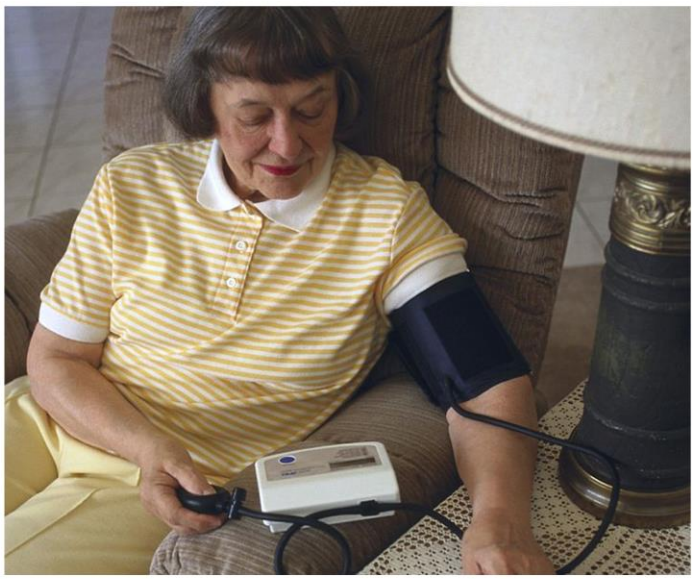
To date there has been little published research that explores how living with a chronic illness in a hazard prone area might matter to people's health and wellbeing. As such there is limited knowledge of what disaster preparedness and subsequent response and recovery needs are for people with chronic illness. Therefore, it is important to query if emergency preparedness and recovery strategies are appropriate and fit for purpose. Asking

these questions can help in the development of preparedness strategies that reduce the risk of adverse outcomes during and following disasters for people living with chronic illness.

There is, however, a lot of research that explores chronic illness in everyday life. The following sections in this chapter provide an overview of the various concepts and existing research relating to people with chronic illness generally, and disasters. It begins with the conceptualisation of chronic illness. This includes discussion about chronic illness as a biographical story, an identity and as a social representation. The discussion then shifts to health and disasters, including preparedness planning. The sections that follow also encapsulate ideas about the role that personal, social, economic, and political conditions have in shaping people's experiences of health and disasters.

Chronic Illness

Figure 5 *Woman taking own blood pressure (HealthDay)*



Chronic illness[1] has many definitions and refers to multiple conditions (e.g. diabetes, cancer, cardiovascular diseases, respiratory diseases, neurological diseases, kidney disease, chronic pain etc). For the purposes of this research, a definition from Aotearoa New Zealand's National Health Committee is used as it aligns with other countries' definitions, including that used by the World Health Organisation (WHO). Aotearoa New Zealand's National Health Committee defines chronic illness as:

> "any ongoing, long-term or recurring condition that can have a significant impact on people's lives." (National Health Committee, 2007, p. 7)

WHO reports that 71% of all deaths worldwide are due to chronic illness, with more than 41 million people dying each year (WHO, 2005, 2020). In Aotearoa New Zealand chronic illnesses accounted for 89% of deaths or 27,400 people in 2019 (WHO, 2020). The financial impact for countries is significant. Take for example, China, which in 2005 was projected to lose 558 billion dollars over the next 10 years due to premature deaths from chronic illnesses (WHO, 2005).

[1] The question addressed by this study concerns people with a "chronic illness". This expression was chosen for its general familiarity, especially with the people who participated in the study (the "tellers").Expressions like "chronic illness" and "chronic disease" are problematic for their imprecision and inconsistent usage. There is no consensus in the literature about the range of specific "illnesses/diseases" involved (though this language is not likely to capture long-standing functional disabilities that do not result from a disease), or about the length of time that qualifies as "chronic". The potential outcome, as Bernell and Howard (2016, p. 1) observe, is "confusion and misunderstanding when speaking in generalities about the impact of chronic disease". The Ministry of Health website currently refers to "long-term condition" (implying a long-term "health" condition), though how long this more inclusive expression has been used on that site has not been enquired into. This wider category is preferable for research purposes only if there is consensus about the range "conditions" and about the meaning of "long-term". Redrawing the parameters of the category may not, on its own, avoid the confusion that Bernell and Howard point out. The risk of confusion about categories does not directly concern this study. The present focus is not on numbers and trends, but rather on the lived experience of people with chronic illnesses. These people are in a category, but it is the nature and qualitative value of their experience that matters. The potential relevance of this experience to people in a wider category – such as persons with a chronic/long-term condition or, even wider, vulnerable persons – is a matter for further study and discussion.

WHO's narrative regarding chronic illness is simple. It is both a healthcare and economic crisis on a global scale that is increasing as people live longer and maintain unhealthy lifestyles (WHO, 2005, 2020). This narrative is repeated in most healthcare contexts throughout the world, where the chronically ill are described not only in terms of being a burden, but also as being responsible for their illness due to poor lifestyle choices (Walton & Lazzaro-Salazar, 2016). This matters to understanding the lived experiences of people with chronic illness living in Petone, because their sense of self and relationships with others is shaped by how they are represented in society.

Personal experiences

In the field of chronic illness studies, stories are commonly used as the bases of research to better understand people's experiences, because the story making process is how people make sense of themselves and others in an ever changing world (Murray, 2000). A lot of research exploring the experiences of people with chronic illnesses has conceptualised illness experiences in terms of biographical disruption where illness is not only understood as a biological process but also a personal and social process (Bury, 1982; Lyons & Chamberlain, 2006; G. Williams, 1993). Bury (1982) proposed that people experience chronic illness as a disruption to the life they assumed they would have when healthy, and that conceptually this is understood as a intertwining of identity with biography (Tuohy & Stephens, 2012). This manifests as an identity challenge where the chronically ill person has to reconsider their biography and identity within an illness context (Tuohy & Stephens, 2012).

On the other hand, there is research that indicates that people's experiences are not limited to disruption, with stories of chronic illness also including experiences of resistance

and resilience. For example, Tuohy and Stephens (2012) explain that, while chronic illness can be experienced in terms of a disruption to personal identity, it can also be experienced as a continuity of self. For them, the biographical way in which these experiences are storied allows "meanings of experiences to be expressed while enabling identity and purpose to be shaped with the narrative as told" (Tuohy, 2012, p. 27). "Shaped" is a more useful term because it represents shifts and changes and is not limited to the idea of disruption.

Faircloth, Boylstein, Rittman, Young, and Gubrium (2004) argue that some people who develop a chronic illness experience the process of the illness as another step in their biography as a human being, and whether a person experiences biographical disruption or 'flow' depends on the person's context. Consider an 85-year-old pensioner diagnosed with diabetes, compared with a 21-year-old university student diagnosed with diabetes. The pensioner may view the diagnosis as part of the aging process and engage in resilience-building to maintain a continuity of self-identity. However, the student may experience a sense of loss for the person they could have been.

The same can be said of chronically ill people's experience of disaster. Tuohy and Stephens (2012) say:

"The storied experiences of a disaster, like the storied experiences of chronic illness can construct meanings and identities in the context of disruption that extend our understanding about disasters and their impact." (p. 28)

In this quote, disruptions are the ongoing effects to people and places from the disasters. Tuohy and Stephens (2012) found that the way people told their disaster stories actually shaped and supported their personal identities as works in progress. For example, in their narrative-based study one participant used her flood experience to frame the development of her self-identity. Before the flood she identified as someone defined by a

phobia, then through her experience of the flood she became an independent person who could now cope with life. Tuohy and Stephens (2012) uncovered other stories of psychological strength, as well as notions of biography. They argued that a person's biographical story gives them reference points of understanding that helps them make sense of current events in terms of how they affect their sense of self and their daily lives. Within the context of a natural hazard event, people gained strength from their lifetime of experiences by using these past experiences as a resource for how to manage current challenges.

Coleman (1999) goes further and asserts people's biographical stories are important because they can be used by others as guides for how to cope, and that the storied experiences of how people managed disasters are valuable resources for others in preparing for future events. From this perspective it is important to consider personal context (e.g. skills, competencies, vulnerabilities etc) portrayed in biographical stories and how such stories can shape people's experiences when researching the impact disasters have on people with chronic illnesses.

Social representations of chronic illness

How people narrate health is important because it shapes how they and society act (Lyons & Chamberlain, 2006). Health used to be understood as something that mattered to the individual (a private matter). Though as Beck noted in 1992 this changed as western neoliberal societies' notions of risk came to dominate people's lives, making health a public matter (Lyons & Chamberlain, 2006).

Neoliberalism for the purpose of this thesis is understood as a capitalist ideology that originated in and was popularised by the West, which through various measures (e.g.

privatization of education and health, significant public sector expenditure and size cut backs etc) has resulted in a minimisation of a welfare state and created a free-market economy (Danaher, Schirato, & Webb, 2000; Parker, 2015). Under this regime, citizens are considered marketplace participants who freely "choose, consume, and innovate while taking personal responsibility for their self-care, self-determination, and efficiency and remaining autonomous, adaptive, and flexible" (Parker, 2015, p. 445). Neoliberalism has resulted in increased poverty, inequality, and disempowerment which disproportionately affects those least able to participate in the system (Parker, 2015).

Crawford (2006) explains health became highly valued in such societies and the risk of losing it dominated people's sense of self in this social context. People's understandings of chronic illness are shaped by their personal beliefs and ideas about health, which are derived from social ideologies (Galvin (2002). Herzlich (1995) explains individuals' beliefs and ideas come from a bank of knowledge shared across society, and personal accounts of health and illness are reflective of those shared representations of health and illness held collectively within society. Therefore, a person's account of chronic illness is also a collective view of what it means to be chronically ill (Lyons & Chamberlain, 2006).

In western neoliberal societies being healthy is associated with responsibility and worthiness, making health status moral and value based, according to Radley (1994). Such value laden understandings of health divide society into the healthy (those who are good/right/normal), and the unhealthy (those who are bad/wrong/abnormal) (M. Crossley, 2003; A Radley, 1994). These can also be understood as what Foucault referred to as normative judgements (Danaher et al., 2000). Such judgements serve to monitor and assess people's actions which are divided into normal and abnormal, as determined by those who govern society (Danaher et al., 2000).

According to Radley (1994) the risk that the chronically ill face when they fail to meet society's standards is that they are judged for being less than other people. Being devalued can be felt as a judgment solely on the basis of their illness. This is a problem for the chronically ill who live in a society that places such a high value on health, especially since those with chronic illnesses, unlike people suffering from acute illness, are unlikely to regain their health, and cannot therefore re-establish themselves as 'normal' members of society (A Radley, 1994; A. Radley & Billig, 1996). This stigmatizes the chronically ill from the rest of society and increases their vulnerability to outside forces including disasters through social isolation.

Stigma can play a major role in how the chronically ill view themselves, and how they are viewed by others, and this may affect how they respond to events such as natural hazards. Albrecht, Walker, and Levy (1982) explains people are stigmatized through the attribution of characteristics such as chronic illness which is judged unacceptable as it sits outside a "socially acceptable standard" such as being healthy (p. 1319). Being positioned outside the norm can make people less inclined to be identified with a stigmatized condition such as chronic illness as being ill is socially represented as resulting from personal fault, or being abnormal (Albrecht et al., 1982; M. Crossley, 2003; A Radley, 1994; G. Williams, 1993). Within a disaster context, Blake, Pooley, and Lyons (2020) state stigma can result in people avoiding others such as in emergency community hub settings which provide needed resources when disasters occur. It also follows that stigmatisation could act as a barrier to participating in disaster preparedness activities such as making a plan with neighbours.

Chronic illness as a moral failure is a notion that has developed from liberal ideals of health as an individual responsibility, and a super-value (Crawford, 2006; Danaher et al., 2000; Galvin, 2002). People define themselves according to how well they adopt health practices (Crawford, 2006). Galvin (2002) speaks of "a culture of victim blaming" where it is

unacceptable to be “physically incapacitated”, and to be a worthy citizen people must be active, rational, self-reliant, responsible, and independent (p. 108). Therefore, a diagnosis of chronic illness would be considered a personal failure. As such, when people provide accounts of illness, there is often some justification or expression of guilt for having failed to be healthy, as was found in M. Crossley (2003) focus groups study.

Some argue that this discourse of victim blaming has been perpetuated by government representations of the chronically ill in policies and strategies. Walton and Lazzaro-Salazar (2016) found that Aotearoa New Zealand’s health policy documents represented the chronically ill as other to the norm, responsible for becoming sick, to blame for failing to become healthy, and no longer worthy members of society but merely an economic burden. Key health strategy refers to a list of chronic illnesses as a ‘health burden’, and places the onus of prevention on individuals by focusing on them ‘making healthy choices’ (Ministry of Health, 2016, pp. 9, 12). Such concepts of health set a standard that people measure themselves and others by. They are therefore relevant in understanding how people make sense of being unwell. Such powerful healthy narratives about being chronically ill become integrated into the chronically ill’s understandings of what it means to be healthy and are incorporated into their own illness stories.

Walton and Lazzaro-Salazar (2016) assert that being categorised as unhealthy, abnormal, or to blame for being sick influences the way that the chronically ill make sense of being ill, how they perceive themselves as an individual (not normal), as part of society (a burden on society), as well as the way they are perceived by society. Charmaz (1983) explains this in terms of a social psychological process where the ill person references their “past social experiences, cultural meanings and knowledge” which they use to make sense of their “present physical and social existence” and their identity as an ill person (p. 170).

One way the chronically ill can counter such discourse is through personal accounts of independence. G. Williams (1993) noted how important being independent is for the chronic ill, and how social representation of independence shaped their accounts of illness. He concludes:

"that living with chronic illness is a complex social process, and while individuals express a concern with responsibility and independence they recognize also that society and culture contain powerful forces determining the extent to which those qualities are able to emerge in an individual life" (G. Williams, 1993, p. 106).

One such powerful force is social determinants of health which will be discussed in the following section.

Social determinants of health and disasters

The social determinants of health are the living and working conditions, and the economic and social context in which people live (Wilkinson & Marmot, 2003). These matter to people's health experiences. As such it is necessary to consider the underlying social mechanisms and structures that make up a society when trying to understand the health outcomes for the chronically ill, especially during a disaster (Cragg, Davies, & Macdowall, 2013; Stephens, 2008a). For example, people with chronic illness are more likely to be on low incomes and the relationship between income and poor health outcomes has been well established, as has the relationship between vulnerability[2] to adverse health outcomes in

[2] Vulnerability is a key term used in both health and disaster contexts. Defining 'vulnerability' within emergency management tends to involve susceptibility to or risk from hazards due to social, physical, environmental, and economic characteristics (FitzGerald et al., 2017; Ministry of Civil Defence & Emergency Management, 2019; Wisner, 2004). For this thesis 'vulnerability' in the event of a disaster is understood as being dependent on levels of access to resources (Wisner, 2004).

disasters (FitzGerald et al., 2017; Wilkinson & Marmot, 2003). This effect, known as the social gradient of health, illustrates health's sensitivity to environmental, economic and social influences (Lyons & Chamberlain, 2006; Wilkinson & Marmot, 2003). These influences and how people experience them determines the quality of their health outcomes particularly when disaster strikes (FitzGerald et al., 2017; Lyons & Chamberlain, 2006).

Carameli et al. (2013) note that people with chronic illness are more likely to be poor, have a disability, or be elderly. Studies that have considered social status show that it is a significant contributing factor to a person's risk of adverse health outcomes in the event of a disaster (Bolin & Kurtz, 2018; Naser-Hall, 2013). For example, the majority of people who died in Hurricane Katrina lived in impoverished conditions and had no transport to evacuate before the hurricane hit (Bolin & Kurtz, 2018; Naser-Hall, 2013). They could not afford their own cars and the local government provided no alternative transport (Bolin & Kurtz, 2018; Naser-Hall, 2013). Those who did not drown in the Hurricane died later from starvation, dehydration, or contaminated water. This was because they could not afford the additional provisions and were more susceptible to the adverse post-flood environment as living in poverty had lowered their immune systems and resulted in chronic ill health (Bolin & Kurtz, 2018).

Phibbs, Kenney, Severinsen, Mitchell, and Hughes (2016) argue for the use of the social determinants of health approach in Aotearoa New Zealand's emergency management framework because of synergies between this approach and the Sendai Framework (United

This thesis refers to people and groups who are "vulnerable". This is not intended to have a technical meaning, but rather an everyday meaning. In the context of a disaster event, some people and groups are more likely than others to be adversely impacted, or are likely to be more adversely impacted than others. As such, they are vulnerable in terms of both likelihood and consequences. People and groups might be vulnerable for health reasons, or for other reasons such as poverty. People with a chronic illness are considered vulnerable for the purposes of this study.

Nations, 2015). The Sendai Framework is a global disaster risk and resilience strategy that at its core aims to reduce loss of life, livelihood, and health, through a set of goals and actions enabling flexibility to manage health vulnerabilities like chronic illness (Phibbs et al., 2016). The framework's approach synergises with health as both take into account social determinants including social, economic, political, and environmental factors that attribute to people's risk and vulnerability to poor health outcomes (Phibbs et al., 2016).

Similarly, Aitsi-Selmi and Murray (2015) argue for a relationship between social determinants of health and disaster risk reduction when the Sendai Framework is viewed from a health perspective. Research indicates that disaster preparedness and recovery strategies will only lessen adverse health outcomes for the ill if their vulnerabilities are considered and addressed (Bethel, Foreman, & Burke, 2011; Blake, Marlowe, & Johnston, 2017a; Bolin & Kurtz, 2018; Gowan, Kirk, & Sloan, 2014; Naser-Hall, 2013; D. Paton & Johnston, 2001).

Social support, another determinant of health, is important to people's health because through such support people have access to important emotional and practical resources (Taylor & Repetti, 1997). McAdams, Hoffman, Day, and Mansfield (1996) explain that social support such as assistance and care from friends, family, and community enhances a person's wellbeing. Social support is particularly important in a disaster context as access to social networks can reduce people's risk of adverse health outcomes in disasters (Chamlee-Wright & Storr, 2011; Ministry of Civil Defence & Emergency Management, 2019). In emergency management, social networks and forms of social support and are what make up the social capital of a community (Ministry of Civil Defence & Emergency Management, 2019). As Charmaz (1983) explains, the chronically ill live restricted lives including participation in work, social and community engagements which often lead to social isolation. Being socially isolated can mean an increased vulnerability, and risk for the

chronically ill, because when hazard events occur due to compromised health they may need to rely on their social network (family, friends, neighbours, etc) and people close by for support.

Researchers argue that people's health and wellbeing are also dependent upon them feeling part of a community, which is only possible when people engage in meaningful social relationships (McAdams et al., 1996; Sonn, Bishop, & Drew, 1999). Sonn et al. (1999) explain that the relationship between health, community, and social relationships can be conceptualised as a sense of community, the feelings of belonging and the central role that community plays (Sonn et al., 1999). People's sense of community can be supportive of good health and wellbeing, but can also lead to social isolation when connecting with others in the community is restricted due to illness, or safety issues (Charmaz, 1983; Fisher, Sonn, & Bishop, 2002; Sonn et al., 1999). Fisher et al. (2002) notes people who live in "risky neighborhoods" [sic] due to violence and crime may withdraw from those around them to protect their physical and emotional wellbeing (p. 94). This matters to people's level of disaster preparedness as engaging with others in the community is an important component of being prepared (Becker, 2012; Pooley, Cohen, & Pike, 2005). Having a sense of community is likely relevant to people's experiences of life in Petone, chronic illness, and hazard events. Consideration of Petone as a community (i.e. level of income, home ownership, age range, etc) is therefore important.

Connected to social support and sense of community is a sense of attachment. Petone as a place can be relevant to understanding people's health and wellbeing as a place attachment may influence how people act when a hazard event occurs (Harries, 2008). Harries (2008) proposes that people who have strong feelings of attachment to the place in which they live, perceived natural hazard events as less of a risk as they feel safe at home. Bonaiuto, Alves, De Dominicis, and Petruccelli (2016) supports this view, having found that

people failed to evacuate because of their strong place attachment. Such research is of particular interest when exploring the experiences of chronically ill people living in hazard zones, as feelings of attachment may add to their risk which is already high due to their illness. Also, feeling a strong attachment to a place is important to a person's self-identity, their sense of security, as well as connectedness with community (Adams-Hutcheson, 2015; Lewicka, 2008; McKinzie, 2019; Taylor, 2010; Wiles et al., 2009).

Place attachment is further associated with ontological security. Ontological security is the feeling that the world is consistent, routine and secure (Giddens, 1991). When living in an environment prone to natural hazards such as Petone, people's sense of security can be compromised because their lives depend on the reliability and safety of their homes, family, and neighbours if disaster strikes. Hawkins and Maurer (2011) explain that ontological security is dependent on the environment, such as a community structure and settings. They emphasised ontological security in the rebuilding of New Orleans after Hurricane Katrina and their research provided insight into how significant feeling secure was for people's wellbeing and health (Hawkins & Maurer, 2011). Therefore, it is important to take into account people's sense of security particularly when living in a hazard prone area, and the role place attachment plays in experiences of security.

Health and Disasters

Common to both health and disaster research is the consideration of the risk of poor health outcomes in terms of levels of vulnerability determined by social, political, economic, and environment factors (Phibbs et al., 2016). Some argue that thinking about people in terms of risk can lead to people being categorised based on physical vulnerability alone, which

shifts responsibility for health outcomes away from social conditions and onto the individual (Lupton, 2013). Such categorising within society shape people's life experiences including health outcomes in a disaster (Galvin, 2002; Lupton, 2013; Walton & Lazzaro-Salazar, 2016).

Disaster studies

Disaster research began with the seminal work of Henry Prince who studied the sociological impact of a ship explosion on a Canadian community in 1917 (FitzGerald et al., 2017; Perry, 2018). Prince's emphasis on the social impact of disasters became standard practice for research and subsequent disaster risk reduction practices. Since the early 20th century there has been a shift from a focus on disaster management or emergency response to disaster risk management. This has resulted in the disaster risk reduction and emergency management field growing over the past few decades with a range of disaster research that has investigated the origins and causes of disasters, as well as risk drivers (poverty and inequality etc) that lead to disasters (Aitsi-Selmi & Murray, 2015; Rodríguez et al., 2018; Wisner, Gaillard, & Kelman, 2012).

There are a number of different interpretations of what a disaster means, however there appears to be a strong focus on social disruption as is evident in the United Nations General Assembly definition of disaster:

> "A serious disruption of the functioning of a community or a society at any scale due to hazardous events interacting with conditions of exposure, vulnerability and capacity, leading to one or more of the following: human, material, economic and environmental losses and impacts" (United Nations General Assembly, 2017, p. 13).

This definition and the focus of disruption has been used in the emergency management policy framework that mandates the scope of emergency management activities as outlined by the Aotearoa New Zealand government[3] (Ministry of Civil Defence & Emergency Management, 2019). It is also a good starting point for considering how people make sense of the disruption caused by disaster and chronic illnesses.

As stated above, disasters are not caused by hazard events (Bolin & Kurtz, 2018). It is the existing social, political, economic, and environmental conditions that cause a hazard event to become a disaster (Etkin & Haque, 2012; Perry, 2018; Wisner, 2004). Wisner (2004) stresses the importance of governments recognising that societal structures cause people to be vulnerable to hazards, and when these vulnerabilities are not addressed people can die as evidenced by disaster events such as Hurricane Katrina and others (Etkin & Haque, 2012; Kishore et al., 2018; Rodríguez et al., 2018). Bolin and Kurtz (2018) noted that "lower-income and non-white" New Orleans residents who did not evacuate did so because they relied on the public health system for medical treatment, but it was destroyed by the hurricane (p. 194).

Failure to consider existing social inequalities has also been evident in Aotearoa New Zealand. For example, in the 2011 Canterbury earthquake those living in the poorer eastern suburbs of Christchurch experienced considerably more damage to housing and infrastructure yet did not receive the same access to resources as the wealthier suburbs (Phibbs et al., 2016).

[3] The terms "disaster management" or "emergency management" are used interchangeably throughout literature as are the terms "disaster risk reduction" and "disaster management." For this thesis, the term "emergency management" is used because it is this term that is most commonly used in Aotearoa New Zealand, the country in which the research took place. Aotearoa New Zealand's emergency management framework historically followed that of the United Kingdom's civil defence which was developed in response to World War II (*The History of civil defence in New Zealand*, 1988). Aotearoa New Zealand continued with the civil defence model after World War II and focused on responses to emergencies which were defined as a natural or wartime event that resulted in significant loss of life and damage (*The History of civil defence in New Zealand*, 1988). The use of the term emergency rather than disaster has remained in Aotearoa New Zealand even though internationally 'disaster' is more commonly used as evident by the UNs Sendai Framework for Disaster Risk Reduction 2015-2030 (Sendai Framework).

Phibbs et al. (2016) argue that inequitable access to resources could have been avoided had government used “equity-driven approaches” like that advocated in the Sendai Framework (p. 16).

While not extensive, disaster studies (Carameli et al., 2013; Jhung et al., 2007; Miller & Arquilla, 2008; Tomio & Sato, 2014; WHO, 2017) do explore the relationship between chronic illnesses and health related disaster outcomes. This type of research is imperative as the number of chronically ill rises worldwide, and disasters increase due to climate change. Generally, as previously highlighted, disaster research shows that people with chronic illnesses make up the biggest patient numbers during a disaster (Miller & Arquilla, 2008). Figures from Hurricane Katrina show that of the top six conditions requiring medical treatment during the disaster, five were chronic illnesses (Mokdad et al., 2005). Survey data from Hurricane Katrina shows that chronic illness had the highest morbidity rate with five out of six conditions requiring post hurricane treatment for exacerbation of chronic illnesses (Miller & Arquilla, 2008; Rodríguez et al., 2018). Miller and Arquilla (2008) reported that one fourth of those who did not evacuate after Hurricane Katrina reported having at least one chronic illness.

Looking at the 2011 Japan tsunami, Tomio and Sato (2014) also note those with chronic illnesses who survived the tsunami experienced an exacerbation of their condition that for some resulted in death.

Such studies show that the chronically ill suffer greatly when disasters restrict or remove access to life saving treatment including medication. For example, a loss of power resulting from a disaster may cause the expiry of diabetic medication which must be refrigerated (Jhung et al., 2007; Miller & Arquilla, 2008). Carameli et al. (2013) found that system barriers restricting medication for chronically ill people pre-Hurricane Katrina

resulted in a paucity of medication reserves during the disaster. In support of this Jhung et al. (2007) found that post Hurricane Katrina the demand for medication from people with chronic illnesses was greater than the available supply so that people had to go without necessary medication. When they tried to get medication post-disaster, people were faced with having to navigate medical services that were overwhelmed, had limited supplies, and very little or no access to medical records (Carameli et al., 2013). Even when medication was available, prescriptions could not be filled because people's medical records could not be accessed due to power outages and technical failures. As their health could not be maintained through medication, people's chronic illnesses worsened.

Challenges in preparedness action for people whose health is reliant on medications was also argued in a study by Blake, Marlowe, and Johnston (2017b). They found that for people on restricted medications in Aotearoa New Zealand, especially class A medications, access to these medications is highly controlled and can hinder stockpiling necessary to be prepared for disasters (Blake & Lyons, 2016).

Also, loss or damage of medical records and the restriction of appointments can interrupt medical care and stop life sustaining treatments, like chemotherapy (FitzGerald et al., 2017). Studies have found that chronic conditions worsen when disaster interrupts other forms of medical treatment that people were receiving prior to the disaster (Miller & Arquilla, 2008; Mokdad et al., 2005; Tomio & Sato, 2014). People receiving regular treatment for cancer, kidney disease (dialysis), diabetes (insulin and blood tests), and cardiovascular disease (medication and blood pressure monitoring) had increased morbidity and mortality rates due to restricted access to medical treatment (Miller & Arquilla, 2008; Mokdad et al., 2005; Phibbs et al., 2016). Miller and Arquilla (2008) in their study of the impact disasters have on people with diabetes, renal failure, and cardiac disease reported that restricted access to regular medical treatment was a major factor in high morbidity rates

following Hurricane Katrina. Restricted food and water as well as exposure to environmental conditions such as extreme temperatures, infectious diseases, and stress are also reported as contributing to the worsening health of people with chronic illnesses in a disaster context (Jhung et al., 2007; Mokdad et al., 2005; Tomio & Sato, 2014).

Teng, Blakely, Ivory, Kingham, and Cameron (2017) suggest that chronically ill people's needs may not manifest immediately but occur days, weeks, even months after, when their conditions worsen due to disaster related factors such as homelessness, insurance woes, work disruption, and ongoing stress and trauma. This view is supported by other research which has shown that the health of chronically ill people continued to be impacted up to two years after a disaster due to the continuation of disaster related stressors. A study of Christchurch residents with heart conditions found that after the Christchurch quakes, increases in cardiovascular disease incidents were linked to disaster stressors (Teng et al., 2017). In this study people were interviewed two years after a major earthquake, which enables consideration of any long-term effects they may have experienced as a result of the quake (Owens & Martsolf, 2014). Table One summaries the long-term health effects reported by researchers.

Table 1 *Disaster Mortality and Morbidity Rates for Chronically Ill. Adapted from (FitzGerald et al., 2017, p. 29)*

Disasters	**Rates**
Hurricane Iniki, Hawaii, 1992	**One year post hurricane**: 19% increase in cancer-related deaths (Hendrickson and Vogt 1996).
Japan Niigata-Chuetsu earthquake, 2004	**Three years post earthquake**: 14% increase in heart attacks (Nakagawa et al. 2009).
USA after hurricane season and four major hurricanes, Florida, 2004	**Excess deaths**: 5% were diabetes-related deaths 34% were cardiac-related deaths (Brown et al. 2008)
Hurricane Katrina, east coast USA, 2005	**One year post hurricane**: a

	47% increase in mortality and morbidity due to cardiovascular disease (e.g. heart attacks and stroke), diabetes, respiratory diseases and cancers (Ryan et al. 2015b) **Five years post hurricane**: Notable increase in coronary artery disease, (Moscona et al., 2012). **Six years post hurricane**: Threefold increase in cardiac-related incidents in New Orleans (Gautam et al. 2009).
Japan's earthquake and tsunami, 2011	Rate of cerebral infarction in men over the age of 75 years doubled (Omama et al., 2013)
Hurricane Sandy, Caribbean and east coast USA, 2012	22% increase in cardiac incidents 31% increase mortality (Swerdel et al., 2014)

Traditionally the management of disasters has focused on initial response actions to a sudden event including evacuation and acute patient care (Carameli et al., 2013; Jhung et al., 2007). While these studies clearly show that chronically ill people are more adversely affected by disasters, the needs of the chronically ill when disaster strikes have not as yet been specifically addressed by many governments. Studies of disaster preparedness plans show that the specific needs of the chronically ill are often acknowledged but no strategies target their vulnerabilities (Naser-Hall, 2013).

Preparedness and disasters

It has been recognised that approaches to reduce disaster risk through preparedness messages must factor in pre-existing disadvantages in society such as poor health, poverty and social isolation which limit people's ability to resource themselves in a disaster context (Blake, Marlowe, et al., 2017a; Blake, Thompson, Chamberlain, & McGuigan, 2021; Bolin & Kurtz, 2018; Thomas, Phillips, Lovekamp, & Fothergill, 2013).

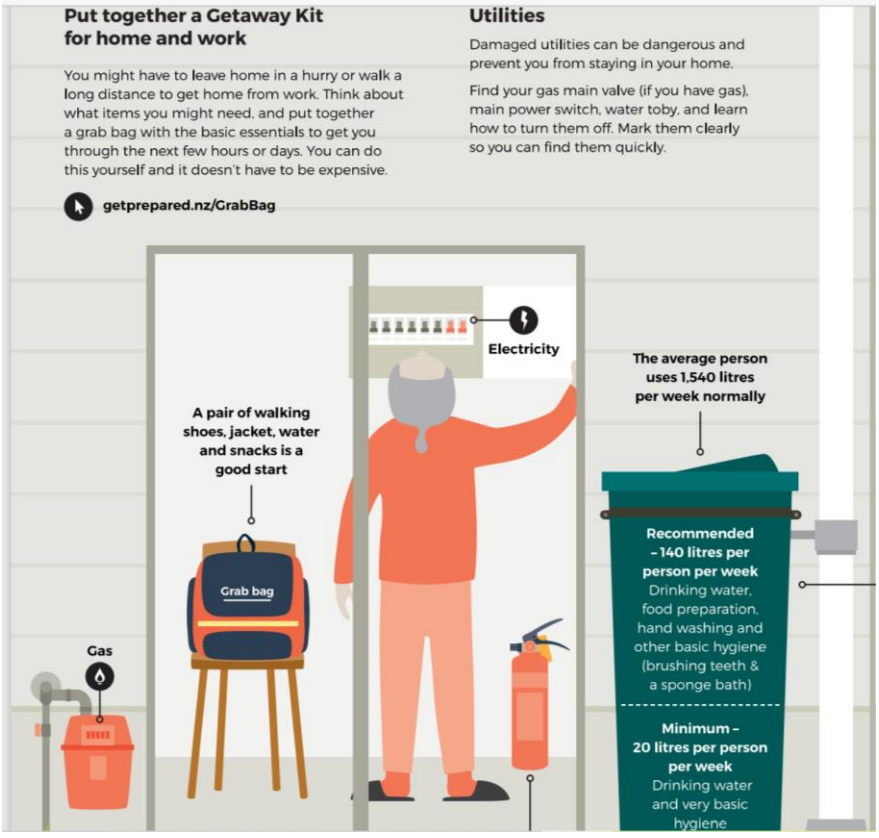
Disaster preparedness messaging that considers diverse communities goes some way to addressing the needs of disadvantaged groups, though Blake, Marlowe, et al. (2017a) argued that more work is needed from emergency sector personnel to meet the preparedness needs of all disadvantaged groups. Preparedness messages should target the needs of diverse groups as failure to consider social context could result in inappropriate preparedness messages that further alienate people like the chronically ill and increase their vulnerability in a disaster (Blake et al., 2021). Illustrative of this is an infographic developed by Miller and Rampton (see Blake, Miller, and Rampton (2017). In an attempt to address disparities for wheelchair users, older people, and people with poor literacy, this infographic came with pictorial instructions that can be easily followed.

Figure 6 *Part of image reproduced in Blake et al. 2017*(p. 44)

The need to improve emergency management for the chronically ill through developing preparedness and recovery policies and plans is recognised in the Sendai Framework (United Nations, 2015). In line with the framework, Aotearoa New Zealand's National Disaster Resilience Strategy affirms that wellbeing and resilience are undermined by

the kinds of social disadvantages experienced by groups such as the chronically ill (Ministry of Civil Defence & Emergency Management, 2019). For example, disadvantage occurs when individual responsibility is promoted in emergency management messaging which holds individuals responsible for disaster preparation. For the Wellington region including Petone, the organisation responsible for facilitating emergency management messages is the Wellington Region Emergency Management Office (WREMO). WREMO's Earthquake Planning Guide (Wellington Region Emergency Management Office, 2021) includes the recommendation that people put together a 'Grab Bag' of essential items in preparedness for an earthquake (Figure 7):

Figure 7 *Page 6 of WREMO's Earthquake Planning Guide (Wellington Region Emergency Management Office, 2021)*



Such a recommendation can prove a barrier to people on low incomes or living in poverty as has been highlighted by the COVID pandemic. For families living on low

incomes, the resources needed to put together such a bag is beyond them as they already struggle to meet daily needs such as food and power costs (Blake, 2020; Radio New Zealand, 2020). Another recommendation from WREMO is that of meeting neighbours which is illustrated in Figure 8:

Figure 8 *Page 8 of WREMO's Earthquake Planning Guide (Wellington Region Emergency Management Office, 2021).*

People with chronic illness may find meeting neighbours a barrier to preparedness because their illness means they are too unwell, or reluctant to engage with others. Such messaging assumes that the responsibility for preparedness lies with the individuals, and that people are physically able to adhere to the directives (Blake, 2020). Problematically, it is

assumed that this could, in effect, cause chronically ill people who are unable to prepare or care for themselves in a disaster to be blamed or feel responsible for any adverse health outcomes because they might be judged as responsible for their chronic health problems. Inappropriate preparedness messaging is a form of structural violence as argued by Blake et al. (2017), as it can exacerbate inequality for groups such as the chronically ill who as a result of poor health are not able to actively prepare like others which can then cause distress (Blake et al., 2020; Rylko-Bauer & Farmer, 2016).

Being friendly with neighbours seems like a reasonable idea, if people live in safe neighbourhoods or if they have the ability or wherewithal to meet neighbours. However, the physical manifestation of some chronic illnesses (e.g. MS which can cause slurred speech and erratic physical movements) may make people reluctant to speak with strangers, including their neighbours, because of how others may judge and react. As a result, people with chronic illnesses can be socially isolated, and unable to network with others, which potentially could make them more vulnerable in the event of a disaster.

Social networking (also known as social capital) is emphasised in disaster preparedness strategies (Aldrich, 2012), which tends to favour those who already have strong social connections and potentially overlook those who do not. Research (e.g. Bury, 1982, 2001; Charmaz, 1983; Daaleman & Helton, 2018) shows that social isolation is a major characteristic of the chronic illness experience, as illness restricts the time and energy needed for people to develop and maintain relationships. Charmaz (1983, p. 177) noted because of "experiences of being discredited, embarrassed, ignored and otherwise devalued" the chronically ill often feel socially isolated, and may purposely withdraw from society to avoid such devaluating occurrences. Also, due to its chronic nature, the likelihood of social isolation will only increase as the illness worsens (Charmaz, 1983). Therefore, having social networking as a major component of preparedness planning without consideration of

diversity can impose a further burden on the chronically ill that could result in them resisting engagement and withdrawing, which would increase their risk to natural hazards.'

Social capital is a key concept in Aotearoa New Zealand's emergency management framework. The Aotearoa New Zealand's National Disaster Resilience Strategy describes social capital as:

"…the norms and values that underpin society. It includes things like trust, the rule of law, cultural identity, and the connections between people and communities." (Ministry of Civil Defence & Emergency Management, 2019, p. 9).

In public health the concept of social capital is used to explain how social effects lead to health inequalities (Cragg et al., 2013; Stephens, 2008a). It is argued that the quality of a person's social life, such as levels of community and civic engagement, determines the quality of their health (Putnam, 1995). This concept has been widely criticised for lacking definition and theoretical clarity (Cragg et al., 2013; Stephens, 2008a). A key concern is that these social theories fail to critique the social, historical and political influences involved in health inequalities (Stephens, 2008a), like colonisation or racism. It is argued that the extensive use by governments of social capital in social policy has masked health inequalities and shifted responsibility for inequalities, such as low incomes, onto the poor (Stephens, 2008b). This has been supported by Ziersch (2005) study that found health programmes using social capital access to improve health actually privileged those with incomes that enabled access over those whose incomes restricted their access to social capital. This effect is also evident in preparedness campaigns used in Aotearoa New Zealand including that used in response to the COVID pandemic.

This alerts us to a further challenge for the emergency sector in trying to meet the needs of the chronically ill in that there is a likelihood that people have limited financial

resources due to the chronic illness because of their inability to work. Naser-Hall (2013) argues that living in poverty increases people's vulnerability and risk in a disaster, and that "poverty-conscious measures" must be incorporated into disaster preparedness and recovery approaches (p. 57). Blake (2020) notes that when varying levels of social inequalities are not considered by the emergency management sector, people such as those on low incomes are disadvantaged, and potentially exposed to harm.

Poverty is an issue that is recognised as a barrier to resilience in a disaster context in Aotearoa New Zealand's National Disaster Resilience Strategy (Ministry of Civil Defence & Emergency Management, 2019). However, purchasing additional items to prepare for a natural hazard event remains a common discourse in disaster preparedness messages. For example in WREMO's Earthquake Planning Guide people are advised to purchase additional household items including water tanks and emergency kits etc (Wellington Region Emergency Management Office, 2021). Someone on a medical benefit for chronic illnesses has limited resources, potentially restricting their ability to purchase any necessary preparedness items (Blake & Lyons, 2016). Encouragingly disaster messages about preparedness have changed more recently, in that people are now encouraged to think of preparedness as 'camping at home' (Figure 9) (Wellington Region Emergency Management Office, 2021). However, such messaging also assumes people have the necessary equipment to 'camp at home', which as Blake (2020) points out is unlikely for people who have limited income, and live daily 'hand to mouth,' an experience that has been exacerbated by the global pandemic.

Figure 9 *Page 9 of WREMO's Earthquake Planning Guide (Wellington Region Emergency Management Office, 2021).*

Blake (2020) noted the additional risk low-income families face from COVID in that they are unable to afford additional safety items (masks and sanitising products etc), and due to limited income must visit supermarkets frequently which expose them more often to the virus during lockdowns. The government's risk management approach to COVID is based on a community resilience and social capital theoretical framework which has been criticized for its failure to address existing social inequalities, and this is evident by the COVID experiences of Māori and low-income families in Aotearoa New Zealand (Blake, 2020; King, Cormack, McLeod, Harris, & Gurney, 2020; Ministry of Civil Defence & Emergency Management, 2019). Such experiences indicate the need for approaches to risk management to include consideration of how the conditions in which people live impact on their health (the social determinants of health).

Policies and strategies

Researchers have recommended changes to the way governments prepare for disasters so that the needs of people with chronic illnesses are addressed (Jhung et al., 2007; Miller & Arquilla, 2008; Mokdad et al., 2005). Such recommendations include having additional supplies of medication for chronic illnesses. Research into disaster events discovered that the greatest demand for medication came from the chronically ill, and because preparedness plans required the stock piling of medication for acute injuries there was insufficient medication for chronic illness treatment (Jhung et al., 2007; Tomio & Sato, 2014). As a result of such findings, emergency plans including those recommended in Aotearoa New Zealand advocate that people should have spare medication in their preparedness kits, yet because of limits on prescriptions there is still a need for healthcare providers to have additional medication stocked for chronic illness treatment (Blake & Lyons, 2016; Carameli et al., 2013; Miller & Arquilla, 2008; Mokdad et al., 2005; Wellington Region Emergency Management Office).

While internationally there has been extensive research of chronic illness and the overrepresentation of the chronically ill in mortality and morbidity rates in disasters, there is still more research needed in Aotearoa New Zealand to gain a greater understanding of the health needs of chronically ill people. To date Teng et al. (2017) study is the only one that has looked at the needs of the chronically ill, though their study focused specially on the relationship between earthquake damage and rates of cardiovascular disease related hospital admissions. Teng et al. (2017) were interested in the effects housing damage, caused by the sequence of Christchurch earthquakes, had on hospital admission rates for cardiovascular disease over time. They sourced statistical data regarding people aged 45 years and over, average damage levels of the Christchurch residential areas these people lived in, and the

cardiovascular disease rates, and found increased rates of hospital admissions for more severely damaged areas over time.

Tomio and Sato (2014) review recommendations for disaster preparedness and treatment of people with chronic illnesses, and note that post disaster continuity of care is a vital. Researchers of chronic illness and disasters argue that emergency management would improve if they planned for the persistent nature of natural hazards rather than focusing only on the impact of the initial event (Jhung et al., 2007; Miller & Arquilla, 2008; Mokdad et al., 2005). The Sendai Framework provides the policy foundation that would enable the development of plans to better address the needs of people with chronic illnesses. The Sendai Framework expands on its predecessor's (the Hyogo Framework for Action 2005-2015) response and recovery approach, and provides a proactive approach that enables flexibility to manage health vulnerabilities like chronic illness (Phibbs et al., 2016). In Aotearoa New Zealand the Sendai framework is encapsulated in the new National Disaster Resilience Strategy 2019. Given the newness of the framework its effectiveness has yet to be determined. However, it does mention changes to accessing restricted medication, which researchers recommend to reduce the risk of adverse health outcomes from a disaster for many chronically ill people (Carameli et al., 2013; Tomio & Sato, 2014).

Also, by accepting Phibbs et al. (2016) argument that key concepts in the framework align with Aoteaora New Zealand's public health concepts, it is possible that emergency management in Aotearoa New Zealand will become better at addressing the needs of the vulnerable including the chronically ill. While the framework approach is being built into the countries' relevant policies, strategies and plans, there is opportunity for this thesis to add to the body of research this framework is based on, as well as the limited research in Aotearoa New Zealand investigating chronic illness and natural hazards

This thesis provides a platform for people who have a chronic illness to contribute to the conversation, as mandated by the Sendai Framework, and to help to identify areas where more targeted preparedness strategies are needed such as input to back-up plans for accessing medial resources (e.g. blood pressure machines, sleep apnoea devices) when power outages occur, or temporary removal of system barriers such as three month limits on prescriptions so that medication can be accessed to supply 'Go Bags'.

Conclusion

To gain a better understanding of what it means to be chronically ill in a western society such as Aotearoa New Zealand, how people are represented in society was considered. WHO's narrative of the chronically ill is one of burden as it reports that an average of more than 70% of deaths globally result from chronic illnesses and records the significant financial cost of these premature deaths on countries (WHO, 2005, 2020). Within healthcare contexts, the chronically ill are represented as both a burden and responsible for their ill health due to poor lifestyle choices (Galvin, 2002; Walton & Lazzaro-Salazar, 2016). Such representations attribute to social norms which shape how the chronically ill make sense of themselves, and how they relate to others.

The underlying social mechanisms and structures that make up a society influence the experiences people have of health care and contribute to varying health outcomes across groups (Cragg et al., 2013; Stephens, 2008a). Political ideologies shape social context. With the adoption of liberal ideologies, countries including Aotearoa New Zealand have seen increases in health inequalities even though overall wealth has risen (Coburn, 2000). Such ideologies require the reduction of government-provided welfare that results in people either

resourcing their own health needs, or risking poor health outcomes (Coburn, 2000; Lupton, 1997). Government policies illustrated this shift in responsibility from the government onto the individual.

Emergency management policy requires individuals take responsibility for their own well-being and must prepare themselves for a disaster by evacuating, or storing food, water, and other essential items (Blake, Marlowe, et al., 2017b; Bolin & Kurtz, 2018; Naser-Hall, 2013). Those unable to prepare because of system barriers (limits on prescriptions etc), ill health and / or because they cannot afford the necessary resources, are at greater risk of dying, injury, or exacerbated ill health (Blake, Marlowe, et al., 2017b; Bolin & Kurtz, 2018; Naser-Hall, 2013).

Disasters magnify underlying social inequalities and inequities faced by the chronically ill, resulting in disproportionately high rates of mortality and morbidity (Jhung et al., 2007). This will only worsen if countries continue to fail to address the vulnerability needs of people with chronic illnesses (Blake, Marlowe, et al., 2017b). The knowledge gained from speaking with chronically ill people living in hazard prone Petone, will help better inform the emergency management sector about what matters to the health and wellbeing of the chronically ill in a disaster.

Chapter Three: Theoretical Perspective and Methodology

> "*Methodology: the strategy, plan of action, process or design lying behind the choice and use of particular methods and linking the choice and use of methods to the desired outcomes.*
>
> *Theoretical perspective: the philosophical stance informing the methodology and thus providing a context for the process and grounding its logic and criteria"*
>
> Crotty (1998, p. 3)

Introduction

The aim of this thesis is to better understand the experiences of people with chronic illness living in Petone, Lower Hutt, Aotearoa New Zealand, which is prone to natural hazard events, and how this context may matter to their health and wellbeing. As discussed in the previous chapter, this requires consideration of the people's personal experiences, as well as social, economic, and political processes that shape those experiences. To better understand such influences on people's experiences it is necessary to break down the theoretical perspectives (Narrative and Foucauldian theories) that underpin this thesis so that it is clear where this work sits in relation to existing research and to make the research assumptions explicit.

Health Psychology

Like other fields of knowledge and activity, health psychology is a product of its own historical and cultural context, with its development deeply rooted in the mainstream fields of medicine and psychology, which have an individualist and positivist epistemological stance (Chamberlain & Murray, 2009; Murray & Campbell, 2003). By emulating medical science's positivist epistemological approach, health psychology established value and legitimacy within the scientific world, but also limited the value of its own contribution and subjected itself to criticism (Murray & Chamberlain, 1999).

In traditional health psychology, a positivist epistemological approach assumes that meaning and consciousness are separate, and that the world can be explained through the examination of objects, resulting in definitive truths and objective knowledge (Crotty, 1998). Such an approach assumes that there is a 'truth' to be uncovered which is fixed, individually based, and separate from the social world. This approach also assumes that individuals are rational so their behaviour can be explained by focusing on measurable cognitive and behaviour variables such as diet choices and levels of exercise (Lyons & Chamberlain, 2006; Murray & Campbell, 2003; Willig & Stainton Rogers, 2017).

In contrast, applying a critical health psychology lens to research, as Lyons and Chamberlain (2006) explain, directs attention to social injustices and inequalities resulting from dominant discourses and advocates for the value of insights gained from people whose knowledge is otherwise subjugated. There is no one plan, agreed steps, or fixed understanding of how to apply a critical lens to research however (Lyons & Chamberlain, 2006; Murray, 2015). From a critical health psychology perspective, knowledge is fluid and is produced within a cultural, historical, political, and social context, and issues of power

within these structures are key to people's health and illness experiences (Chamberlain & Murray, 2009; Lyons & Chamberlain, 2006; Murray, 2015).

Taking a critical approach enhances our understanding of experiences of chronic illnesses in a disaster context by challenging the assumptions made by dominant knowledge sources in these fields. These include neo-liberalism and the biomedical model of health, that are dominant knowledge sources in Western societies. Neoliberalism is an economic paradigm dominant in western countries which involved the reduction of protective barriers and economic regulations to facilitated a free-market economy and minimise a welfare state (Danaher et al., 2000; Newheiser, 2016). From a Foucauldian perspective this means that market forces set the scope of the workings of government (Danaher et al., 2000).

Also, a dominant paradigm in the west is the biomedical model of health. This model of health stems from medical knowledge that focused on bodily processes as separate from those of the mind (Lyons & Chamberlain, 2006). Disease and treatment are identified and explained in physical terms, and health is defined at a physical or biochemical level (Lyons & Chamberlain, 2006).

These forms of knowledge are the basis for the political and social structures that shape people's experiences of the world. Take for example, the chronically ill's illness experiences within a disaster context, which are shaped by individualistic discourse and medicalisation critiques that operate within neo-liberal societies (Beck & Beck-Gernsheim, 2002; Lupton, 1997). Similarly, emergency management practices are shaped by these knowledges, which result in strategies that privilege the able bodied and well resourced, and disadvantage those with health concerns and/or who are poorly resourced (Blake, Marlowe, et al., 2017b; Tuohy & Stephens, 2012). Taking a critical approach to health can empower the disempowered, such as the chronically ill, by advocating for a shift in the dominant value

system, for instance from promoting autonomy to promoting interdependence (Prilleltensky & Prilleltensky, 2003).

This chapter tells the story of the theoretical perspective and methodology behind this research by presenting an overview of a narrative approach, and then outlines some key Foucauldian strategies that informed the research. It outlines important background information about the discourses that dominate health and disaster fields.

Methodology and Theoretical Perspectives

Applying criticality to matters of health and disaster research means arguing that people and their lives are complex and changeable, as well as striving to understand and gain insight into their experiences of the world (Murray, 2015). Narrative psychology enables such examination by providing an alternative theoretical perspective that proposes that illness experiences are storied in nature and examination of such stories provides a means of understanding illness (Lyons & Chamberlain, 2006).

Narrative

Narrative has been defined by scholars such as Sarbin (1986) and Polkinghorne (1988) in terms of an organising principle or as a set of rules for human conduct, conceptualising people as natural storytellers who think about life in storied form "unfolding over time" (McAdams, 2018, p. 364; Stephens, 2011). Narrative is a theoretical perspective that when used as an approach to understanding people's stories can uncover "how identity and experience are constructed at the intersection of personal, interpersonal, and cultural narratives" (Stephens, 2011, p. 15). Also important, is identifying the social and cultural

issues by exploring how resistance and power, for example, operate within the social and cultural context (Lyons & Chamberlain, 2006).

The storied nature in which people construct their thoughts and share their views of the world is a concept from narrative psychology, and narrative approaches are commonly used to explore the illness experience (Murray, 1997; Murray & Chamberlain, 1999; Stephens, 2008a). Such approaches are based on the notion that people understand their experiences of the world through narration (Murray, 1997). For example, making sense of an illness involves a narrative process where people restore meaning (and, therefore, order) to their life by conceptualising and sharing the experience in storied form. A narrative approach is an effective way of developing a better understanding of the experiences of people with chronic illness living in Petone because their stories help to explain and understand the impact of having an illness in a hazard zone. These stories of chronic illness can be understood as a personal process involving biographical disruption and biographical flow and also as a social process where social representations of health and chronic illness shape individual experiences, as well as others' understandings of the chronically ill.

Understanding health as a set of highly valued social practices provides insight into how people give meaning to their health and illness experiences, because meaningfulness is intertwined with lived experience. Meaningfulness is historically and contextually based, and the understanding of it is a matter of interpretation (Crawford, 2006). As Crawford explains "meanings have consequences" not only in how they shape and alter people's experiences, and behaviours, but also the effect meaning can have on ideology" (2006, p. 402). People make sense of their lived experiences through stories and interpretation of these stories provides a better understanding of issues of power and marginalisation, as well as sociocultural changes that impact on people's experiences of health and wellbeing (Chamberlain & Murray, 2009).

Narrative allows for the consideration and examination of how people perceive themselves and others, how they organise and make sense of these perceptions, and how they convey understandings of self, their experiences, and the world around them (Stephens, 2011). Narrative provides robust details about social life as it enables the expression of connections between personal, social, and cultural conventions (E. G. Mishler, 1995). Illness narratives provide, according to Herzlich, "a basis of meaning, a signifier whose signified is the individual's relationship to the social order" (1995, pp. 160-161). She argues that, when people conceptualise their understandings of illness, they are actually sharing reflections of society and their relationship with it. Illness as signifier of the relationship between the signified (the ill person) and society is evident when considering how certain terms signify the status of people within the social order. Illness narratives also represent wider social discourses that interact with and uphold narratives, as such this thesis is also informed by ideas from Foucault which are now discussed.

Foucault, 'truth', and individual responsibility

Foucault's notion of governmentality provides an explanation for how dominant knowledge can be used by those in power to manipulate populations. Foucault conceptualises this as a process whereby the State asserts discourses to educate and regulate citizens about appropriate actions that lead to people monitoring their own behaviour and taking individual responsibility for themselves rather than being supported by the State (Danaher et al., 2000). Governmentality for Foucault was a process where the government regulated its people through discourses distributed by approved bodies and institutions (Danaher et al., 2000). Through these discourses (e.g. health), people learned to regulate their behaviour through self-surveillance (Danaher et al., 2000; Lyons & Chamberlain, 2006). Foucault's

governmentality is helpful when trying to make sense of the manner in which people with chronic illnesses are regulated and controlled through neoliberal government institutions.

It is the role of government institutions and universities to produce and distribute the knowledge that educates people about how they should behave. Such knowledge is given the status of "truths" (White, White, Wijaya, & Epston, 1990, pp. 19-20). It is through these "truths" that social norms are embedded into people's lives through a process of normalisation (Lyons & Chamberlain, 2006; White et al., 1990). For Foucault, normalisation involves governments (and other authoritative institutions such as universities) moulding, organising, or punishing (i.e. by exclusion) their subjects through its "truths" which determine the type of lives they live (Danaher et al., 2000; White et al., 1990).

White and Epston (1989) argue that such "truths" act as normalisers by specifying societal norms by which people's lives are constructed or shaped. Critical researchers argue that the "truths" about health and illness prescribed by the biomedical model are so embedded in people's understandings of health, that lived experiences of bodily sensations are mediated and influenced by constructs of health information (Lyons & Chamberlain, 2006). For Foucault, aligning 'truth' to specific knowledge systems like health and emergency management is all about power in that it involves a determination of a specific kind of individuality ('healthy' or 'abnormal'; 'at risk' or 'vulnerable') which is used to exert power for the benefit of dominant social groups (Danaher et al., 2000; White & Epston, 1989). Foucault considers that the effect of this type of power is to subjugate rather than repress, and 'forges persons as "double bodies," conscripting them into activities that support the proliferation of "global" and "unitary" knowledges, which as techniques of power can be claimed as the objective truth (White & Epston, 1989, p. 20).

Foucault argued that the reciprocal power "truth" dynamic determines an individuality that is powerful, and which subjugates rather than represses (White et al., 1990). Through subjugation, people, specifically their bodies, are "judged, condemned, classified, determined in our understanding, destined to a certain mode of living or dying, which are the bearers of the specific effects of power" (White et al., 1990, p. 20). Therefore, in accordance with the dominant biomedical narrative the responsibility for poor health is placed on the individual and behaviour change strategies are used to educate people of the right way to behave so they can choose to be healthy, and as such good citizens (Crawford, 2006). The relationship between individual behaviour and illness was legitimised as 'truth' through medical research which supported the ideological shift from State welfare to individual responsibility for health, using approved theories which became known collectively as social cognition models (Lyons & Chamberlain, 2006; Murray, 2015).

Violence and justice

Some argue that the use of truth in fields such as psychology can be a kind of violence where discourses that offer different 'truths' are marginalised or excluded (Rose, 1998). Teo calls this an 'epistemological violence' that those in power use to marginalise certain groups (Fox, Prilleltensky, & Austin, 2009). From a critical perspective, it is argued that presenting one form of knowledge as 'truth' draws attention away from the influence of other issues such as the impact of social inequalities on health in a disaster context (Chamberlain & Murray, 2009).

A critical approach has the potential to counter such injustice by giving people a platform from which to be heard, considering the influences of social context on the health of the chronically ill. So far, the biomedical model of health dominating Western society has

silenced people's subjective experiences by assuming that illnesses are only caused by biological and behavioural factors. However, research shows that these factors alone do not explain the development of chronic illnesses such as type two diabetes or cardiovascular disease (Lyons & Chamberlain, 2006). Such illness development is influenced by multiple factors including physical, psychological, and social factors that shape people's experiences of health and illness. Therefore, the role that social context plays in the lives of people with chronic illnesses needs to be considered.

Disaster and Health Dominant Discourses

From a critical narrative and Foucauldian perspective, dominant discourses are used by governments, institutions and private organisations, to exert their power through directing knowledge that informs social practices (Blake, Marlowe, et al., 2017b; Chamberlain & Murray, 2009; M. Crossley, 2000). Examining these discourses helps to make sense of how people experience the world, and the role that dominant discourses play in influencing those experiences. As such health and disaster discourses are relevant to people's disaster and health and illness experiences.

Discourses and narratives around chronic illness are embedded in social context which Prilleltensky and Prilleltensky (2003) argue is a bounded relationship between health and power that results in a power differential between the healthy and the sick. According to them "when we value physical independence above all else and regard it as imperative to a positive sense of self, we marginalize and exclude those who cannot attain it" (Prilleltensky & Prilleltensky, 2003, p. 198). Challenging these discourses would require a shift to valuing the diversity of living with chronic illness instead of measuring a person's value by the level

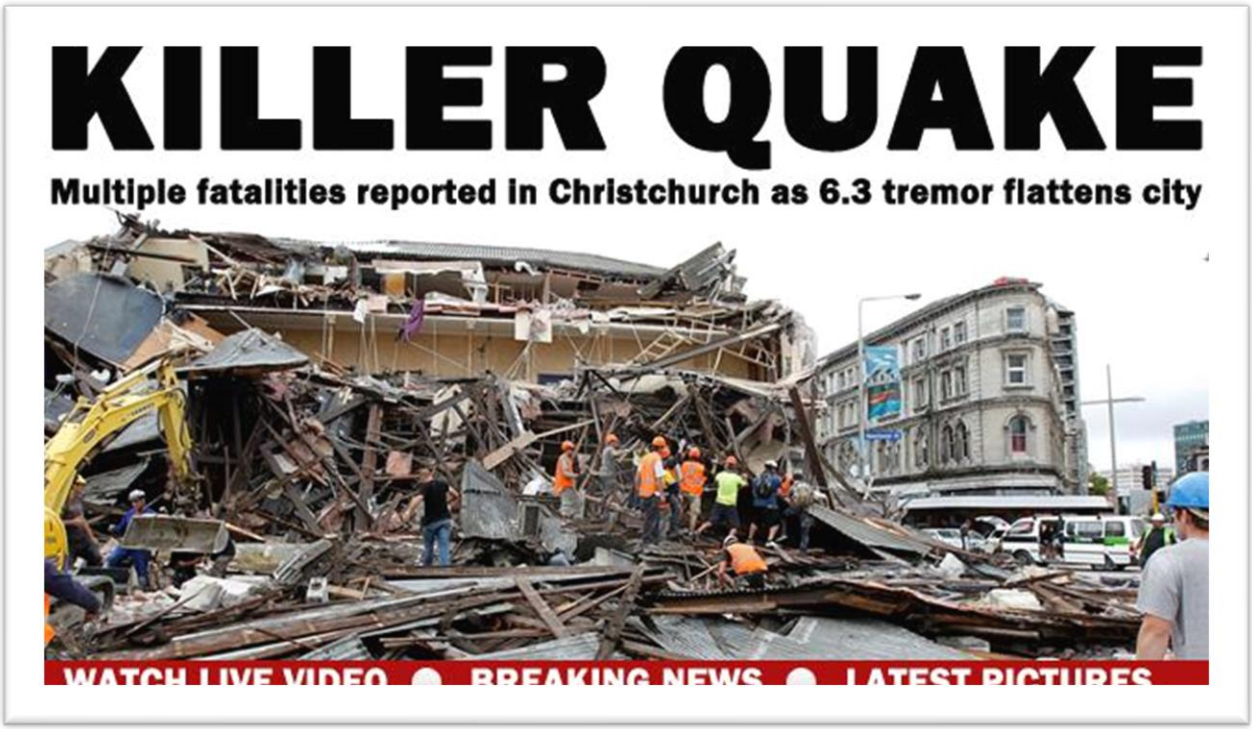
of physical independence they can or cannot achieve (Prilleltensky & Prilleltensky, 2003). Another way of looking at this relationship between health and power is by considering how privileging certain understandings of health can shape people's perception and interpretation of illness experiences as illustrated in people's narratives of these experiences.

Dominant medical discourse (including that produced by dominant forms of knowledge production) subjugates lay people's illness knowledge to the lower levels of society because it comes from patients rather than professionals and is therefore considered separate from the legitimate and accepted forms of knowledge (Lyons & Chamberlain, 2006; White & Epston, 1989). Foucault's concept of 'subjugated knowledges' helps explain why the majority of this type of research provides a scientific narrative that focuses on statistical analyses of the problem of chronic illness. However, critical researchers argue that 'lay' experts can contribute valuable knowledge about chronic illness (Lawton, 2003; A Radley, 1994). In support, Herzlich (1995) proposes that, through the mastery of medical techniques and knowledge (e.g. home dialysis used by kidney patients), patients can cease to be passive as they shift from being someone who submits to the imposed discourses of medical professionals as expert.

The dominant disaster discourse is said to have links with the Enlightenment period when positivist science viewed nature as something to be empirically and objectively observed and studied. Alternatively, society and human behaviour was considered a metaphysical phenomenon outside of the scope of science (Scandlyn, Simon, Thomas, & Brett, 2010). Also, dominant disaster discourse is connected with the Cold War period when the United States developed a civil defence approach that would provide protection from attacks made by outside enemies (Scandlyn et al., 2010). As such Scandlyn et al. (2010) argues disasters were approached and examined in terms of causes attributed to nature not humans.

Such beginnings have resulted in dominant disaster discourse being based on the positivist assumption that disasters can be understood and measured objectively. Therefore, as a dominant approach most disaster researchers view disasters as events triggered or caused by natural hazards (hazards such as earthquakes, tsunamis etc) that impact on people to varying degrees depending on their level of vulnerability. For instance, the dominant disaster approach to measuring vulnerability is through determining risk factors that can be investigated and measured objectively through the use of scientific technologies (Bolin & Kurtz, 2018; Wisner, 2004; Wisner et al., 2012). Scandlyn et al. (2010) explains, this notion of disasters as "natural events" resulting from "extremes of nature", is a commonly held theory worldwide as evident in media reports of such events (p. 38). Figure 10 provides a good example of how media reporting represents natural hazard events:

Figure 10 *News headline after 2011 Christchurch earthquake (News.com.au, 2011)*



Through dominant discourses, disaster research tends to emphasise risk and people's physical vulnerabilities, ignoring personal capacities and pre-existing social conditions. This is particularly evident in studies of the impact disasters have on the chronically ill, where the focus is on risk and vulnerability caused by the limiting physical nature of chronic illness and adverse health caused by disruption of treatment (Wisner, 2004). Wisner (2004) further argues that terms like 'vulnerability' used in disaster research affects how particular groups are understood. He notes that even research that emphasises the role of social, economic, and political processes in people's vulnerability to disasters, can ignore people's competencies and instead highlight their limitations and weaknesses, and represent them as passive or victims. Wisner (2004) argues that disaster analysis must show the relationship between disasters, and those vulnerabilities that are part of people's everyday life. While in this work, the term vulnerability is used, it is understood as layers that can be added and removed.

According to scholars such as Becker (1963), Spector and Kitsue (1977) and Gusfield (1967), the use of categories such as 'vulnerable', 'disabled', 'abnormal' etc, are used intentionally by those in power to exert a type of social control, to define how certain people should behave (Conrad & Barker, 2010). Take for example, the power of a label such as 'chronic' and how it can be used to define a group of people purely on biological terms alone. Conrad and Barker (2010) assert that the use of illness labels like 'chronic' have real social consequences for people as being labelled identifies whether a person is socially acceptable or not (Chamberlain & Murray, 2009).

Along with discourses of vulnerability, as demonstrated disaster research is also dominated by risk discourses that are embedded within society through strategies that normalise privilege and exclude certain groups (Lupton, 2013). The effects risk discourses have on particular social groups such as the chronically ill includes stigmatisation and marginalisation as "other", "abnormal", "unhealthy" and has resulted in this group being

represented as responsible and to blamed for their conditions (Lupton, 2013; Petersen, 1997; Walton & Lazzaro-Salazar, 2016).

The risk discourse is not limited to the study of disasters. Its importance and pervasiveness have resulted in it becoming a powerful cultural concept in modern society (Beck, 1992; Lupton, 2013). Risk has become synonymous with health, with health a powerful social practice that requires significant social resources, pervades core institutions, and creates knowledge, commercial enterprises, professionalism, services, and goods (Crawford, 2006). It has resulted in the medicalisation of everyday life that affects the way people think about their bodies (Chamberlain & Murray, 2009; Lyons & Chamberlain, 2006).

Also, influencing how people think about health in disasters is medicine's biomedical model of health and disease. This model emphasises physical processes and explanations for illness and injury which are observable and measurable, and separate from body and mind (Lyons & Chamberlain, 2006; Thompson, 2014). This understanding of health and illness is deeply embedded in Western society and has been legitimised as the 'truth' having come from dominant knowledge sources such as medicine. This dominant health discourse must be considered as this thesis, along with having roots in emergency management, is grounded in health psychology which has a strong interdisciplinary relationship with both medicine and psychology.

These dominant discourses frame the way people, including the chronically ill, understand themselves, the way they are perceived by others, and how they are represented in society. Yet such discourses are only one way of thinking about health and disaster. A critical narrative approach challenges these understandings, and places the emphasis on people, the social world, and the effects of power dynamics imposed on people through the social, economic, and political systems in which they live (Murray, 2015; Petersen & Lupton, 2000).

Conclusion

So far, research has provided us with a specific understanding of the impact of disasters on the chronically ill, and how to ameliorate this impact. Most research tells us that there is a problem with the chronically ill (they experience significant health risk due to vulnerable health) without further insight. This type of research, though dominant in this field, does not identify the preparedness and recovery needs of the chronically ill beyond additional medication and medical assistance, and so does not equip governments to effectively reduce the impact of disasters for those with chronic illnesses.

Critiques of the current positivist approach to disaster research about the impacts of disasters on the chronically ill argue that the failure to address their needs in a disaster is a manifestation of underlying socio-political inequalities which are masked by dominant discourses that focus attention on illness and away from individualist social and political agendas (Blake, Marlowe, et al., 2017b; Lupton, 1997; G. Williams, 1993). Critical research shows that preparedness policies and practices tend to be based on discourses of risk and vulnerability and privilege certain groups over others (Blake, Marlowe, et al., 2017b; Lupton, 2013; Tuohy et al., 2015). These discourses dominate Western societies, guiding governments to place responsibility for health on the individual. This is evident in the use of social cognition models, which focus on behaviour change for which the individual is considered responsible. The use of such models does not identify or address the needs of the chronically ill. Instead, by positing/assuming that people are rational, in control, and responsible for meeting their own individual health needs, it avoids the task of identifying or addressing individuals' needs, and instead legitimises the dominant discourse of health derived from medicine's biomedical model of health. Therefore, beyond the numbers of chronically ill adversely impacted by disasters, little is known about the experiences of

people with chronic illness living in areas prone to disasters. This limits the insight that can be provided into how preparedness strategies might be developed in a way that ameliorates the high impact of disasters on the chronically ill. Through a critical lens, this thesis considers the fields of health and disaster from a narrative psychology and a Foucauldian perspective to help make sense of the relationship between dominant discourse and power, and how this relationship contributes to people's experiences of chronic illness in the disaster context.

Chapter Four: Methods

"*It is argued that as social scientists we can use illness narratives as a means of studying not only the world of biomedical reality, but also the illness experience and its social and cultural underpinnings*." Hydén (1997, p. 48)

Introduction

This chapter outlines the methods used in this research. Important to the research design are the research questions and the context that shape the research. This research broadly asked how people with chronic illnesses experience living in Petone, a seaside settlement located in Lower Hutt, Aotearoa New Zealand that is prone to natural hazards and how living in this area prone might impact on people's health. As such this section begins with an overview of Petone. It then covers the recruitment of people for the study and information about those people who took part in the study. Next the interview process is outlined and narrative interviews detailed. Following this is the consideration of the ethical issues for this study. The chapter ends with discussion of the analytical process.

Research Context and Design

Petone

Petone has historically been known as a major industrial area for Aotearoa New Zealand with big manufacturing companies producing wool, meat, and vehicles based there from the late 1870s through to the 1960s (Butterworth, 1988). As such, traditionally Petone residents were working class. This began to change with the closure of a number of the big

manufacturers in the 60s, 70s, and 80s, resulting in the exodus of working-class residents who had to seek employment elsewhere. Figure 11 depicts the General Motors car factory in the 1940s, which was the biggest manufacturers of cars in Aotearoa New Zealand until its closure in 1984 (Butterworth, 1988).

Figure 11 *General Motors Plant, Petone 1940 (Gordon Onslow Hilbury, 1940)*

While the closure of many large-scale manufacturers in Petone was devastating for local workers, these closures did have a positive impact for the natural environment which benefited from the reduction of pollutants which plagued Petone through its industrial boom. With the improvement to the environment and its access to the sea for recreation as well as its views of the ocean, Petone went through a ‘gentrification’ period that has resulted in it now

being predominately a suburb of middle to high household income residents (Butterworth, 1988; Hutt City, 2020; *Petone (Pito-One) first 100 years, 1840-1940 : progress & prosperity : history and traditions from farms to factories*, 1940).

Petone is prone to natural hazard events such as earthquakes, tsunamis, flooding etc because of its geographical location, geological make-up, and medium density population (Saunders & Beban, 2014). Petone is a popular coastal suburb located on reclaimed land and a floodplain making it prone to flooding, erosion, and slips (Grant et al., 2005; Saunders & Beban, 2014). It is also near the Wellington Fault making it susceptible to earthquakes, liquefaction, and tsunamis (Blake et al., 2018; Grant et al., 2005). Petone residents experienced significant disruption from the 2016 Kaikoura earthquake which resulted in a tsunami evacuation, power outages, and road closures (Blake et al., 2018). As this study was interested in people's experiences of illness and natural hazard events, it was decided that a hazard prone area such as Petone would provide a sample of people with both chronic illnesses and natural hazard event experience.

Recruiting Petone residents

After receiving Massey University ethics approval to conduct this research (Ethics approval number 19/17), eight people were recruited using personal networks that I had developed as a Massey University student as a volunteer at Citizens Advice Services Lower Hutt, a service that provides people with information, advice, and support about a wide range of issues. The manager of Petone's Citizens Advice Service was contacted and research information sheets were distributed to volunteers. They in turn distributed them to anyone that they thought might be interested in participating. Contacts in the Petone Advice bureaus were also contacted due to their connections with Petone, and provided with information

sheets which they distributed to Petone residents with chronic illnesses. Also, a contact made through Massey University was approached as they were involved in a Petone volunteer group. This type of recruitment strategy is commonly referred to as snowball sampling, where an initial contact suggests other people who may potentially meet the selection criteria and be interested in participating (Rohleder & Lyons, 2015).

Through these personal networks, nine people agreed to participate in the research and were interviewed. In narrative research, sample sizes are generally smaller because of the depth of analysis that is conducted, with in-depth interviewing generating rich data (Guest, Bunce, & Johnson, 2006; Romney, Weller, & Batchelder, 1986). Research has found that smaller samples are effective in providing accurate and robust information when participants have sufficient experience in regard to the topic (e.g. having a specific condition or living in particular area) (Guest et al., 2006; Romney et al., 1986). Guest, Bruce, and Johnson (2006) propose that there is no specific right number of participants, rather that sample size is dependent on the type of research undertaken, and the point where data saturation occurs is when data collection and analysis no longer provides new information.

The eight people who participated in this study will be referred to as ‘tellers’ instead of participants. This is because ‘participant’ is terminology usually associated with quantitative research and its individualistic, biologically focused discourse. As Chamberlain and Murray (2009) argue, people are more than just “fixed objects” for science to study, and the use of a critical approach enables the complex, evolving, and diverse nature of people to be explored (p. 146). Given this study’s critical narrative approach it was decided to refer to the eight people as storytellers (‘tellers’ for short).

Enrolment of tellers

An information sheet (Appendix 2) was provided to tellers at the time of recruitment and again before interviews took place. The sheet included a description of the study and asked that those interested in participating contact either the researcher or supervisor directly. People who had been given information sheets and shown an interest in participating by providing their contact details were contacted by the researcher and asked if they wished to participate. It was explained that the sheet's list of illnesses was not exhaustive, and people were asked to decide based on their own experience if they had a chronic illness rather than the researcher.

Feedback at the time of recruiting was that there was confusion regarding the definition of a chronic illness and that some people may have chosen not to participate because of this. There was also feedback from a friend, who on my behalf had approached chronically ill people they knew and asked if they wished to participate in the study, that people did not wish to participate because "they had already given enough time to their illness". This issue may be worth considering by others who wish to conduct similar research. These issues resulted in a much longer recruitment period than expected and interviewing occurred later than predicted, which increased the research's overall timeframe.

Once people had agreed to participate, a suitable date, time, and location for the interview was organised. People were also advised they could have a support person present at the interview. No one requested a support person, though on two occasions a spouse was present. In one case the spouse agreed to be a teller also and was interviewed along with their spouse who was the original teller. This was particularly useful as they were able to speak on behalf of their child who had a chronic condition as discussed above.

In the other case, a spouse provided some input during the interviewing process when the teller asked on a few occasions to clarify details about events including how long they had lived in Petone, and where they were when the Kaikoura earthquake occurred. While the spouse provided some support they were not specifically interviewed for this study. Therefore, it is not considered that they participated in the research other than as a support person for their spouse.

Of the nine interviewed, one person's interview was excluded from analysis. The person was interviewed because while they did volunteer work in Petone, they did not live or had not lived in Petone. From the interview it became clear that the person's only connection with Petone was a couple of hours a week volunteering in the area. It was determined that their lack of familiarity with life and the community of Petone meant they had little to contribute in terms of lived experiences in the suburb and therefore, did not meet the research objectives.

Tellers' Demographics

The remaining eight tellers had lived in Petone. Seven were currently living in the suburb, and one had lived in Petone for many years but at the time of interview was living elsewhere in the region. This teller wished to participate in the study because as a person with a chronic illness who had lived in Petone, they had experiences they wished to share. To accommodate their request a minor amendment to the research's ethics application was made so it read "participants must have lived in Petone at some time" rather than "must live in Petone". This amendment was approved by Massey's Human Ethics Committee.

Three people identified as male, with five identifying as female. Seven identified as Pākehā / European, and one as a New Zealand citizen born in England. Aotearoa New Zealand has a diverse range of ethnicities and cultures, including Māori and Pacific Peoples. Despite this diversity, the recruitment process resulted in Pākehā / European participants only. The limited ethnic diversity may be due to utilising personal networks based on volunteer work, postgraduate study, and work contacts, rather than purposeful cross-cultural recruitment. Such social contexts in turn may lack ethnic diversity. However, while the people who agreed to participate are valuable as "cultural artefacts"(Goodley, 2011, p. 137) because they offer a glimpse into the social and cultural world for Petone residents, additional cross-cultural research is necessary. This would better serve to support a more culturally inclusive knowledge about experiences of chronic illnesses in hazard prone areas. This is particularly important in a country that claims to support the human rights of its indigenous people, who are unfairly bearing the consequences of the long-term effects of colonisation (Came, 2021). This includes greater prevalence of long-term chronic health conditions due to disproportionate numbers of Māori living in economic hardship (Bloomfield, 2017).

The tellers in this study are diverse in socio-economic status and age. The types of housing they lived in varied from state owned housing, privately owned, and private rental. Four lived on their own and four lived with spouses and / or children. Interviewing tellers from a range of socio-economic backgrounds was important to this research because of the significant role socio-economic positions play in shaping peoples' health and disaster experiences. As previous discussed, research categorically shows social inequalities such as social status can cause significant health care inequities and health disparity before and after a disaster and is therefore relevant to people's experiences of health in the event of a disaster (Bolin & Kurtz, 2018; Lyons & Chamberlain, 2006; Naser-Hall, 2013; Stephens, 2008a).

The tellers' ages ranged from mid 40s to 80 plus years of age. Two people spoke on behalf of their child (14 years of age) who had a chronic condition which required daily management. The child wished to participate but ethics approval for this research did not include interviewing children. However, the Massey's Human Ethics Committee approved the parents speaking for their child. The inclusion of the parents introduces the caregiver's perspective into the study and expands the story of life in Petone with a chronic illness. It is also in keeping with Massey's Code of Ethics value of justice by including all those who wish to participate in the study.

It was decided that having a chronic illness could include such things as diabetes, cancer, cardiovascular diseases, respiratory diseases, neurological diseases, kidney disease, and chronic pain. This was not an exhaustive list so there was flexibility should a person with a condition that was not covered by this list wish to participate. The chronic illnesses that the eight people who agreed to participate in the study have are: High blood pressure; arthritis; cardio-vascular disease; a chronic blood condition; chronic pain; celiac disease; ME; and hyperthyroidism.

One of the tellers had an autoimmune disorder which did not fall within the list but did meet the definition of chronic illness chosen for this research: "any ongoing, long-term or recurring condition that can have a significant impact on people's lives." (Walton & Lazzaro-Salazar, 2016, p. 460).

The Tellers

A more in-depth introduction to each of the eight people is warranted as it is their stories that are being scrutinised. Valuing people's anonymity, the biography for each teller

provided does not include identifying details, and only includes details they were willing to share at the interview. It is hoped that these biographies will provide some personal context for the stories the tellers shared, and will ensure their voices are not lost in the analysis process.

Teller One

Teller One is a long-time resident of Petone and loves living there because "*…it's like a community, a little community…"*, it's "*…got everything I need here.*", and "*…a lot of my friends 90-80% of my friends or 90% live in within the area.*" Having got sick of "*that big corporate world*" she chose to work locally, securing a job in the neighbourhood which she loves. Teller One has a car but prefers to walk or cycle when possible.

Having "*had an eating disorder most of my life*", Teller One is very health conscious. Alongside fulltime work, she worked in the fitness industry until she chose to give this up when she became ill with high blood pressure. She enjoys helping others even if this has sometimes meant she has sacrificed her own well-being. Though having had several emergency trips to the hospital due to high blood pressure and the subsequent self-management of that condition, she is working to say no to others and taking care of herself.

Teller Two

Teller Two has lived in Petone for 22 years and dedicated considerable time to serving the Petone community on various community boards. She has considerable local knowledge about Petone's heritage, it's geography, land resourcing and planning, and emergency management. Teller Two also has some experience of the "*the effect and possible aftermath of earthquakes*" having survived the 1968 Inangahua earthquake. The 7.4 magnitude earthquake occurred in the early hours on 24 May and resulted in 3 deaths, 14

injuries, and caused both property and infrastructure damage (Anderson et al., 1994; Earthquake War Damage Commission, 1969). Residents were cut off from the rest of Aotearoa New Zealand, with roads closed due to slips making evacuation by air the only option for some time (Earthquake War Damage Commission, 1969). Teller Two remembers "*having to go to collect water from somewhere, and we had to cook outside*", and "*that bottles of brandy became the thing you needed…to help get you to sleep*".

Teller Two has high blood pressure which she manages with daily medication and check ins with her doctor. Aside from the medication, the chronic illness features little in her daily life in Petone.

Teller Three and Teller Four

Teller Three and four are a married couple that wanted to speak about their teenage daughter's experience of Celiac disease. They have lived most of their married life in Petone with their three children. They are both professionals working in Wellington, while enjoying the Petone lifestyle, such as the sense of community and the beach. Teller Four explains:

"*For us we can just walk down to the shops. We can go to a pub or have dinner, go to a movie and then walk home*."

As identified above, their daughter was too young to speak about her chronic illness in this study, however both her parents provided stories of their experiences. Their daughter has suffered from Celiac all her life. She and her parents have become subject experts and highly skilled at managing the chronic illness which at its worst resulted in the daughter suffering from significant malnutrition due to constant vomiting. With forward planning, careful monitoring of food intake, and food being prepared separately, the impact of the illness is limited, though even with planning things can go wrong as Teller Three explains:

"*That fancy place in town for dinner, and I'd spoken to them first and they'd assured me that we'll be fine, but that night when she got home she was so unwell and I'm like they've obviously done something that she couldn't eat, so people aren't…sometimes people just aren't very careful*."

Teller Five

Having lived in another suburb for fifty years, Teller Five and his wife are relatively new residents of Petone. They moved there in early 2016 after the completion of the renovations to their home which is close to where their son and daughter live in Petone. While he misses the familiar faces of his old neighbourhood, Teller Five has settled into the Petone community well.

Teller Five has had a few health issues but remains as independent as possible, preferring to downplay the impact chronic illness has on his life, despite concerns of family and medical professionals. The same day as our interview, Teller Five had his driver license cancelled "*in the interests of peace*" instead of his failing health. He was also determined that having had a stroke, ongoing blood condition, or chronic joint pain did not mean he had a chronic illness because he did not think illnesses listed on the information sheet were chronic conditions. He did say that "*my only chronic condition is that I'm a pain in the butt to everybody"*. Teller Five has a wicked sense of humour which was utilised throughout our interview. His humour was evident in his first words at the interview when he asked "*Why have you picked on Petone?*" Later after I had sneezed, he asked if I *"was going to survive*".

Teller Six

Teller Six described himself as a "*mystic*" who has "*always been part of the new age era*" and refers to himself as "*the big I am*" which he explains means feeling "*...a part of the*

universe… I'm part of everything." He has had to contend with two chronic illnesses in his 90 plus years. He developed ME (myalgic encephalomyelitis), also known as chronic fatigue syndrome, while working in the late 1970s, and more recently had been diagnosed with hyperthyroidism. He described ME as "…*a terrible inconvenience and a hazard to myself and nobody else I don't know that I ever need support in any shape or form I worked until retirement*". Though in comparison he said that he would "*rather have ME than this hypo (hyperthyroidism)…truly truly truly would. ME is dreadful…hypo can destroy you mentally emotionally*".

Teller Six has lived in Petone since 1978 after buying his home there so that he was closer to work. He is proud of where he lives and the life he has made for himself. He enjoys having friends close by, though prefers to manage his life independently without support from others.

Teller Seven

Teller Seven, at the time of the interview, lived in Lower Hutt with her husband and two school children. She and her husband lived in Petone for several years at the beginning of their married life. Teller Seven wished to be included in the study because she felt her experiences as a past resident of Petone were as valid as those of current residents. As such, her experiences have been included. Teller Seven and her husband are professionals.

Teller Seven did not wish to share the origins of her chronic illness or provide specific details including diagnosis. Based on negative experiences she attributed to having a visible chronic illness, Teller Seven was reluctant to provide details in case they identified her. A focus of her illness story was her experiences of being stigmatized and disadvantaged due to her chronic illness, and how that lead to advocating for others. Teller Seven often spoke of her illness journey in reactionary terms:

"*People say oh you are so brave you're a role model an inspiration it's like (sigh) no I'm not I'm just coping with something*." Teller Seven

Teller Eight

Teller Eight immigrated from England with her husband after World War II as part of the "*Ten Pound Pom"* scheme, as it was commonly known at the time. They moved to Petone in 1979 and have lived in the same house ever since. She has remained in the home alone after her children became adults, and moved out, and her husband died.

Teller Eight worked for a local manufacturing company in Petone until she retired. In her retirement she has enjoyed being part of the local community and has established a strong social network amongst her neighbours. She catches up with people as she takes her daily walks around the neighbourhood, and on the bus up to the local shops in Petone. Now with chronic arthritis in her legs, and particularly when the wind is blowing, Teller Eights needs the support of a walker when she is out and about.

Interview Process

As stated above, before the interview the tellers were taken through the Information Sheet and asked if they had any questions. Answers were given and an overview of the study was provided. Each person was advised that they could interrupt anytime during the interview if they had questions, concerns, or wished to stop the interview because they were feeling distressed for any reason. Each person was advised that the interview would be audio-recorded and that copies and transcripts of the interview would be provided if the participant

asked for them. None requested a copy of the audio recording or a transcript of the interview prior to being interviewed.

All tellers agreed to having their interviews recorded. One participant was concerned that some of what they said might identify them, so it was agreed that any parts of their story that may be included in the research findings be checked with them for approval (this was outlined in their bio above). The interview was then recorded. All participants confirmed that they were happy to participate by signing a consent form (Appendix 3).

Each teller was advised that at any time during the interview the recording could be stopped. One teller at the end of the interview requested that the recording stop as they did not think that what they were talking about was relevant to the study. The recording was stopped immediately and started again on request.

Narrative interviews

Narrative interviews are a collaborative event where the interviewee and interviewer work together to create shared meanings that can be understood by both. The story teller and listener are necessary in the construction of the story, with the story teller steering the structuring of meaning, and the listener assisting through questions (Tuohy, 2014). This co-construction is the linguistic and cognitive manifestation of people's efforts to organise and make meaningful experiences within a specific context (E. Mishler, 1986). Narrative is contextually grounded so that experiences and events are bound to the situation in which they occurred. Without context, socio-cultural influences are not considered and meanings can be limited or shaped to create specific knowledge according to particular agendas (Lupton, 2013; White et al., 1990).

Narrative inquiry utilises an in-depth method of interviewing founded on the key principle of listening to develop an understanding of a person's lived experience (Chase, 2003). It is a collaborative approach with the researcher taking on the role of learner who listens to the participants' stories.

The narrative interview method involves asking people to tell their life stories or aspects of their lives including experiences of illness, while the interviewer listens without controlling the narrative through direction or interruption (M. Bauer & Gaskell, 2000). In keeping with the narrative method of interviewing, all the interviews were semi-structured. Semi-structured interviews enable people to express themselves narratively, as they are encouraged to tell the interviewer about their experiences through stories (Hiles, Čermák, & Chrz, 2007). In a semi-structured interview, there are no set questions, though an interview guide is generally created and used at interview should people need some encouragement to speak about themselves.

The questions in the interview guide for this research (Appendix 4) consisted of general open-ended questions that promoted extended answers, enabling the people to organise their experiences of events in a meaningful way that is then shared as a story (Rohleder & Lyons, 2015; Tuohy, 2014). In other words, the people were able to lead the interviews and tell their stories in the way they preferred. Such authenticity is intrinsic to the personal narrative concept, and is ethically important because tellers were informed that they would be telling their story as they preferred.

The interview guide questions were developed around themes of chronic illness, and natural hazards to keep the focus of the interview relevant to the research aim(s). Though they maintained a generalness that ensured sensitivity and reflexivity to accommodate tellers' individual experiences. The MUHEC approved this method of data collection.

Ethical Considerations

For the protection of the tellers in this research it was important that full ethical protocols were followed and approval sought from the Massey Human Ethics Committee ("ethics committee"). Details of the research were submitted to the ethics committee for consideration, and approval was granted before recruitment took place, as stated above.

The ethical issues that were considered included the potential for people to become distressed during the interview and maintaining privacy. As with most in depth, face to face interviewing there is a potential risk that participants may experience some emotional distress when talking about their experiences of chronic illness and natural hazards. For people with chronic illness, there is also concern that people will experience some physical distress.

To minimise such risks, the tellers were well informed throughout the research process. At the time of recruitment, the tellers were provided with an information sheet (Appendix 4) that informed them of the potential for distress from recollecting past experiences or talking about their condition. The tellers were also offered flexible interview times and lengths, as well as location choice such as conducting interviews in a familiar and safe environment including their homes or a favourite café. Tellers with mobility issues chose to be interviewed in their homes rather than meeting at a public place. Also, as discussed earlier, all tellers were given the option of having a support person present, and access to support organisations (e.g. Lifeline and Anxiety Line) if needed. None of the participants requested a support person be present, and no participant expressed any distress.

Tellers' privacy and confidentiality was maintained by replacing their names with pseudonyms based on the order in which they were interviewed (e.g. Teller One, Teller Two, etc). Their information was held on a password-protected system accessible only to the researcher and supervisor, and only used for this research.

The core value of respect was embodied in the use of the in-depth interviewing method previously discussed (narrative interviewing) which was also founded on the principle of collaboration and listening to develop an understanding of a person's lived experience. This involved the researcher taking on the role of learner by listening to tellers' stories, which aligns with Massey's Code of Ethics values kaua e takahia te mana o te tangata, and kaua e mahaki." Respect was practiced in every aspect of the research design and writing up stage.

Analysis

The audio-recordings for each of the interviews were transcribed and the transcribed data was coded and analysed using the methods set out in the Narrative Orientated Inquiry (NOI) model. The NOI model was designed to align with the idea that narratives function as a meaning making process, and are set within social, psychological, and cultural contexts (Hiles et al., 2009; E. G. Mishler, 1995; Riessman, 2008). This is achieved by incorporating the concept of narrative into each stage of the NOI model, namely, the development of a narrative based research query, narrative interviewing, and narrative analysis. Such a methodology enables the analysis to be deeper than the contents of stories. This exposes the functions storytelling play in cultural and social processes that are fundamental to how people structure and organise behaviour and experience (Hiles et al., 2017). In other words, analysis of narratives exposes the narrative structuring of how we think and the things that shape such structuring.

The NOI model was used as a guide for this study because it provides a level of analysis essential to better understand the lived experiences of the eight tellers who had

various SES backgrounds, with varying chronic illnesses, living in various types of homes, in disaster prone Petone. Each one of these people had their own story to tell and the NOI model provides an effective guide for making sense of each story within the context of this study.

The NOI Model of Narrative Analysis

NOI's close analysis of the way tellers position themselves within their narrative discourse (identity positions) provides very helpful insight into how they create meaning out of events such as chronic illness and natural hazards. The sjuzets (the way in which the story is told) of the tellers' narratives were relied on because they "are especially important in understanding the way in which an individual creates personal meaning" and reveal "the 'way' in which the person relating the story positions themselves in relation to the event being retold" (Hiles, Cermák, & Chrz, 2010, p. 110). It is via the analysis of the way that the tellers tell their story (sjuzet) and position themselves within the narrative that themes emerge. Therefore, once sjuzets were identified and the tellers' identity positioning coded, major themes were then identified using NOI's Categorical-Content analysis;

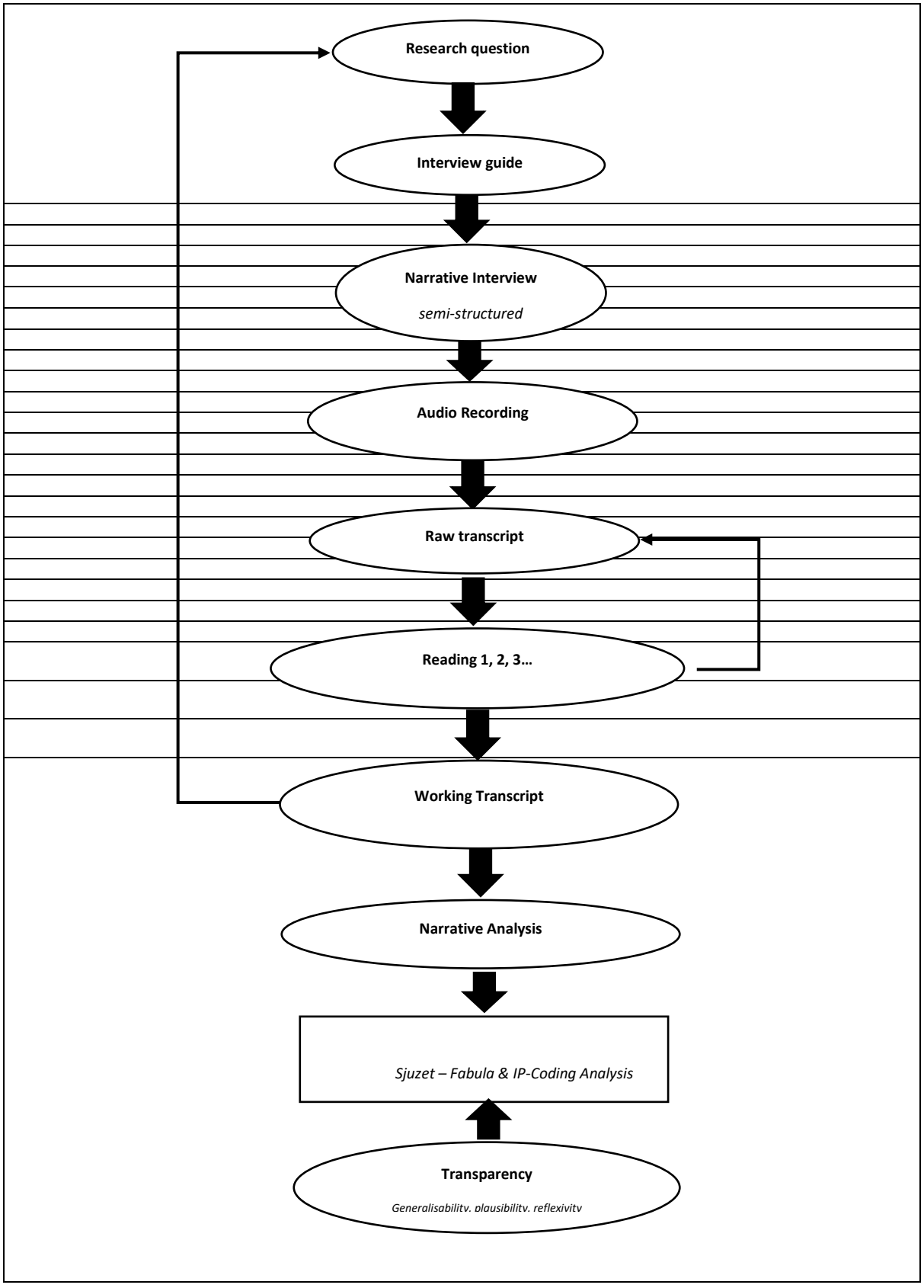
Hiles et al. argue these layers (or steps) of analysis distinguish the NOI process from a purely "thematic analysis", which can limit understanding to a set of themes, losing sight of the essence of the story and its teller (Hiles et al., 2010). The use of NOI's categorical-content analysis of the tellers' narratives involved defining the themes (or subcategories as Hiles et al. refers to them) within each person's narrative (Hiles & Cermák, 2008). The subcategories are selected based on relevance to the aims of the study. For example, illness experience is a focus of this study, and a major theme across all the tellers' illness stories was agency. Through categorical-content analysis of these stories, subcategories such as

independence, responsibility, and self-management were interpreted as contributing to the major theme of agency.

The final step in analysis from a NOI perspective is a critical examination of the tellers' stories. Consistent with my critical narrative and Foucauldian assumptions, this involved considering issues such as power dynamics, social and political contexts, and subject and identity positioning (Emerson & Frosh, 2004). It was important to take a critical approach to analysis to examine the effect that any dominant knowledge sources may have in shaping the tellers' narratives.

The NOI process is illustrated in Figure 12 and begins with development of the narrative-based research question through to narrative data analysis.

Figure 12 *Diagram of NOI research process adapted from Hiles et al. (2017).*



Central to this model is the narrative interview which Hiles et al. (2017) propose should be a collaboration of ideas between interviewer and interviewee. As outlined prior, this enables a co-production between teller and listener that results in each being able to make sense of structure and share what they understand of themselves, their experiences, and the world around them (E. G. Mishler, 1995). Instead of taking on the traditional roles of subject expert (interviewer) and subject (interviewee), in a narrative interview the interviewer and interviewee engage in a conversation where they jointly exchange ideas and create meaning (Hiles & Čermák, 2007; Hiles et al., 2009).

In accordance with the NOI narrative, the interviews were recorded so that transcripts were produced as a verbatim record of the interview including punctuation so that the transcript is read in the way the conversation took place (Hiles et al., 2017). Under the NOI model it is essential that justice be done to the whole story (Hiles & Čermák, 2007). Therefore, the only material removed is that which may identify the participant including their name.

The transcript was read several times to ensure that it reflected the interview. Once this was achieved the transcript was broken down into events or episodes to create a raw transcript. Segments (episodes/events) were numbered in sequential order. A table (e.g. Appendix 1) was then created and the segmented text placed on the left-hand side of the table, on the right-hand margin coding and comments were recorded (Hiles et al., 2017). Once it is at this stage, the transcript underwent basic NOI coding with text being identified as either a sjuzet, fabula or both.

Identifying sjuzet from fabula is the first of six interpretive perspectives involved in the NOI process (Hiles & Čermák, 2007). Hiles, Čermák and Chrz (2017) define a fabula as the story itself and involves an overview of how events may or might have occurred (Hiles et

al., 2017). As stated above, the sjuzet is the way in which or how the story is told. It relates to how a person places themselves in the story in relation to the action or an event, and is important because it shows how people make sense of themselves. The NOI model emphasises the importance of the sjuzet in understanding the psychological workings behind people's narratives, as it is the use of the sjuzet that indicates from whose point of view the story is being told, in what way it is being told, for what occasion, and in what order events are retold (Hiles et al., 2017).

Sometimes a word or phrase can be both a fabula and sjuzet, and when this occurs the word/phrase is bracketed to indicate the dual coding. Once a fabula or sjuzet is identified further content coding occurs. This includes the identification of the various identity positions (i.e. IP) that the narrator adopts throughout the telling of their story (e.g. IP -1 Sick person). Also, coding of narrative modes (e.g. CU – cultural etc) occurs and indicates the narrative type behind a phrase (i.e. CU – cultural, e.g. 'sweet as'). Table 2 provides a snapshot of the NOI Coding and Analysis Steps:

Table 2 *NOI Coding and Analysis Steps (Hiles & Čermák, 2007; Hiles et al., 2009, 2010)*

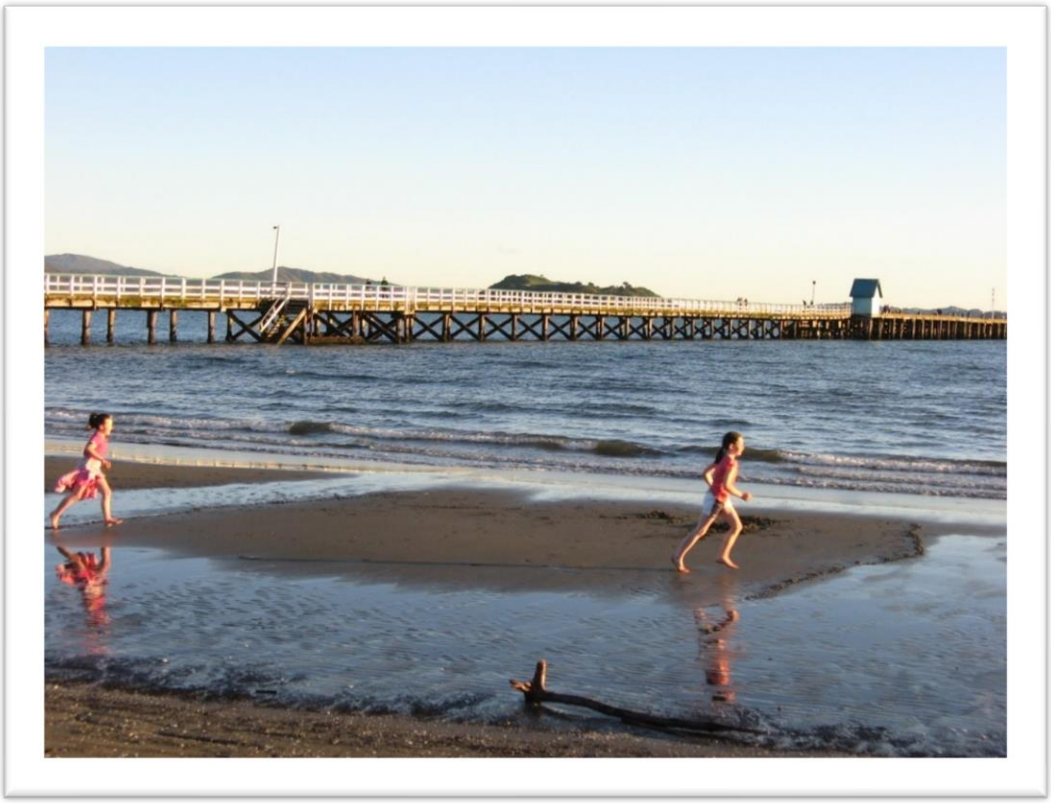
NOI Coding & Analysis Steps	**Details**
Preparing transcript 1. Raw Transcript	
2. Segmenting – raw transcript broken down into episodes/moves involved in telling of story, and numbered sequentially	1. 2. 3. 4.
3. Create table – Left hand side place segments; Right hand side for coding notation/notes/comments	Segments Coding notation/notes/comments 1. 2. 3.
Coding transcript a) Break text into Fabula/Sjuzet	Sjuzets are underlined; if both fabula and sjuzet (e.g. a metaphor) highlight and bracket text [*when pigs fly*]

b) Identify identity positions (IP)	IPs must be numbered: IP1, IP2, etc
c) Identify subplots	Subplots are identified as **Fab** which is noted on the right-hand side of the table
d) Identify structure of subplots	Each subplot/ **Fab** is like to include: *Abstract*/*Setting*/*Complication*/*Evaluation*/*Result* / *Coda*
e) Identify narration modes	Modes include: Cu., Im., Di., Pr., Ae., Co., Em.
Analysis: 5 techniques/perspectives	Refer Hiles et al (07) p6-7 for definitions
1. Holistic-Content	*Holistic-Content* relates to the links and associations throughout the story i.e. identification of a major theme for the entire story or a segment that illuminates the whole story.
2. Holistic-Form	*Holistic-Form* focuses on the story's form specifically the plot i.e. progression of the story e.g. U shaped
3. Categorical-Content	*Categorical-Content* relates to text being broken down into self-contained content that is then analysed for emerging themes
4. Categorical-Form	Categorical-Form requires an analysis of sjuzets for sighs, crying, laughter etc that may indicate un-integrated or difficult experiences
5. Critical-Analysis	Relates to the kind of account a narrator gives of their life i.e. What sort of narrative account of their life is a person constructing for themselves? How do they position themselves with respect to their sense of self in context of the series of events they recount?

The NOI process shown in the above table was used to guide the analysis process and therefore was not strictly adhered to. Text that was identified for analysis underwent an analysis that included fabula and sjuzet identification, identification of identity positions, and a categorical content analysis, all with a critical lens.

Chapter Five: Themes of Independence

Figure 13 *Children playing on Petone beach (Unconditional.co.nz).*



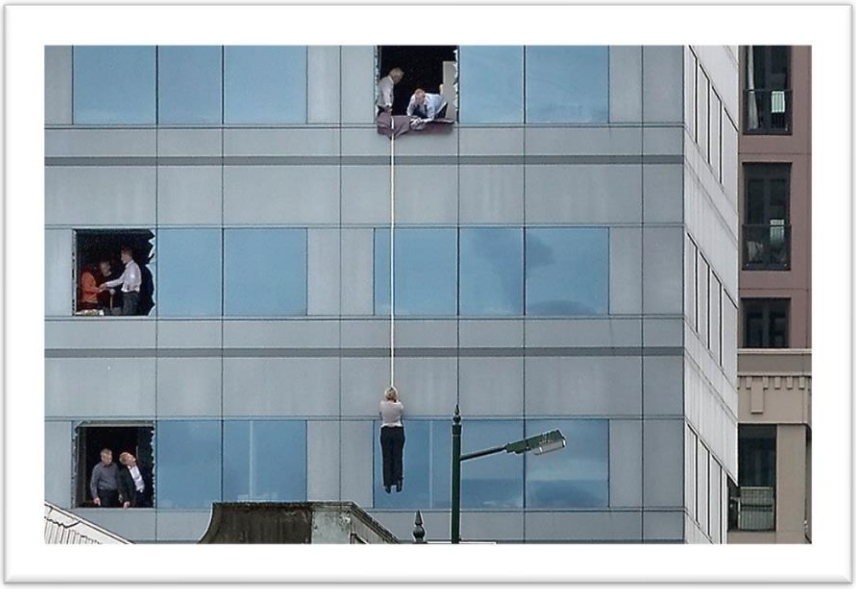
Introduction

The research sought to better understand the experiences of people with chronic illness living in Petone, and how these might influence their sense of health and wellbeing. In this chapter the themes of independence will be considered and discussed. This theme is considered in relation to agency and communion because, as argued by a number of researchers (J. Bauer & McAdams, 2000; McAdams et al., 1996), they make up the content of people's stories and give purpose and unity to people's lives. McAdams et al. (1996) applied the concepts of agency and communion to guide an understanding of human motivation. This understanding was a useful tool within this study for categorising the

content of the eight people's stories. Social connection has been used instead of communion for this study so as not to create confusion as the term 'communion' is more notably known as a religious act.

Early in the analysis process it was apparent that agency as independence and communion (or social connection as it is referred to for this study) became key components in the content of all the stories in this research. Agency refers to living as an individual, independently, and being the master of one's environment (e.g. feelings of autonomy, power, independence) (McAdams et al., 1996). While social connection represents a person belonging to or being part of something bigger than themselves (e.g. intimate relationship, family, friendship) the desire to feel connected and cared about (McAdams et al., 1996). Figure 14 illustrates social connection at work after the Christchurch earthquake when people found themselves stranded in a building. Each theme will be discussed separately in terms of use by the tellers, and what this might mean.

Figure 14 *Survivors working together after Christchurch earthquake (Stuff.co.nz, 2011).*



Themes of Independence

The tellers in this research illustrated independence in various ways, so this theme has been categorised into seven subcategories. Table 3 lists each of these subcategories, along with extracts from tellers' transcripts to provide a snapshot of how this study's tellers made sense of having a chronic illness and experiencing an earthquake through various positions of independence. These extracts were identified as part of the NOI categorical content interpretation process, which involves identifying speech that is meaningful to the study's research question.

Table 3 *Subcategories that contribute to the major theme of independence*

Subcategories	**Examples of Tellers Expression of Themes**
Declaration	"…I never thought of calling for support because of my independence." Teller Six
Defiance	"so I made a point early on that I wasn't going to be a victim but I was going to be an advocate and educator." Teller Seven
Rules	"I always sleep with shoes by my bed…" "Never go to bed without a bra on". "always make sure your phone is charged" Teller One
Acceptance	"yes I say if your times up that's it so why worry about it." Teller Eight
Experience	"I was in the Inagnahua earthquake…, and I guess because of that experience I've always been a bit aware, more aware than some people I think so I've always had, for a long time quite a lot of water stored and food and grab bags…" Teller Two
Responsibility	"Cause no one else is going to look after you ." Teller One
Surveillance and Self-management	"But we are always looking ahead, thinking what's coming up?" Teller Three "It's like an emergency every time we go out for dinner"." Teller Four

These subcategories of independence and how they relate to living with a chronic illness and in a disaster-prone area will now be discussed. As listed in the table above this discussion begin with 'Declaration' and then addresses each one in turn.

Declaration

To date the majority of research regarding the chronically ill within a disaster context has focused on the disproportionate adverse physical health outcomes experienced by the chronically ill, presenting them as at risk and vulnerable (Bethel et al., 2011; Carameli et al., 2013; Miller & Arquilla, 2008; Tomio & Sato, 2014). Social representations of the chronically ill are also framed through dominant health ideals, with the chronically ill portrayed as abnormal, to blame, dependent on others, and a burden based on their unhealthy status (G. Williams, 1993). Foucault argued that the understanding of embodied behaviour must not be restricted to the physical body alone and behaviour and conduct must also be considered so that the influence of social and historical context can be explored (N. Crossley, 1996). From a health perspective, social determinants of health such as living and working conditions, and economic and social context matter to people's experiences of health and illness (Lyons & Chamberlain, 2006; Wilkinson & Marmot, 2003).

The tellers in this study all share stories of their experiences in relation to their social and historical context and natural hazard events in terms of how they maintained their independence despite having a chronic illness. Countering social representations of the chronically ill as dependent on others or vulnerable in disaster research, some of the tellers even declared themselves independent, which they illustrated with anecdotes of how they acted independently rather than seeking help from others. Take for example Teller Six who declares his independence in his story of how he broke his arm:

"*…by nature I'm a very independent person um the interesting thing was that when I fell over even though I was concussed and in shock I came home assessed the situation and took a taxi they said why didn't you call an ambulance? I said it never occurred to me*."
Teller Six

Teller Six positions himself as having agency by declaring his independence. He illustrates this by telling how he took control and got himself to hospital without assistance:

"*…even though I was really bad state I never thought of calling for support because of my independence."* Teller Six

As is evident in Teller Six's narrative, for him independence means managing any event autonomously even if it means suffering alone or unduly. His need to be independent seems to be highly motivating, and may have influenced his actions after the 2016 Kaikōura earthquake. He explains that based on his own knowledge he chose not to evacuate after the quake despite the tsunami warning:

"*When it got to 12:30 I thought well that would have to be a pretty bloody big tsunami to get this far (laugh)*." Teller Six

In their study, Khan, Crozier, and Kennedy (2012) noted that people living in areas susceptible to natural hazards, like Petone, often have a heightened hazard perception that affects their decisions and actions. Certainly, Teller six was very aware of Petone being characterised by local government as at risk from tsunamis, though when deciding whether to evacuate after the earthquake he acted independently based on his own knowledge. It seems that as Khan et al. (2012) noted in their study, a person's perception of the level of risk of a natural hazard can influence their actions, as it did with Teller Six who did not evacuate because he did not consider that he was at risk from a tsunami. Though it is also likely that his need to manage his life independently also influenced his actions.

Like Teller Six, Teller One makes a declaration of independence when talking about her experience of the Kaikōura earthquake after mentioning that they live on their own:

"*so, I have to be dependent on me…can't rely on anyone else. … so I know where things are, my house isn't that big and I don't have a lot of stuff but I know where the important things are.*" Teller One

For Teller One independence seems to be about being in control of her life, and maintaining independence in an earthquake requires being prepared by knowing where the necessary safety and survival items are in her home. Teller One's declaration of independence is expressed in terms of necessity as she reports being forced to take care of herself because she lives alone. Whereas, Teller Six expresses his independence as a choice to take care of himself rather than seeking help. These variations in expression of independence may possibly reflect gender or age differences although this would require a greater number of people than those in this study to establish.

Both Teller One and Teller Six live alone. Both tellers convey that despite being alone and having a chronic illness they remain independent by relying on themselves in the event of an emergency. Teller Six's declaration of independence involves trusting his own judgement rather than looking to others for help. He explains:

"*…I never thought of calling for support because of my independence. I never occurred to me to reach out (laugh)….*" Teller Six

G. Williams (1993) stated that notions of independence play a critical role in the daily lives of people with chronic illnesses. He argues that socially, chronic illness represents a loss of control, therefore it is important for some people with chronic illnesses to reconstruct themselves in their stories as having control over their daily lives, so that they are portrayed as being independent. Consistent with Williams' findings, both Teller Six and Teller One's stories involve reconstructions of themselves as being in control through descriptions of

taking charge and being prepared, as well as their declarations of independence. This matters within an emergency management context because notions of independence can shape risk perception which influences how people act when faced with a natural hazard event.

In their Wellington based study, Khan et al. (2012) notes a deficit between individual perception and actual risk which impedes the effectiveness of preparedness and response measures developed by government. Therefore, narrative accounts provided by the tellers in this study, which adds to the pool of knowledge provided by Khan et al and others, are an important resource for emergency management personnel wishing to develop effective preparedness strategies. As Khan et al. (2012) argues, it is more likely that strategies that include input from locals will be taken up by locals. This would provide people with a sense of agency which certainly is important to the tellers as illustrated by the extensive use of themes of independence in their stories.

Summary

Given the importance of independence, and being in control for the chronically ill it seems that the emergency management sector would benefit from gaining input from people in the community about hazard management in their area (as recommended by Khan et al. (2012) because what the sector understands as a hazard may not be perceived in the same way by those faced with an event. This would also be in keeping with the Sendai Framework which prioritises input from the chronically ill in emergency management development (United Nations, 2015).

Being in control is significant to people with chronic illnesses as represented through declarations of independence in the stories of chronic illness and natural hazard events. Being

in control is illustrated by Teller Six and Teller One in their descriptions of taking charge and being prepared. Teller Six speaks of taking charge when he broke his arm, and how he relied on his own knowledge to guide his actions rather than government messages when the Kaikōura earthquake struck. For him, government earthquake and tsunami education did not affect his behaviour as he did not 'Get Gone', as recommended by the National Emergency Management Agency (Figure 15), after the earthquake.

Figure 15 *'Get Tsunami Ready' Image National Emergency Management Agency (2020)*

In comparison, Teller One's accounts of disaster preparedness and response, which she used to position herself as being in control when faced with an earthquake, suggests that government messaging may have affected her actions as she evacuated shortly after the earthquake. Six of the other tellers also evacuated.

Defiance

Figure 16 *Historic Police Station, Jackson Street, Petone. Author's photo collection.*

Some of the tellers strongly resisted being identified with a chronic illness and presented themselves as independent in defiance of such labelling. As has already been discussed, for the chronically ill, independence plays a critical role in their daily life. Also, the need to be perceived as independent may shape how the chronically ill prepare and respond to natural hazard events and events outside their control, which may worsen their chronic illnesses as they fail to seek support when most needed. Defiance may be one way that the chronically ill can present as in control when faced with something outside of their control. Defiance may also be a response to being devalued as chronically ill - dependent and a burden (Walton & Lazzaro-Salazar, 2016; G. Williams, 1993). Such social representations can be isolating and may have a negative influence on how people respond to such things as natural hazard events. Though for some, resisting these labels may be indicative of resilience.

Teller Seven, when speaking about her experience of chronic illness, tells how she has rejected labels imposed on her, as demonstrated in the following excerpt:

"*People say oh you are so brave, you're a role model, and inspiration. It's like (sigh) no I'm not I'm just coping with something that is completely beyond my control in the best way I know how. Nothing more or less*." Teller Seven

Through defiance of the labels or positions imposed on her by others, Teller Seven attempts to control her own narrative and how she wants to be identified. This is also highlighted below:

"*So, I made a point quite early on that I wasn't going to be a victim but I was going to be an advocate and educator*." Teller Seven

Teller Seven actively rejects the label of "victim", instead engaging in a positive construction that enables her to make sense of the impact the illness has on her life, particularly who she is now compared to who she was before the illness developed. It seems defiance against the 'victim' label is her way of reinventing herself and is a motivator for her actions. Teller Seven illustrates this by telling the story of how she persisted in trying to find work despite being stigmatised and discriminated against due to her chronic illness, and how she now educates others about disabilities. In these stories she positions herself as an active agent who takes control of her life, rather than letting her life be controlled by illness, or the actions of others. Teller Seven states that "*I've had to fight all the time*" in terms of the impact the chronic illness has had on her life, including fighting against physical limitations, and people's lack of support and negative behaviour. Through defiance, she is able to separate herself from the illness, enabling her to position herself positively as independent from the condition.

In her study of chronically ill people, Charmaz (1983) identified that those whose illness was visibly obvious, and as a result encountered stigmatisation, often discredited themselves and were discredited by others. Walton and Lazzaro-Salazar (2016) found that stigmatisation can alienate people and discourage them from engaging in policy and strategy development. Discrediting a group can lead to them being overlooked, which can set people up to fail when their needs have not been considered (Blake & Lyons, 2016; Blake, Marlowe, et al., 2017a; Tomio & Sato, 2014).

Supporting Charmaz's findings, Teller Seven spoke of being discredited by others due to the physical manifestation of her chronic illness. However, at no time did she discredit herself, preferring to position herself as fiercely independent, possibly in defiance of any assumptions people may make based on her appearance. As A Radley (1994) explains, to be seen as 'normal' the ill person must present a sustained image of self-worth, and be seen to achieve those standards set by the healthy, otherwise they will be discredited. Similarly, Galvin (2002) argues that because being chronically ill has been connected with individual responsibility (that a person chooses an unhealthy lifestyle and so is culpable) in contemporary society, being ill conflicts with good citizenship, and acceptable norms of being responsible, self-reliant, and independent. Therefore, the chronically ill must present themselves in these ways to be socially accepted or face stigmatisation and social isolation. Teller Seven's defiance of her illness is therefore an understandable strategy.

Teller Five also uses defiance as a way of separating himself from ill health. From first contact Teller Five was determined not to be labelled as chronically ill. In a telephone conversation, and during the interview he made it clear that he had no chronic condition. During the interview when discussing the term chronic illness he said:

"*Yeah, well, my brother's wife's brother, he died about a week ago, but he had chronic..., he had everything going. He had diabetes to odd bits of cancer, and my sister's partner, he's got all manner of things wrong with him too, so I would say he has chronic, some chronic conditions. My only chronic condition is that I'm a pain in the butt to everybody*." Teller Five

Teller Five's defiance of other people's judgements about his health provides him with a strategy to make sense of his failing health. Through defiance he is able to maintain control and position himself as independent, separate from others' judgements. For example, when told by his family he can no longer drive having had a stroke, he explains:

"*Yeah. They reckon, seeing as I'd had that that's why I' shouldn't drive, cos I'd be a danger to other people on the road. I reckon I'm alright, thank you very much*." Teller Five

Then he tells how he chose to give up his driver licence to keep his family happy; though he still did not mention his ill health in this narrative:

"*Well, they have won because this morning I went to the vehicle testing station and said here's a letter, cancel my driver's licence in the interest of peace and.... yeah*." Teller Five

In this statement, Teller Five positions himself as the one in control. It was his decision when he "*went to the vehicle testing station*" and handed over his licence. By telling the story this way, Teller Five becomes an active agent who determined when to give up his licence, and on his terms, therefore maintaining a sense of independence even though by giving up his licence he lost some ability to be independent.

Teller Five's defiance of others' judgments is not limited to health matters. In his story of the Kaikōura earthquake he defies his son's demand to evacuate, choosing instead to go back to sleep. In the following excerpt, Teller Five explains what happened:

"*[My son] knocked on the windows and called, come on, get out of here, we've got to get out. There's a tsunami. I told him rubbish… I don't think any tsunami would come in here. It's got to get past the Wellington heads and if it does it's just going to be a surge of water, and I've lived here long enough that if you look across..., well, you look down towards The Esplanade, the bit of a rise as it comes up from the sea, where the sand has built up, from whatever… so my thinking here is that these things have been caused by periodic sea changes or something, and if they've happened up there they're not likely to happen down here.*"
Teller Five

Based on his knowledge of the area, Teller Five defies the call to evacuate, confident that there will be no tsunami. Relying on his own knowledge and judgement is how he makes sense of a range of disruptive events, like earthquakes and strokes. As he states when telling of his extensive experiences with earthquakes that "*Nobody told you to do anything. You did what you thought*." Through this identity positioning Teller Five's defiant action of not evacuating has a creditability that his physical presentation may not convey. He identifies as someone who cannot be told what to do, and he makes up his own mind regardless of his health.

Williams noted something similar with a participant with chronic illness, which he referred to as "a posture of resistance" (1993, p. 96). He explains that in their narrative the participant made a clear distinction between the lack of control they had over their illness, and their resistance to outwardly convey the physical impact they experienced. For Faircloth et al. (2004) defiance does not adhere to the concept of biographical disruption that many researchers have adopted in understanding the chronic illness experience. Biographical disruption is the understanding of chronic illness as a biological, personal, and social process, involving people making sense of the disruptive impact chronic illness has on their identities

in terms of how they see themselves, and how others perceive them (Bury, 1982; S. Williams, 2000).

Faircloth et al. (2004) found themes of resistance in people's stroke stories, arguing these narratives represented resistance against stroke as a disruptive event. People spoke of stroke experiences as a normal part of the aging process, or not as severe as other conditions or previous stroke experiences. Teller Five and Teller Six, both of whom were almost 90 years of age, spoke of their illness within the context of other conditions which they considered more severe. Teller Five compared his illness as "*a pain in the butt*" rather than a physical illness, comparing his situation to others who he considered had chronic illnesses including diabetes and cancer. Teller Six who had ME (or chronic fatigue syndrome) and hyperthyroidism said:

"*I'd rather have ME than this hypo…hypo (hyperthyroidism) can destroy you mentally, emotionally…the saving grace when you hit 90 you say what the fuck (laugh)*." Teller Six

As with those in Faircloth et al. (2004) study, Teller Six's account is one of defiance where he resists the illness's impact through comparison with a more severe condition, which he minimises by referencing his age. The defiance of both tellers also indicates a level of resilience based on age and life experiences, which according to Tuohy and Stephens could produce a "basis of resilience" (2012, p. 33). This also suggests biographical continuity which helps people make sense of, and have better resilience against, disruptive events including disasters.

In contrast with Tuohy and Stephens (2012) and Faircloth et al. (2004) studies, Teller Seven predominately reconstructs her accounts of chronic illness in terms of defiance and disruption. Teller Seven's storied account of her difficulties getting work after becoming ill,

illustrate the disruption her illness has had on her daily life, on her identity as a mother, and how others perceive her. Lyons and Chamberlain (2006) note that biographical disruption is socially located, therefore the older people interviewed by Faircloth et al. (2004) are likely to have had different levels of disruption to their daily lives from chronic illness than younger people. Teller Seven is much younger than Teller Five and Six, still raising children, and needing to work, whereas Teller Five and Six are retired and primarily only responsible for themselves.

Both Teller Five and Teller Seven had physical characteristics that indicated they were chronically unwell. Both tellers, however, positioned themselves as active agents through expressions of independence, which defied their ill health. They also told their stories in ways that challenged any assumptions people may make about them based on their chronic illness. Teller Five defied the use of the label 'chronic illness' even though the medical conditions he spoke of having are categorised within a health context as chronic illnesses. While Teller Seven defied those that said she could not work due to her chronic illness, by getting work.

Both Teller Five and Teller Seven's stories demonstrate that labelling people as chronically ill can result in people being judged and treated according to their health status. For example, Teller Seven was deemed unemployable, and Teller Five's family demanded he give up driving. This treatment has shaped these tellers' illness stories. Their defiance and determination to position themselves as independent could be in response to the negative social representation of the chronically ill. Consider for example Charmaz (1983) findings of the significant impact negative attitudes toward the chronically ill has on people's self-identity. She found that some chronically ill people had hidden their illness from others for fear of being discredited or judged. This is understandable given the dominant narrative about

the chronically ill is of being personal responsible for getting sick, a financial burden, and different to the ‘normal population (Galvin, 2002; Walton & Lazzaro-Salazar, 2016).

Summary

The tellers accounts are a window into how some people make sense of being ill and deal with natural hazards from a position of defiance. Defiance for the tellers meant resisting being labelled as chronically ill. Teller Five uses a natural hazard event story to show that they were in control of their own narrative. He described rolling over in bed and going back to sleep in defiance of the tsunami evacuation warning that occurred after the 2016 Kaikōura earthquake. While Teller Seven’s story of getting a job is about her defying those who discriminated against her because of the chronic illness. Such stories of resistance enable the tellers to separate themselves from the chronic illness, so that they could redefine themselves as independent people in control of their lives. Also, positioning themselves as independent despite illness is indicative of a level of resilience that is rarely attributed to the chronically ill. By understanding that not everyone experiences such significant events as chronic illness, and natural hazard events in the same way, the emergency management sector could move from their ‘one size fits all’ approach, and utilise the experiences of the chronically ill to improve community resilience.

Rules

Figure 17 *The Golden Rules (extract)* (Ministry of Health, 2021)

In the film *Gremlins* there are three rules that must be followed to ensure disaster does not occur when caring for the fantastical creature know as a Mogwai. First, no bright lights. Second, no water. Third, no feeding after midnight. When his human fails to follow the rules Mogwai produces several Gremlins that destroy an entire town. Within a disaster context, such as the COVID pandemic, rules or guidelines (for example the 'Golden Rules' brochure above) are designed to help people prepare so that they can reduce the negative effects from disasters. Similarly, some of the tellers use a set of personal rules to reduce their risk from chronic illness and natural hazards. Following these rules also helps them maintain a sense of control and independence.

Several of the tellers spoke of rules they had created to help them manage their chronic illness or a natural hazard event. These rules seem to provide the tellers with a sense

of control and were developed out of past experiences. Teller One for example places herself in a position of control in her stories of past experiences with earthquakes, by detailing the set of rules she has put in place. These rules include "*always sleep with shoes by my bed*"; "*Never go to bed without a bra on*"; and "*always make sure your phone is charged*."

Teller One also ensures that she has drinking water, access to transport, additional medication, and plans with her neighbours in preparation for a disaster. She spoke of how successfully she and her neighbour's plan to evacuate after an earthquake worked when the Kaikōura earthquake struck:

"*yeah and - well we had a plan. Be in contact… the plan we had in place actually worked.*" Teller One

According to D. Paton and Johnston (2001) taking actions to plan improves people's capacity for coping, and Teller One's positive account of how successfully she managed the Kaikōura earthquake suggests that she coped well with the event thanks to her earthquake preparedness. Preparedness measures like having additional medication help to minimise the impact such an event could have on Teller One's health because she would have the means to manage her chronic illness without the need of medical assistance. Research shows the necessity for access to medication for the chronically ill during disasters to reduce the risk of adverse health impacts for this group (Barbato et al., 2021; Blake & Lyons, 2016; Carameli et al., 2013; Jhung et al., 2007).

Recent research by Barbato et al. (2021) reported that despite the greater risk of morbidity for the chronically ill during a disaster, this group does not have higher preparedness levels. However, in the current study several of the tellers' narratives indicate that they are well prepared in the event of a disaster. For example, all of the tellers on

medication spoke of having additional medication set aside should a natural hazard event mean they could not access a chemist or medical services. For these tellers, stockpiling medication was an informal rule. Stockpiling of medication is noted by Blake and Lyons (2016) in their study of opioid access during disasters as an informal preparedness strategy used by pharmacists.

Teller One's rules, including setting aside medication, helped her manage and cope with the fear of natural hazard events, while Teller Three and Four's set of family rules helped them control their daughter's chronic illness. In their illness stories, both parents refer to various rules that had been put in place based on lessons learnt from earlier experiences of their daughter getting sick. Teller Four explains they have learned to, as much as possible, control their home environment:

"…*because we had a testing* [gluten levels test] *and she had levels of gluten, and we're like how can she, and we found we were cross contaminating stuff, and that's when we decided she needed her own toaster, her own margarine, her own jams, basically her own drawer full of food*." Teller Four

This narrative is representative of the type of household rules needed to keep their daughter safe from a health disaster. Teller Four describes eating out "*like an emergency every time we got out for dinner or if we don't know where we're going or what they've got…*". This is in contrast to the home environment where a certain amount of independence from the illness is maintained through rules to control the risk of exposure to gluten. These rules also assist Teller Three and Four to share their knowledge of the illness with their daughter, who through this knowledge can develop an independence from her parents as well as from the illness.

While Teller Three and Four have rules to manage their daughter's chronic illness, they spoke of having no rules or preparation for when a hazard event occurs. Research shows that this is not unusual as preparedness levels in communities are generally low (Levac, Toal-Sullivan, & O`Sullivan, 2012; Ministry of Civil Defence & Emergency Management, 2018; D. Paton & Johnston, 2001). A 2018 survey of Aotearoa New Zealand's preparedness levels found several barriers to people preparing for a disaster, which included lack of knowledge, optimism, likelihood of event, and effort (Ministry of Civil Defence & Emergency Management). Teller Three and Four spoke of having little time to think about disaster preparedness, which indicates that the likelihood of an event is not thought about. According to the 2018 survey, people who did not think about events occurring were unlikely to prepare. This may be a reason that Teller Three and Four had no specific preparedness plan. However, as Levac et al. (2012) points out preparedness is a complex matter that has multiple influences including self-efficacy, health, type of emergency, and level of community support.

While Teller Three and Four had no preparedness plans in place, the stories of preparedness actions they undertook to maintain control over their daughter's health represented extreme preparedness that will assist with emergency events. Researchers have argued that due to the individualisation of health, people have had to independently manage their health (Petersen, 1997; Tuohy & Stephens, 2016). This has resulted in the development of skills and competencies such as calculating, evaluating, prioritising and monitoring preparedness strategies to maintain their independence (Tuohy et al., 2015). Take for example Teller Three, who spoke of constantly surveying the environment for potential threats, and positioned herself and Teller Four as people who:

"*… are always looking ahead, thinking what's coming up? What's she got on" What will she need for that" It does involve a lot of, quite a lot of forward thinking.*" Teller Four

Teller Four's strategy of forward thinking is similar to the preparedness behaviour identified by Tuohy et al. (2015). They reported that older adults' perception of preparedness was not restricted to the disaster context, and was utilised by them to "anticipate risk and adapt to change" (Tuohy et al., 2015, p. 621). Through rules, Teller Three and Four have been able to independently manage their daughter's illness and develop a level of preparedness that they can utilise for other emergency events such as natural hazards.

Summary

Researchers argue that preparing for a disaster can strengthen people's resilience against such events. Teller One's narrative indicates that adhering to certain personal rules to prepare for a hazard event helped her cope during the 2016 earthquake and tsunami event. One of these rules included stockpiling medication which was also a measure spoken about by other tellers. In other research, stockpiling medication was spoken of by pharmacists as one of their informal preparedness measures.

The level of preparedness spoken about by the tellers contrasts with recent research that reported low levels of preparedness among chronically ill people in the United States. While some of the tellers did not have specific preparedness plans or rules for when a hazard event occurred, the rules they spoke of in relation to managing chronic illness suggests that they have developed skills and competencies that will assist them in coping when disaster strikes.

Acceptance

Within the context of this study, 'acceptance' for the tellers was another way of expressing agency when a situation (like a natural hazard disaster) was outside their control. It is possible that their acceptance may be the only way that they know to achieve a sense of active agency in an emergency situation. Research shows that acceptance is a strategy used by some to cope with chronic illness (McCracken & Eccleston, 2003; Stanton & Cameron, 2000). Charmaz (1983) points out that for some people, repeat episodes of worsening health are used as opportunities to self-evaluate and make changes. Teller One conveys this when she narrates finding reason and a sense of self through adversity:

"*So actually getting sick was a good thing because it actually highlighted a few things that …I had to get that sick to come out and find out what um you know to better myself*." Teller One.

Teller One's description of being sick demonstrates her acceptance of the illness by seeing it as important in the development of her "better" self. Teller One's reflections about her lived experience of illness is also an exemplar of the quest narrative, where a person talks about the experience in positive terms such as accepting and learning from the illness (Hiles & Cermák, 2008). In a study of one woman's experience with cancer, Hiles and Cermák (2008) found that the acceptance of the illness was one way that the woman expressed her agency.

Other tellers in this study also seemed to draw on acceptance as a way to express agency, and a way of coping. Teller Three tries to make sense of her daughter's illness by

accepting that the illness will not kill her daughter. The mother describes the "worst case scenario" for her daughter:

"*…and worst case scenario is she eats something and she's really sick. She's not anaphylactic. She's not gunna die. She's just going to feel really rubbish*." Teller Three

When Teller One has to go to hospital for treatment, she also draws on a narrative of acceptance. This acceptance involved a sense of relief that she would get medical help. Teller One describes how she felt when she was put into the ambulance:

"*…as soon as I got into the ambulance (lowers voice) I felt safe (whisper) and I relaxed. And oh you know I'm so sick and just look after me. And it made me happy and I could just not have to worry about anything anymore*." Teller One

Rather than experiencing any loss of control over her health, Teller One focusses on handing control over to the medical professionals - accepting what is happening and that she needs help. Under McAdams et al's (1996) concept of motivation and agency, the notion of empowerment involves a person perceiving their agency to be empowered or enhanced by an association with another's agency or something more powerful than themselves. In Teller One's case, her acceptance of the ambulance workers and doctors seemed to enhance her sense of agency, where she was physically powerless. When Teller One narrated how she managed this disrupting event, acceptance was represented as "moving on":

"*So I can live with that. Thanks for telling me now I can move on*." Teller One

By indicating that she accepts whatever she has been told about her illness as part of her life going forward, Teller One seems to be take back power over her life. Acceptance is also related to context and age. Lawton (2002) found that behaviour change was related to people's perception of their future health and death, and the older people are, the more likely the perceived illness and death in their future. As such, an elderly person who is already dealing with morbidity and the possibility of death due to chronic illness, may accept that the future is nigh when faced with a natural hazard. Take for example the fact that Teller Five did not evacuate during the 2016 tsunami warning following the Kaikōura earthquake because he thought he understood Petone's geography and that any wave would not reach his home. In his 80s, his focus could have been quality of life rather than quantity of years left, and therefore he could be less inclined to concern himself with what he perceives to be uncontrollable life events.

Teller Six also uses acceptance as a way of making sense of a disruptive event, specifically a tsunami:

"*Now in so far as I know we live in a tsunami prone area here. But if that doesn't worry me I mean I don't allow that to worry me anymore than I allow President Trump or other things going on in the world to worry me. There are things that I completely out of my control and they will happen or they won't. So I don't live with daily fears or worries*." Teller Six.

Like Teller One, Teller Six accepts that an event such as a tsunami is beyond his control, and therefore not worth worrying about. Teller Six demonstrates a form of empowerment by acknowledging that there are powers (such as tsunamis) greater than the self, and therefore acceptance is a way to cope with the unknown. Teller Eight and Teller

Five also express an acceptance of the tsunami's risk in Petone, but do so by drawing on more fatalistic narratives:

> "*I've lived a good life*." Teller Five;
>
> "*Yes I'd say if your times up your times up — that's it — so why worry about it."* Teller Eight.

In the context of a possible tsunami, these tellers use acceptance as a way of opening themselves up to the possibility of harm, while maintaining their positions as active agents. Viewed through a disaster research lens, such acceptance can be attributed to a fatalistic attitude (McClure, 2017). Fatalism about natural hazard risk is defined as "the belief that nothing can be done to reduce harm from natural disasters" (McClure, 2017, p. 2). Such a belief stops people from preparing for hazards.

Both Teller Five and Eight's fatalistic narratives were in response to the likelihood of a tsunami hitting Petone. They use themes of acceptance to position themselves as in control when the uncontrollable occurs, as though accepting the situation is the only way they can express their agency. Their fatalistic attribution of tsunamis with uncontrollable events would, according to McClure (2017), restrict them from preparing for such an event. While a sense of fatalism might be present, both Teller Five and Teller Eight also talked about the various ways they have prepared for future events, such as storing extra medication and water. Teller Eight also mentioned how she and her neighbours had an evacuation plan in place, and that they used this plan when the tsunami warning was issued after the Kaikōura earthquake.

Teller Five and Eight's fatalism and preparedness narratives suggest that they do attribute unavoidable harm to events that they have no control over (e.g. tsunamis), but that

they also believe they can do something to minimise harm from such events by preparing, which is an action they have control over. This mixture of fatalistic and can-do attitudes seems to assist the tellers in understanding their experiences of natural hazard events.

How people cope with disruptive events like chronic illness can be a valuable resource for those seeking ways to build resilience in communities prone to natural hazards and disasters. Tuohy and Stephens (2012) found that flood stories told by the elderly in their study were a valuable exemplar of resilience in a disaster context for the wider community. Coleman (1999) explains that the sharing of people's life stories was important because at a social level such story sharing provides people with valuable life lessons. Coleman's study provided examples of how older people coping with intermittent, unpredictable episodes of worsening health developed strategies, such as acceptance, to help them make sense of crisis situations and build resilience to better cope with such events in the future.

Summary

Acceptance was a coping strategy used by many of the tellers as it gave them a sense of control over events that they may have had limited control over. Research shows that some people's use of acceptance is related to their perception of the future. For example, an elderly person may accept illness as part of getting old. Others' acceptance of natural hazard events may be shaped by whether they perceive the event as uncontrollable and therefore harmful. By accepting the inevitable they maintain a sense of control. Themes of acceptance in people's hazard narratives may provide further understanding of why people fail to take action when faced with risks such a tsunami which they consider uncontrollable.

Past experience

As previously discussed, past experience provided a context for tellers' narratives of chronic illness and natural hazards. Research of people living in areas close to Petone found that past experience of earthquakes does matter in their judgement of future events (Doyle et al., 2018; McClure, Henrich, Johnston, & Doyle, 2016). McClure et al. (2016) reported that previous earthquake experience affected people's judgments about the risk of further earthquakes and the likelihood of preparing for such events.

People who have experienced a disaster know to be prepared, and can also use that experience as a reference point for dealing with other challenging life events (Tuohy, 2014). Some of the tellers draw parallels between natural hazards and experiences of chronic illness as "emergencies". Teller Four likens taking his daughter, who has celiac disease, to a potential emergency every time they need to eat when travelling. In an unfamiliar environment all they can do is rely on their past experience. This narrative is a reminder that every day involves risk when living with life threatening chronic conditions.

Coleman (1999) argues that stories where past and present experiences are evaluated and integrated can be used by others as an adaptive framework for future events. Tuohy and Stephens (2012) found that competencies and skills developed through the experience of chronic illness helped survivors of a flood manage the event, and that their stories provided a valuable untapped resource for others on how to better manage such events. Teller Three and Four, for example would be able to provide expert advice to those responsible for disaster preparedness regarding food supplies for celiac due to their extensive experience in managing their daughter's illness.

Several tellers in this study talked about how their experiences of chronic illness and natural hazards helped prepare them for future disruptive events. For instance, as previously

highlighted, Teller Two proposed that she was better able to prepare and cope with natural hazards because she had lived through the 1968 Inangahua earthquake. The extensive damage done to homes as a result of that event is indicated in Figure 18.

Figure 18 *Damage caused by the 7.1 1968 Inangahua earthquake (flickr.com, 1968).*

Teller Two's experience of the earthquake provided her with a reference point which she uses to prepare herself for future events including the 2016 earthquake:

"People with young families, it was terrible. I mean, some of them flew out when they possibly could weeks later and never came back really. It was traumatic for the children especially... I guess because of that experience (with the Inangahua earthquake) I've always been a bit aware, more aware than some people I think so I've always had, for a long time, quite a lot of water stored and food and grab bags and so when I had to take the medication for blood pressure that's become..., those tablets...., those supplies…" Teller Two

Teller Two's experience motivated her to prepare for a future disaster and provided her with a reference point for managing other disruptive events such as her high blood pressure. Like Teller Two, when talking of her experience of the Kaikōura earthquake, Teller One spoke of being better prepared based on past earthquake experience:

"*it was a real good shake. So I ah um (pause) I from previous earthquakes I had already set up a bit of ah ah I thing with my friend around the corner.*" Teller One

Having a preparedness plan with a "friend" helped to alleviate anxiety about a disaster for this teller. However, knowing the importance of being prepared and being able to prepare are two sides of the same coin. For instance, while Teller Two knows of the importance of being prepared, she narrates the challenges of stockpiling medication due to restrictions on access for some medications:

"*I said I like to keep a safety supply and she said, "Oh no, I can only give you ninety days" and she said, "Oh well next time just come a bit earlier". So, I've done that and then I realised that I have still got some of the old medication so I'll put that in the bag ….*" Teller Two

Not being able to store life sustaining medications is concerning, especially in societies where dominant discourses promote risk and self-responsibility, so even when there are previous experiences warning of the importance of preparedness this is not always possible. Several of the tellers spoke of how they had developed other ways of accessing medication as a result of their past experiences of doctors being unable to provide them with additional medication due to tight restrictions on the amounts of medication over a certain

period. As a result of these experiences, some would go earlier to the doctor or rely on personal connections with medication providers to stockpile for hazard events.

Teller One explains that she needs her blood pressure medication to prevent her having a stroke. Based on her past experience of unexpected disruption due to illness, she knows that to live she also needs to be prepared with extra medication should a disaster strike. She links the management of her chronic illness with managing an earthquake:

"*… it's like at least I can try and do what I can do to prevent things. Prevent the event and that's what I'm trying to do and all the things in my life. Try and prevent the event and sometimes things are out of your control and you can only deal with them at the time. Like the earthquake. But you can be prepared*". Teller One

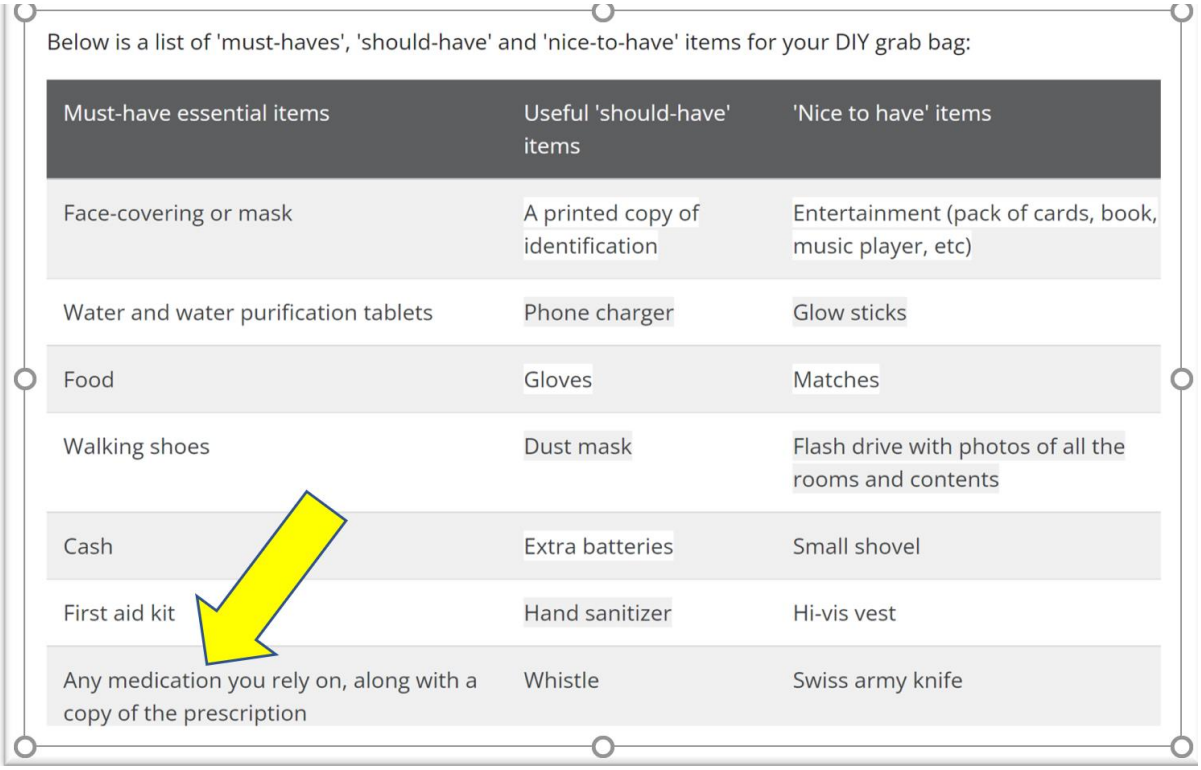
Similar to Teller Two, Teller One spoke of her experience of the Kaikōura earthquake, and how this past experience made her better prepared:

"*it was a real good shake. So I ah um (pause) I from previous earthquakes I had already set up a bit of ah ah I thing with my friend around the corner.*" Teller One

The tellers' narratives about medication demonstrates that issues with access to medication for disaster preparedness remains. Tomio and Sato (2014) point out the complexities in changing the system to accommodate the medication needs of the chronically ill within a disaster context, yet affirm the necessity for policy makers to relax restrictions so that critical medication can be available for disaster preparedness. Similarly, Carameli et al. (2013) recommend that drug-dispensing policies be more flexible so that people can have additional medication set aside for disasters.

Aotearoa New Zealand's emergency management sector recognises the necessity of medication for preparedness as indicated by its listing of medication as a 'must have' for Grab Bags on its 'Get Prepared' website shown in Figure 19.

Figure 19 *An exert from 'Get Prepared' website (Wellington Region Emergency Management Office, 2022).*



Below is a list of 'must-haves', 'should-have' and 'nice-to-have' items for your DIY grab bag:

Must-have essential items	Useful 'should-have' items	'Nice to have' items
Face-covering or mask	A printed copy of identification	Entertainment (pack of cards, book, music player, etc)
Water and water purification tablets	Phone charger	Glow sticks
Food	Gloves	Matches
Walking shoes	Dust mask	Flash drive with photos of all the rooms and contents
Cash	Extra batteries	Small shovel
First aid kit	Hand sanitizer	Hi-vis vest
Any medication you rely on, along with a copy of the prescription	Whistle	Swiss army knife

However, as the issue of not having access to additional medication remains, the chronically ill will be disadvantaged compared to others because their ability to prepare fully according to guidelines remains compromised by medication restrictions. Such disadvantage in turn increases the risk of poorer health outcomes for the chronically ill in a disaster.

Summary

Past experiences helped the tellers understand their experiences of chronic illness and hazard events. These past experiences acted as reference points which were used as guidance and motivation to prepare for future events. Preparing helped the tellers to cope with anxiety about disasters and is a strategy used in emergency management to improve community resilience. For some tellers however, trying to prepare was frustrated by difficulties in obtaining additional medication for disasters. Strict rules governing medication allocations meant that tellers had to find ways around the system to stockpile medication for disaster preparation.

Challenging experiences in managing chronic illness can be used as reference points for managing hazard events. These experiences can also be useful resources for those responsible for policy and strategies designed to improve people's resilience to disaster situations. The tellers, through managing their own health, have extensive experience in adjusting to disruption, because taking responsibility for their own health has meant the tellers have had to develop preparedness strategies to maintain their health. Therefore, the expertise they developed through these experiences make them well placed to advise on how best to face known risks such as hazard events. Teller Seven's experiences discussed in the next chapter further demonstrates how being responsible can shape and inform within a disaster context.

Being responsible, surveillance and self-management

Being responsible is a common theme in narratives about the chronically ill within a health context (Galvin, 2002). As has been argued, health and illness in Western cultures has

become an individual responsibility resulting from neo-liberalism, individualism, and the medicalisation paradigms (Coburn, 2000; Galvin, 2002; Lupton, 1997; Petersen, 1996).

Making sense of the themes of responsibility in the tellers' narratives is an exploration into how people's social context can shape their experiences. Through surveillance and self-management of chronic illnesses, people can become experts in managing their own health. These 'experts' can provide valuable information on how best to manage themselves in a disaster context, because of the skills and competencies they have developed through their chronic illness experiences. They can also provide information about the difficulties they have experienced such as getting additional medication. However, feeling responsible for one's health may have negative consequences, with some of the tellers expressing reluctance at seeking help or support, which can result in actions that place them and others at greater risk.

Teller Five and Six both refused to evacuate after a tsunami warning. Both men strongly identified with being responsible and independent, which could have shaped their actions when faced with uncontrollable events such as a tsunami. Rushton, Phibbs, Kenney, and Anderson (2020) contend that the risky behaviour of some men in disasters can be understood in terms of the influence of "gender hierarchy and hegemonic masculinity ideals, related to maintaining a controlled stoic, masculine image (p. 3)." Rushton et al. (2020) explain that believing in oneself is a coping and recovery strategy for men, and is related to a sense of control which corresponds with the stereotype of being a 'strong bloke.' These beliefs manifest as failure to seek help which is evident, for example, in men refusing to evacuate the 2007 Tewskesbury floods.

Teller Six speaks often of choosing to take responsibility for his own health instead of seeking help from others (e.g. when he broke his arm and took a taxi to hospital). Yet his

reason for refusing to evacuate his home in Petone after the 2016 tsunami warning was his belief that a tsunami was impossible due to the geography. When he did choose to leave hours later due to siren noise he did not require help from others as he had his own transport, and needed no physical assistance.

Another way responsibility was evident in the tellers' stories was through relinquishing responsibility. Teller Seven speaks about the Kaikōura earthquake and having to relinquish responsibility for her children's safety to others because of her chronic illness. Teller Seven has a chronic neurological condition that severely impacts her physical movements. She explains that this means sometimes her husband has to carry a lot of responsibility:

"*and also, I guess with the condition I have to be more aware that I am going to be slower and that I may not be able to help as much as I want to. Um ah so I'm mindful that a lot of responsibility is likely to fall on husband, you know, due to the strength of someone saving them pulling them out of rubble*." Teller Seven

With concern about the added responsibility on her husband and acknowledgement of her physical limitations, Teller Seven describes how their children have learned to help themselves in a disaster:

"*Um the awareness of things and drills at various you know school level so the kids know what to do and what to expect*." Teller Seven

"*well she needs to have or needs to know that its ok that we've reassured her and that her brother is going to be upstairs in the bedroom next to her and if anything serious happens he will grab her or vice versa*." Teller Seven

Through her stories of handing over responsibility, Teller Seven demonstrates how she has had to come to terms with her illness and the limitations it places on her physically. This also highlights a relationship between letting go of responsibility and acceptance. By having a plan in place, Teller Seven is able to alleviate any worry about her children's safety with knowledge that her children know what to do. Like Teller Three demonstrates earlier, through forward planning Teller Seven is able to reassure her daughter that her brother will take responsibility for her should an earthquake, tsunami or "*anything serious happen*".

Teller One embodies discourses of individual responsibility in her story of taking her own blood pressure. She presents herself as responsible for the illness by self-monitoring and reporting the results to her doctor. She demonstrates that she can remain independent. She explains that she monitors her own blood pressure at home with a machine given to her:

"*So, I was at home taking my blood pressure…so I take it regularly and I've got it at home so I um monitor that then email through to my doctor my readings so that she knows where I'm at*…" Teller One

By presenting herself in this way she positions herself as someone in control of a chronic illness, rather than the chronic illness representing a loss of control. G. Williams (1993) explains that being responsible can be closely aligned with self-surveillance and self-management as awareness and preparation are required to manage health. Teller Six speaks of managing his health through supplements and lifestyle adjustments including the use of filters to remove toxins from the air and water. According to McAdams (1993), narratives of self-mastery are about people demonstrating through action that they have self-control and autonomy, resulting in a stronger and more powerful self in the world. Self-mastery therefore,

could be an important narrative tool for someone with chronic illness wishing to convey independence.

G. Williams (1993) also argues that themes of independence such as self-surveillance are characteristic of people's discussions of the impact of chronic illness on their lives. Williams explains that notions of independence are typical of chronic illness stories because they are representative of an individualistic society where an individual's value is measured by their ability to be in control, and chronic illness means a lack of control. As being in control is highly valued socially, it is important to reconstruct oneself as having control over your health through the performance of daily tasks such as taking medication and adhering to medical advice (G. Williams, 1993).

Summary

Themes of responsibility throughout the tellers' narratives can be understood as a way of adapting to the impact illness can have on their lives and those they are responsible for. Being prepared for Teller Seven helps her cope with letting go of some of her responsibility for her children during a hazard event. For other tellers, being responsible was about taking responsibility for the management and surveillance of their illness. This echoes the dominant narrative that the chronically ill are responsible for their ill health. However, for the tellers, surveillance and self-management was about presenting themselves as independent, which is in contrast to the social representation of them as dependent, a burden, and vulnerable found in emergency management and beyond.

Conclusion

This chapter highlights how all of the tellers positioned themselves as independent, and did this through the use of a mixture of subcategories. For example, Teller One exerts her independence by showing she has control over her life by being prepared in the event of an earthquake, while Teller Six declares himself independent enough to manage himself, even after falling and breaking his arm. Teller Five and Teller Seven use themes of defiance in their stories to position themselves as independent. Both defy being labelled as chronically ill, and express the extent of their agency with stories of doing things despite being unwell (e.g. getting work and driving). Their stories conveyed a need to be viewed as independent, to separate themselves from illness. However, for other tellers their stories of illness and hazards were constructed around the theme of acceptance.

When faced with the possibility of a tsunami, which was beyond their control, Tellers One, Five, Six, and Eight all spoke of accepting their fate. The tellers' acceptance was the strategy they used to cope with an event they could not control. Teller One also spoke of acceptance in relation to her chronic illness, which enabled her to positively position herself despite the negative impact the illness had on her daily life. By accepting an illness, Teller One was able to focus on the positives including learning more about herself, so that she could become a better person. Acceptance afforded all the Tellers a way of focusing on the positive things in their lives, rather than the risks to their lives. The tellers show that acceptance can be a helpful psychological tool for coping with disruptive events and can help build resilience in the long-term.

Other tellers used their past experience to manage disaster events. Teller Two and Teller Five included in their stories past earthquakes to explain the independent actions they took. Both disregarded others and chose to do their own thing because their past experiences

made them confident that their decisions were right. For Teller Two this meant evacuating immediately after the Kaikōura earthquake, while for Teller Five it meant remaining at home. These responses are in keeping with research which has found that past experiences of earthquakes do influence people's judgements in future events (Doyle et al., 2018; McClure et al., 2016).

For some of the tellers, past experience resulted in the development of rules to manage chronic illness and natural hazard events. Teller One spoke of the rules she had developed from having experienced earthquakes in the past, and how these rules helped her independently manage the Kaikōura earthquake. Tellers Three and Four used their experience of their daughter's illness to help her become independent of the illness. These learnings are applied as family rules which assist their daughter to develop her own illness independence. Their stories echo disaster discourses of being prepared including Aotearoa New Zealand's 'Get Prepared' earthquake preparedness strategy.

Another dominant narrative reflected in the tellers' stories was that of being responsible. Teller Seven constructed her earthquake story around her responsibility as a mother, and how due to her chronic condition she was unable to take full responsibility for her children during an event. This occurred through constructing her stories around sharing responsibility with her husband and the children themselves. This story highlights the importance of having a context specific personal plan in place, particularly as most Aotearoa New Zealand's disaster plans are designed for the able bodied (Blake, Miller, et al., 2017).

While not all of the tellers spoke of having preparedness plans, their experience in managing their chronic illness suggests they have the resources to cope when disaster strikes. Part of being independent for all of the tellers was about managing their illness. This included taking medication, following medical advice, and self-monitoring. For example, through

themes of self-surveillance and self-management, Teller One takes back control of the illness and her body by taking her own blood pressure and providing her readings to the doctor. She maintains her independence by managing her condition and her body. The skills and competencies developed by the chronically ill in managing their health are a useful resource for how to manage unexpected events including natural hazard events.

Themes of independence in the tellers' stories are expressions of agency and agency can influence whether people prepare, and how people may react in a disaster context. This matters to health and wellbeing and therefore, themes of independence can provide a better understanding of life in Petone for the eight tellers and its impact on their health.

Chapter Six: Social Connection

Figure 20 *A sunny morning on Jackson Street, Petone. Author's photo collection*

Introduction

In this chapter, the influence of the social context in the tellers' lives will be discussed. Research shows that social connection such as friendship, love, belonging, helping, caring, and sharing are significant to people's sense of wellbeing and health generally (Lyons & Chamberlain, 2006; McAdams et al., 1996; Taylor & Repetti, 1997) and also during disaster events (Aldrich, 2012). In this respect, the role social context plays in the tellers' illness and hazard experiences is important to explore, including how social representation, the idea that knowledge from various areas of society including politics, medicine, and science that shape people's ideas and beliefs (Lyons & Chamberlain, 2006) may shape the tellers' experiences.

Narratives of social connection in the tellers' stories represent how social networks or social capital, such as family, friends, community, and wider social groups influence health and wellbeing in a disaster. As defined earlier in this research, social connection is understood as "the desire to feel connected to others – to love and care, and to be loved and cared for", and appear in stories about friendship, caring and connecting with others (J. Bauer & McAdams, 2000, p. 277). Social connection also includes the connections the tellers have to the place they live, Petone, and how that place has shaped their social identity. As illustrated by Taylor and Repetti (1997), various environments (e.g. family, work, community, physical environment) impact on the development of chronic illnesses (Lyons & Chamberlain, 2006). While Bonaiuto et al. (2016) contend that those who identify too strongly with a place prone to natural hazards may not perceive the level of risk from a hazard event sufficiently to avoid harm.

Themes of Social Connection

Three main themes of social connection in the tellers' narratives were identified: Community; Social Support; and Family and Friendship. Table 4 illustrates the various ways the tellers use the themes of social connection as a focal point for their stories of life in Petone.

Table 4 *The Social Connection Themes used by Tellers*

Themes of social connection	**Examples of themes in Tellers' stories**
Community	"…Um I love that um it's like a community, a little community…I've got everything I need." Teller One
Social Support	"That lady across at number 19 have been good. They came and got me for the last one." Teller 8
Family and Friendship	"She makes a day of it. She invites her friends to come along and they just go round sampling stuff." Teller Three

For some, the importance of living in Petone is about being part of a community, and others value the social support available in such a community. To help better understand the use of these themes, ideas around sense of community, social support, social capital, and place attachment frames the discussion. Collectively they contribute to experiences of health for the tellers and the environments in which they live.

Community

Figure 21 *Te Puna Wai Ora The Spring of Life aquafer. Author's photograph collection.*

People's wellbeing is reliant on having meaningful social relationships that promote feelings of belonging to a community (McAdams et al., 1996; Sonn et al., 1999). As outlined in Chapter 2, a sense of community involves belonging to a community and that community being the cornerstone of people's lives. A sense of community provides people with relationships, social identities and roles because they generate feelings of identification (Sonn et al., 1999). McAdams et al. (1996) define connection to community as:

"experiencing a sense of oneness, unity, harmony, synchrony, togetherness, belongingness, allegiance, or solidarity with a group of people, a community, or even all of humankind together" (McAdams et al., 1996, p. 351).

All of the tellers had themes of community in their stories of chronic illness and natural hazards, where community largely represented convenience and accessibility. For instance, Teller One described convenience as an important aspect of living in Petone:

"*…everything is accessible by foot so if you want to think 'Oh I want to go to the Hospice shop and see what's happening down there.' Or meet for a coffee down the road there's heaps of lovely local cafes here…*" Teller One

Other tellers in this research also highlighted how the convenience of living in Petone provided them with independence, aspects of which were discussed in the previous chapter. This is significant to Teller Eight's safety in an emergency situation. She has mobility issues so the social connections Teller Eight has made living in Petone means there are people she can call on if needed, as well as people to check that she is safe and well. When asked about living in Petone, Teller Eight said:

"*Well is nice and handy…You got a lot of shops just up the road within walking distance which is good. Even now at my age with wheels (laughs [points to walker] um yeah its good.*" Teller Eight

While Teller Eight has mobility issues requiring her to use a walker, which some may consider a limitation, she remains active and agentic because she lives within walking or bus distance of shops and community amenities. For others, like Teller Eight, having convenient and ease of access to amenities is more important than any potential hazard event. In their study, Tuohy and Stephens (2016) found that older adults chose convenience over hazard risk when deciding where to live because the community in which they lived enabled them to maintain their independence, which was crucial in preparing for later life. The same could be

assumed for the tellers in this study based on their accounts of living in a community like Petone, which include tales of convenience and good access to amenities that enables them to live independently. This was more important than risk.

Similarly, Teller Five who too has restricted mobility and sometimes uses a walking stick or walker, constructs an account of his life in Petone as one of social connection, but also of independence. Life in Petone provides him with everything he needs - it is convenient. He explains:

"*If I don't feel up to it I've got a walker and I can get that out and walk up to the bottle store and that's not that far away. Or to Pak n Save, or... I can walk to Jackson Street with my walking stick, most days … I've walked down the street and I feel quite good about it, because very rarely do men offer a shoulder to lean on while you're walking down the street. Quite often young ladies will*." Teller Five

Living in Petone with amenities close to home has enabled Teller Five to maintain a sense of belonging and social connection as well as a sense of agency, because even with limited mobility he is still able to get out and walk to places and meet people. However, there are potential risks to health when people choose to live in a place due to convenience.

In their study of older people's experiences of a flood event, Tuohy and Stephens (2012) found that the older people interviewed chose the flats they lived in because it put them closer to public amenities, which enabled them to be self-reliant and independent. However, the flats were located next to a flood bank, and were flooded when the river broke its banks. The residents were unaware of the risk until firemen knocked on their door and evacuated them, and the local authorities were unaware of the residents because they were

living independently. This shows that access to social support can be just as important as convenience when it comes to where to live.

As well as convenience and ease of access, Teller One has good social support and expresses a strong emotional connection to Petone, suggesting that a sense of community engenders good feelings. She said:

"*Love it…Um I love that um it's like a community, a little community feel…I work in Seaview so it's close to home. The gym's close…I've got everything I need here. And a lot of my friends 90-80% of my friends or 90% live in, within the area*." Teller One

For Teller One living in Petone is also about belonging. She feels part of a community that provides her with everything that she needs, including work, recreation, amenities, and friendship which are all important to wellbeing. Teller Six also refers to living in Petone in terms of love, which seemed to be an elixir when asked about the risk of living in an area prone to natural hazards. Teller Six explains:

"*I have no anxieties about living in Petone ah actually I love Petone. I think I was fortunate to bought property which is now a historic precinct area. It's a nice street with nice people. And I think because of the historical precinct we tend to feel more together*." Teller Six.

As this quote suggests, Teller Six also values the history of the residential street he resides in and the connection it creates with his neighbours. This connection seems to engender a feeling of ease and allays fear of living in Petone with its various hazards. Additionally, living on a distinctive street both connects Teller Six with his neighbours while

also positioning him as unique from others who do not live there. This combination of sameness and uniqueness afforded to Teller Six by the place in which he lives can be interpreted as him defining his identity in terms of his physical environment. Perhaps a physical environment that overlooks or ignores any potential hazard risks.

Such characteristics of people's environments have been found to directly relate to health outcomes including the onset of chronic illnesses when environments failed to facilitate the meeting of such needs (Taylor & Repetti, 1997).

Figure 22 *A community garden in Petone. Author's photo collection.*

Petone has various community groups (Figure 22 being one example) and Teller Two is a member of many. Similar to Teller Six, Teller Two defines herself in terms of her physical environment with most of her stories centring on her work in, and being part of, the Petone community:

"*... I got involved with the Community House and the Historical Society, and with Rotary... now I decided that perhaps it was time to stand for the Community Board, that maybe there was another way to try and keep an eye on what might be happening in Petone,*" Teller Two

Teller Two not only positions herself with respect to her community, she also identifies herself as an integral part of that community when she refers to "*keeping an eye on*" Petone. Having a strong place identity, according to Lewicka (2008) enables people "to preserve a sense of continuity, to build positive self-esteem, and to create a sense of self-efficacy" (p. 211). Taylor (2010) speaks of the connection between people and the places in which they live, in terms of local identities. This is evident when the tellers speak of life in Petone, and refer to 'we', positioning themselves as belonging or being part of the local community, rather than someone living separately to others. Take for example, how Teller Two positions herself in stories about her life in Petone. Also, by positioning herself in a guardian role, Teller Two indicates a strong emotional bond with Petone, a relationship potentially based on place attachment. This aligned with Teller One's narrative about how a *community feel* has contributed to her staying

"*I'll take less money to have more of a community feel. Nice relaxed not that corporate scene that's not for me. As soon as I made that decision my job (pause) um came up and I just I took it and I've been there for 10 years*." Teller One

In regards to health, some researchers view strong place attachment as a positive influence on health because it facilitates wellbeing (Lewicka, 2008; McKinzie, 2019; Wiles et al., 2009). Strong bonds with place, or place attachment facilitates good psychological health

through feelings of security, strong self-identity, and community mindedness (Lewicka, 2008; McKinzie, 2019; Wiles et al., 2009). According to Wiles et al. (2009), strong place attachment provides people with meaning, a sense of security and identity that promotes wellbeing, particularly as people adjust to aging. Take for example the sense of belonging and identity conveyed by Teller Five as he speaks of his walks up the street:

"*I walk up the street here and there's not many places where if there are people living there and they're sitting out in the front in the sun, they'll say good day. They'll remember my name, but I was never any good at names*." Teller Five

This connection with community members has helped him adjust to living in Petone where he has resided for three years. Previously he had lived in another suburb nearby for approximately 50 years. Teller Five told how a number of his adult children lived in Petone, and his wife went to church there, so, he already had an attachment with Petone. Also, through local encounters he has developed a stronger sense of attachment to Petone which enables him to make sense of who he is in this new environment and how he fits into it. This in turn helps him feel more secure and enhances his sense of wellbeing as he knows that when he is out and about in the community he is known:

"*Fella in that house over there, he and I speak together and he's a rich computer gaming designer or something… If he sees me anywhere he picks me up in his car… Yeah. The woman and her husband next door there, say good day, and in that flat, the fella out the back, he greets me every day, hiya… you know*." Teller Five

It is through his social connection with the community that Teller Five's attachment to Petone grows, and his sense of security develops. Pooley et al. (2005) explains that a

person's sense of community is a reflection of their attachment to that community, which can contribute to feelings of ontological security.

Place attachment is of relevance to disaster research as strong attachment to place can have an influence on people's residential mobility after a disaster, and whether people choose to stay or go (Adams-Hutcheson, 2015). Bonaiuto et al. (2016) review of research found that place attachment affects how people perceive the risk from natural hazards such as tsunamis, as well as how they cope with an event. Across the research, people with strong place attachment underestimated the risk from a hazard event, were less likely to evacuate and more likely to return to high-risk areas. Given their findings, Bonaiuto et al. (2016) argue that disaster management planning needs to factor in the effects of place attachment on how people will behave in the event of a natural hazard event, as it may be an area of risk that has been overlooked.

Bonaiuto et al. (2016) findings are of interest to the current study as many of the tellers expressed strong attachment to Petone. Having strong attachment to a place prone to natural hazards, while living with a chronic illness, potentially increases the risk of adverse health outcomes for the tellers. As Bonaiuto et al. (2016) explains through the term "self-protection vs connection," people with strong place attachment are less likely to adopt effective coping strategies when a hazard occurs, instead denying it is occurring and failing to avoid the subsequent hazard. Such responses increase the risk of adverse health outcomes (Bonaiuto et al., 2016).

This may be of interest to those responsible for preparedness strategies, particularly given the low tsunami evacuation rates reported in Blake et al. (2018) study of the tsunami response and evacuation behaviour of Petone and Eastbourne residents three weeks after the Kaikōura earthquake. Similar responses were reported by the eight people who participated in

this study, with only two evacuating within the 10 minutes timeframe promoted by Aotearoa New Zealand's National Emergency Management Agency (National Emergency Management Agency, 2020).

Take for example Teller Five, whose response to being told to evacuate due to a tsunami warning, was to roll over in bed and go back to sleep. Meanwhile, Teller Six denied the possibility of "*any big waves hitting*", remained in the area long after the event, and left only to get away from the noise of the flood siren. Both expressed strong attachments to Petone. However, other tellers who also expressed their strong attachment to Petone, did treat the threat as serious and evacuated. As Bonaiuto et al. (2016) point out, the issue of place attachment and hazard risk is complex and needs further exploring. The complexity of the issue is apparent when considering that an integral part of strong place attachment is people feeling secure or being ontological secure in where they live. Ontological security (having a sense of security) and trusting in the safety of a place based on routine occupation of that particular environment can be more important to physical wellbeing for some (Harries, 2008; Hawkins & Maurer, 2011).

Hawkins and Maurer (2011) also highlight that "having confidence in the routine and reliability of persons, places and things", is necessity for ontological security. They explain that ontological security "creates a cognitive order and sense of safety and trust in the world" that functions "as a coping mechanism against existential anxiety, enhances psychological wellbeing, and provides a 'protective cocoon'…and a 'firewall against chaos'" (Hawkins & Maurer, 2011, p. 144). Therefore, when the world no longer functions as expected, people's sense of security is threatened (ontological insecurity), and they become anxious about the reliability and safety of their environment (Hawkins & Maurer, 2011). When Aotearoa New Zealand went into lockdown because of COVID in March 2020, for example, it is likely that

many experienced a shift to ontological insecurity as the reliability of their daily routines ceased and the physical environment was deemed unsafe.

In contrast, the tellers who at the time of interview were yet to face the ongoing COVID pandemic, spoke mainly of the sense of security they experienced from living in Petone. Teller Five positions himself as ontologically secure through his stories of life in Petone, which he represents as a community where people feel safe, and trust one another through a shared sense of reality and identity. Taylor (2010) explains that the place where someone lives is particularly relevant to their identity because for people like Teller Five who has actively chosen to live where he does, his choice is a reflection of who he is and what is important to him. Trust and safety are important to Teller Five's wellbeing as without these he is unlikely to walk for his health or provisions.

Summary

Research has shown that wellbeing is dependent on social relationships that result in people feeling they belong to a community. Based on the tellers' accounts of life in Petone, their wellbeing is linked to being part of the Petone community. For the tellers, life in Petone meant social connection, a sense of belonging and security, accessibility, and convenience. Petone enabled them to live independently while also feeling a sense of security, because as a member of the Petone's community they had access to all that they needed.

However, having such strong feelings of attachment to a place can also be detrimental to health as for some it negatively impacts on their perception of risk from a hazard event. The concept of place attachment may help to understand why two of the eight tellers did not

evacuate after a tsunami warning, and may be worth further investigation in terms of the low tsunami evacuation rates in Aotearoa New Zealand.

Social Support

Figure 23 *Community building begins early in Petone (Best Start).*

According to the World Health Organisation, good social support is a social determinant of health that improves health as it ensures people receive needed practical and emotional resources (WHO, 2017). McAdams et al. (1996) asserts social connections engender social support, assistance, and aid as care/help given or received which enhances wellbeing. Norris, Stevens, Pfefferbaum, Wyche, and Pfefferbaum (2008) define social support as:

"…social interactions that provide individuals with actual assistance and embed them in a web of social relationships perceived to be loving, caring, and readily available in times of need." (p. 138)

From a health perspective, social support can influence people's health either positively with strong levels of social support helping to reduce mortality levels, and poor or no social support resulting in social isolation increasing the risk of death (Lyons & Chamberlain, 2006). In emergency management, forms of social connections like social support are what make up the social capital of a community which relates to the various kinds of interactions between people in a community (Chamlee-Wright & Storr, 2011; Ministry of Civil Defence & Emergency Management, 2019; Pooley et al., 2005). As all the tellers spoke about the importance of social relationships in their lives, it was decided to refer to this theme in their stories as social support.

For some of the tellers, strong social support ensured their survival, especially when their physical health or their chronic illness prevented them from taking speedy actions during an emergency. For example, the help Teller Eight received from neighbours during the Kaikōura earthquake was important. Teller Eight explains what happened directly after the quake:

"…*that lady across at number 19 have been good— they came and got me for the last one…took me up the top of Mangaraki hills…yes so that was good… two people across the road there came across and phoned up to see that I was alright*." Teller Eight

Teller Eight suffers from rheumatoid arthritis in her legs, lives alone, has no family close by, and does not own a car. She has lived in the same place since the early 1980s and

she spoke at length about the relationships she has built with her neighbours. Through these relationships she has a network of people she can rely on for support when she needs it. She has developed an identity within the network as someone who may need care or help, and someone who cares and helps others:

"*yeah I've got number 21 they are very good… I go over there about fortnightly and share a bottle of wine with them. And they've got a key… they've got a key just in case… those on that corner they're pretty good they come over now and raid my lollie jar…(laugh) mind you perhaps I keep it there for that reason… so they're pretty good*." Teller Eight

When talking about her neighbours, Teller Eight positions herself as both someone who receives and provides social support. As Lyons and Chamberlain explain, being part of a social network such as neighbours can "help towards identity and defining oneself in relation to others" (Lyons & Chamberlain, 2006, p. 163). Being a good neighbour is important to Teller Eight, and that means developing social relationships with those living around her. In turn she is rewarded with supportive neighbours, which provides her with a sense of belonging and security. This is particularly important in times of need as was evident when Teller Eight's neighbours evacuated with her after the earthquake.

Akin to Teller Eight, Teller One also drew on social support as when she became seriously ill one night, she woke her neighbour at 4 o'clock in the morning knowing that they would help her get to the hospital. In telling this story, Teller One portrays her level of social connectedness which influences her sense of vulnerability in a natural hazard event. Both Teller One and Teller Eight's stories indicate that the strong social relationships between neighbours has positively influenced their health. This was also evident in Teller Six's story about tsunamis.

When talking about Petone being prone to tsunamis, Teller Six speaks of how any anxiety he may feel, perhaps a sense of ontological insecurity, about the possibility of a tsunami is reduced by knowing "*there is support if need it*." Throughout his stories Teller Six makes it clear that he is an independent person. As such, themes of social connectedness are limited in his stories. However, Teller Six was willing to concede to seeking help from others when faced with something beyond his control like a tsunami. Other tellers also spoke of seeking help from others in the event of a natural hazard.

Social support was pivotal to wellbeing because of a lack being prepared. In the event of a disaster Teller Three and Four spoke of a reliance on others who were prepared compared with their lack of preparedness:

"*The answer to your questions, no we didn't, we're not that prepared*." Teller Four

"*We have got water in the shed now, but all we did was we grabbed the kids and the dog. We've got water in the shed, but we are so unorganised. They're much more organised at school…".* "*…Yeah, some people we know are so organised. We say we're coming to your house*." Teller Three

These statements contrast with their expressions of agency in their stories of managing their daughter's chronic illness as outlined in the previous chapter. Teller Three and Four talked about being active agents in dealing with their daughter's illness, in that being prepared helped them successfully navigate many illness-related challenges. However, when faced with a natural hazard event, or potential disaster, their roles shift from active agents to that of community members seeking support within their social network.

Aldrich and Meyer (2015) identify that social support as a form of capital is essential for people to survive and recover from a disaster. This argument is common knowledge

within the disaster field and has resulted in various strategies for preparedness and recovery (Akbar & Aldrich, 2018; Chamlee-Wright & Storr, 2011; Ministry of Civil Defence & Emergency Management, 2019; Vallance, 2011). However, not everyone has access to supportive or safe people or neighbours, and as such access to health and wellbeing in a disaster.

It is argued that disaster risk reduction or management practices that rely on various forms of social connection or community cohesion tend to favour people that have access to financial, social, political, human resources (Blake, 2020). Therefore, those who can afford the necessary resources to survive or thrive, and are able to develop strong social networks tend to be better off in a disaster context (FitzGerald et al., 2017; Rodríguez et al., 2018).

This social injustice has been seen to play out more recently in Aotearoa New Zealand's COVID risk management response. Blake (2020) pointed out that the 2020 strategies deployed by government to keep people safe from the first experiences of the virus did not factor in the social and political disadvantage for communities most at risk. Failing to recognise and address such disadvantage in a disaster leads to poorer wellbeing and resilience, an issued acknowledged in Aotearoa New Zealand National Disaster Resilience (Ministry of Civil Defence & Emergency Management, 2019). A range of other research (e.g. Bolin & Kurtz, 2018; Thomas, Phillips, Fothergill, & Blinn-Pike, 2011) also determines that disasters intensify and expose disadvantage and risk in society, as demonstrated in the earlier literature review.

Summary

In this section the tellers' stories of chronic illness and natural hazard events demonstrate how they have benefited from their strong social connections in Petone. Whether it be neighbours making early morning trips to the emergency department, or driving a teller

to safety after a tsunami evacuation alert, all of the tellers have expressed a sense of security knowing that there will be support available should any disaster strike.

The tellers' accounts of social support and how it improved their health and wellbeing in a disaster context bolsters earlier research reiterating the importance of practical support such as sharing of supplies and transport during a hazard event. However, not everyone has the same level of access to social support as the tellers. Therefore, preparedness and recovery strategies that are dependent on communities having high levels of social capital are not effective for those in the community who, for example, are socially isolated or similarly disadvantaged.

Family and friendship

Figure 24 *Three generations working together. Author's photo collection*

Close personal relationships such as family and friendships were also a key theme of the tellers' stories about how they managed a health crisis or natural hazard event. These relationships are intertwined with and related to social connection and social support, which collectively make up social capital. The tellers narrated how working together, or receiving or providing help to someone they had a close connection with, mattered to their health and wellbeing. McAdams et al. (1996) defines friendship as close positive relationships involving emotional bonds unique to those involved. It is through such relationships that the tellers made sense of particular illness and hazard experiences.

As previously discussed, Teller One's experience of the Kaikōura earthquake was both something she managed independently as well as a shared event. This shared event involved making disaster plans with friends for what to do after an earthquake:

> "*I…thing with my friend around the corner. If anything happens we're in it together and another neighbour*." Teller One

Through this excerpt, Teller One positions herself as someone who cares and is cared about by others. It is through friendships that Teller One portrays herself in a positive light, something that according to Charmaz (1983) chronic ill people struggle to do after becoming ill. Charmaz (1983) argues that the illness experience invokes a new self-identity, as well as a social identity that is often rooted in experiences of illness and social isolation due to the toll their health has on friendships.

Like Charmaz, this study includes stories of the impact that living with chronic illness has on friendships. Teller Three narrated how her daughter would get sick when attending friends' parties so they eventually decided she would no longer attend the parties. This left

her daughter feeling isolated from her friends. Teller Three also explained that her daughter felt left out at school events that were centred around food, and because she could not eat the food she was singled out and missed out on socialising. For Teller Three and Four's daughter not having access to celiac friendly food not only impacted on her health, it also impacted on her social identity and wellbeing.

To better understand how social connections like friendship and family influences health and wellbeing it is helpful to further ponder the role of social capital in the context of health and disasters. From a health perspective, social capital helps explain how the quality of people's social lives can lead to health advantages and disadvantages, including health inequalities for groups like the chronically ill (Cragg, 2013; Putnam, 1995; Stephens, 2008b). The chronically ill are shown to be at greater risk of experiencing health inequalities compared with those who are healthy because being ill often leads to a restricted lifestyle (i.e. the impact of living from home and having limited physical capacity on relationships) (Bury, 2001; Charmaz, 1983). Similarly, as previously outlined, within a disaster context social capital is key to anyone's survival, with access to high levels of social capital bettering people's chances of recovery after a disaster, while low levels mean people's chances of recovery are reduced Aldrich (2012). As Aldrich (2012) points out, access to social resources such as physical assistance, sharing food, water, and shelter can act as buffer against the adverse conditions caused by a natural hazard.

Teller One presents herself as someone with high social capital because she has people that she can rely on and trust when she needs help (e.g. friends to evacuate with, and to provide trips to the emergency department). Friendship bought her to Petone, and remains a major reason for Teller One's strong attachment to Petone. In Teller One's evacuation story she actively positions herself as interdependent, and describes how she and friends worked together to evacuate and get to safety:

"*…um my friend who was in Queenstown with me that was up here she's got a family and she was in touch with me and said "I think we need to get up the hill, get up the hill". I said ok so I got my friend around the corner and we got her car cause she's got heating good heating and we drove up Korokoro*." Teller One

Teller One lives alone, but has developed strong friendships with neighbours who she can rely on to support her when in need. She explains that through these friendships she has a sense of ontological security as though she were not alone, because there is help close by:

"*Kristine and Jason around there. Deborah is at the end of that street. Maggie's there...*". Teller One

For Teller One, her friendship network has enabled her to live independently with a chronic condition, with support from friends as needed. Teller Three and Four also value a sense of community and the friendships that develop from living next door to other people. They tell of how they were happy to allow their children to walk and bike locally because of the friendships the family had developed with neighbours:

"*And everyone's really nice. Everyone looks out for each other. We borrow things off people, so there's definitely a sense of community. It's really strong in Petone…. And I think the kids, you know, they like to go out on bike rides or walks just by themselves sometimes and you feel totally safe them doing that, and they know lots of people round here, and also they know the area well, and we don't have any concerns do we*? Teller Three

Both Teller Three and Four speak of how their friends helped by trying to ensure the daughter is provided with celiac friendly food at social occasions, which has helped their daughter to feel less socially awkward. For all tellers, friendships have meant a collective response to natural hazard events including preparedness planning, pooling of resources, and evacuation.

Summary

The tellers' stories about their illness and natural hazard experiences involved family and friendship themes. For some of the tellers, their illness experiences involved social isolation when due to their illness they were unable to participate fully in social events. This had a negative effect on their social identity and wellbeing. However, by preparing for social events they had reduced the likelihood that illness would restrict their lifestyle.

Through a social capital lens, such exclusion is seen as an inevitable risk and burden for the chronically ill as illness places restrictions on their lifestyle such as maintaining friendships through social engagement. Within a disaster context, access to social capital (i.e. family, and friends) can mitigate the adverse effects of a disaster. For Teller One, strong friendships meant a sense of ontological security when the Kaikōura earthquake occurred, and when due to worsening illness she required emergency medical care. Like Teller One, family and friendship meant for all the tellers the sharing of a burden whether through working together in preparation for an earthquake or support when ill health worsened.

Conclusion

The influence of social context on the tellers' lives was evident in their stories of social connection which included three main themes, community; social support; and family and friendships. These themes acted as a focal point of their stories of living in Petone. For some tellers, life in Petone was about being part of a community, and for others it was the social support available by having family and friends close by, that made residing in Petone important. For all the tellers, being in a community like Petone was integral to their health and wellbeing, and through the theories of place attachment, sense of community, ontological security, and social capital, a better understanding of why Petone matter to the tellers' health was gained.

Living in Petone was important to the tellers' health because it meant having strong social connections which created a sense of community, belonging, and security. It also meant easy and convenient access to essential services. Petone provides the tellers with access to both 'physical' capital (i.e. supermarkets, medical centres etc) and social capital that enabled some of them to live independently or access social support. According to the tellers Petone provided them with all that they needed, and they all spoke of a strong attachment to Petone. Such strong place attachment can be problematic in a disaster context.

An important element of people's sense of community was attachment to place, and this was evident in many of the tellers' stories of life in Petone. Several spoke of feeling part of the community and the importance of this in their reason for living in Petone. For them, being part of the community meant a sense of security as they knew who lived around them, and that they could count on their support if required. A sense of security provided them with ontological security despite knowing that Petone was prone to natural hazards.

An important component of the tellers' sense of security came from knowing that there was social support nearby. Teller One spoke of having neighbours who would support her by taking her to the hospital when her illness meant having to go to the emergency department. While Teller Seven told stories of how her neighbours checked in on her after the Kaikōura earthquake, and how one drove her to safety after the tsunami warning. Such stories support past research that found accessing practical social support (social capital) such as drives to the hospital or out of a tsunami zone were important as people's level of access to such support determined their chances of survival in a disaster context.

For all the tellers, social support or social capital came in the form of family and friends. Therefore, these were key themes in their stories about illness and hazard events. For some, chronic illness can be a barrier to socially connecting with friends which can lead to feels of socially isolation (Bury, 1982). The tellers spoke of how they had learned to be prepared for social events, and through their preparedness were able to reduce the likelihood of illness restricting their social connections. The theme of family and friendship in the tellers' stories of life in Petone illustrate the importance of having access to social support and networks not only within a disaster context, but also in terms of their health and wellbeing as people with chronic illnesses.

Chapter Seven: Findings & Conclusion

Figure 25 *Petone's Winter Festival Fireworks display on Petone Beach (Pinterest.com).*

Overview

The aim of this thesis was to better understand how living in Petone, Lower Hutt, Aotearoa New Zealand mattered to the lives of people with chronic illnesses. The narratives of eight people with a range of chronic illnesses were analysed through applying a critical narrative methodology as well as a Foucauldian lens to their stories. With little known about the disaster preparedness and recovery needs of people with chronic illness, specific to Aotearoa New Zealand, this research met a gap in knowledge. Pulling together findings from the analysis, this chapter presents the implications of the findings, outlines some research reflections on method and presents ideas for future research. Overall, the chapter reasserts the

importance of supporting people who are known to fare worse in disasters and advocates for more inclusive and diverse disaster management strategies so that all people have the chance to survive and flourish.

Significance: Relevance and Implications of Findings

Independence

Through analysis of the tellers' narratives, it was found that the need for independence shaped reactions, and the actions taken to mitigate risk. As found by past research, being seen to be independent was a key driver for people with a chronic illness who strive to meet this social norm (Prilleltensky & Prilleltensky, 2003; G. Williams, 1993). As demonstrated in the analysis, independence involved defying discourses that position the chronically ill as victims and in need.

Through living with chronic illness, the tellers had developed rules to keep themselves safe from illness and, where possible, be self-sufficient. For some, living with an illness was like living with an ongoing 'emergency' that had to be managed on a daily basis, therefore it was important to be prepared for any scenario. For this reason, when speaking of how to prepare for a disaster, tellers used their illness experiences as a reference point for managing such an event. This is consistent with other research that found people use past life events to navigate present difficult events and help adapt to future challenging events, such as disasters (Coleman, 1999; Tuohy & Stephens, 2012).

This research also showed how past experiences with natural hazard events shape reactions and risk mitigating actions in relation to future events. Tellers spoke about how

previous earthquakes taught them how to be prepared both practically, and psychologically, which also contributed to their sense of independence. Past experiences meant being knowledgeable enough to make independent decisions about whether an event was of risk, or not. However, as has been found in previous research, there are instances where experience can result in people making risky decisions, which was evident in this study with some refusing to evacuate after the Kaikōura earthquake (McClure et al., 2016). These tellers refused to evacuate because they believed, based on their knowledge of earthquakes and the Petone terrain, that they were not at risk of harm from a tsunami even though they were aware of education campaigns about Petone being prone to tsunamis. This is in keeping with research arguing that tsunami education did not increase evacuation rates (Fraser et al., 2016). It seems that independent decision making is key to people's sense of agency. Also important to agency were the strong social connections to place.

Living in a place like Petone meant independence was possible because amenities were close by and accessible for those whose illness restricted mobility. Petone also provided the tellers with a sense of community and a sense of security that collectively acted as a buffer to stresses that may have diminished good health and wellbeing.

Living in a community like Petone enabled strong social connections and these connections were more important than the risk of harm from a disaster. Social connection was evident through tellers having a sense of community, having social support and having a sense of security which all influenced health and wellbeing. Ontological security seems to be important when living in a hazard prone environment, because having a sense of security supports resilience which in turn leads to risk reduction actions such as storing food or having an evacuation plan (Fisher et al., 2002). In a kind of circular process, getting prepared can reduce people's vulnerability and risk from disaster related harms, which in turns helps people feel more secure, which reduces stress. Viewed from a social capital and sense of

community perspective, settings like Petone provide real life examples of the practical role social connections play in a disaster context. Social connections provide a protective barrier for people, particularly during disrupting events such as illness and disasters (Hawkins & Maurer, 2010; Douglas Paton, 2018).

Social support, as part of social connection, can also lead to practical support especially when people with a chronic illness cannot manage independently. In these instances, people can rely on family and friends to assist them, for example with trips to hospital or evacuation after the Kaikōura earthquake for the tellers in this study. Without this support. levels of vulnerability are compromised, especially if people are not able to evacuate, as it increases risk of harm.

The need to be seen as independent also has the potential to lead to decisions that can increase risk, as some in this research choose to manage health emergencies independently rather than seeking medical assistance, while others failed to evacuate after the tsunami warning. Striving to be independent can increase people's level of risk and vulnerability unnecessarily. This could result from excessive social pressure to be independent.

When it comes to risk, people think in social terms, resulting in a categorisation based on physical vulnerability (Lupton, 2013). This has resulted in the individualisation of responsibility which within a health context has led to people being held accountable for their own health. For the chronically ill, and other groups that do not conform to the social norm of being healthy, being deemed vulnerable based on health alone has resulted in them being blamed for their poor health, labelled as a burden, and not 'normal'. It is important to consider the impact such representation can have on a chronically ill person's self-identity, as well as their social identity.

Being healthy positions certain people as privileged members of society, while those with chronic illnesses are stigmatised and disregarded (Galvin, 2002; A. Radley & Billig, 1996). These types of representations manifest in government policies and strategies, and in a disaster context this has resulted in preparedness and recovery strategies that privilege the able bodied (Blake, Miller, et al., 2017). The stigmatisation of the chronically ill in a disaster context can result in risky decision making (as the need to be independent overrides perception of risk) and a reluctance to engage with emergency management (the need to be independent combined with a sense of embarrassment). It also leads to the disregard of the chronically ill through overlooking them in emergency management planning.

To shift this imbalance, the chronically ill must be heard and understood. Through The Sendai Framework (United Nations, 2015) the emergency management sector has an opportunity to do just that, as it requires input from the chronic ill into the design of emergency management plans.

Independence, and the reactions and actions that independence produces, do not merely decrease (or occasionally increase) the risk to the chronically ill person. They are also potentially of value to others. This research has demonstrated how people who are chronically ill have a lot to contribute including the skills and competencies they have developed through the daily management of their conditions, which in turn helps them to be resilient when disaster strikes. Stories of people surviving disasters are a valuable resource for others as they can help them know how to prepare by providing examples of what actions to take or what items to store (McClure et al., 2016; Tuohy & Stephens, 2012). For people who are unable to prepare due to systemic barriers (e.g. restrictions on medication) such stories provide an alternative way for getting prepared for example, getting prescriptions filled before medication runs out so that left over medication can be added to ‘Grab Bags’.

Access to medication

The tellers' narratives echo past research that shows people with chronic illnesses in a disaster context can be more physically vulnerable, and therefore, at greater risk of suffering adverse health outcomes due to interruption in medical treatment caused by disasters (Bethel et al., 2011; Carameli et al., 2013; Jhung et al., 2007; Miller & Arquilla, 2008). Viewed from this perspective, it is reasonable to assume that those people with chronic illnesses like the tellers who experience a disaster will suffer poor health outcomes, without access to medication.

Aotearoa New Zealand disaster preparedness practices and directives strongly advise that people should have additional medication - it is a 'must have' (Wellington Region Emergency Management Office). However, there is no guidance for those who are unable to obtain additional medication, creating unnecessary disadvantage, as shown by past research (Carameli et al., 2013; Jhung et al., 2007; Miller & Arquilla, 2008). As stated above, being unable to prepare due to systemic barriers can impact on people's sense of security. The failure of preparedness directives to consider the actual ability of some people to prepare can be understood as structural violence (Blake, Marlowe, et al., 2017b; Blake, Miller, et al., 2017). Structural violence occurs when socioeconomic structures and institutional practices are imposed on people in a way that causes harm, such as inequity when one group of people is disadvantaged (Hodgetts, Chamberlain, Groot, & Tankel, 2014; Rylko-Bauer & Farmer, 2016).

Most of the tellers spoke of having difficulty sourcing additional medication for emergency kits due to prescription restrictions which do not allow for an additional supply in case of a disaster. These restrictions are an example of structural violence as they render the chronically ill powerless to prepare for a disaster by being unable to adhere to preparedness

directives requiring additional medication be set aside. Failure to procure additional medication places those with chronic illnesses at greater risk, particularly those residing in a hazard prone area where the supply of medication is likely to be disrupted. The tellers were able to mitigate such risk by developing ‘work arounds’ to the system. However, such strategies do not guarantee access to essential medication in a disaster context, therefore a systemwide change is necessary to remove those barriers that prevent people with chronic illnesses preparing for, and recovering from disasters.

The tellers’ strategies for managing access to medication are examples of the practical solutions that people who endure ‘disadvantage’ or extraordinary life events use to address barriers. These ‘work around’ stories show that, while the tellers faced barriers to getting prepared for a disaster, which increased their risk and vulnerability to adverse health outcomes, their experiences of chronic illness gave them skills and competencies that enabled them to be responsive and resilient.

There were two main strategies deployed by tellers to get access to additional medication. Some had strong social connections with pharmacy staff, and as a result of these relationships were provided with additional medication. Others spoke about putting in their prescriptions earlier than required so that they had left-over medication that they put aside in preparation for emergencies including natural hazard events. Until the various agencies (heath and emergency management) come together and make policy or practice changes that allow people to have additional medication for disasters, these practical solutions may be the only options available for those striving to be disaster prepared.

Restricted access to medication highlights a vulnerability in Aotearoa New Zealand’s approach to disaster planning, especially for the chronically ill. Like many other countries, Aotearoa New Zealand health disaster planning focuses on acute injury treatment by

stockpiling medication for such injuries. This is despite research finding that the greatest demand during disasters is for the treatment of chronic illnesses, and this demand cannot be met because treatments like pharmaceutical drugs have not been stockpiled (Carameli et al., 2013; Jhung et al., 2007; Miller & Arquilla, 2008; Niland & Johnston, 2019).

In COVID times medication restrictions are of particular concern, as COVID is already placing pressure on the health sector resulting in staff and bed shortages, with non-COVID related treatment for chronic illnesses such as cancer, and cardiac illnesses being delayed or disrupted (Blake et al., 2021; Gurney et al., 2021; Ministry of Health Manatū Hauora, 2020; Nicholls et al., 2020).

Also, COVID has impacted on supply chains which has resulted in medication shortages, and price increases (Årdal et al., 2021; Collette, 2020). Should a major natural hazard event occur in Aotearoa New Zealand during the pandemic it is likely that those with chronic illnesses will be particularly disadvantaged as the expected medication shortages, and treatment interruption will be worsened by a weakened health system due to COVID. Simultaneous disaster events are of serious concern.

Reflections on Method

The term “chronic illness” can be problematic because how it is used can be imprecise and inconsistent, and there is no one agreed range of illnesses or diseases involved (Bernell & Howard, 2016). There is also no agreement about what time period makes an illness chronic. As Bernell and Howard (2016) contend, these issues can make general statements about the impact of chronic illness challenging. Also, the use of “chronic illness” in this study has the potential for confusion that may for example have limited people’s willingness to participate

with some deciding not to participate as a result not identifying with term chronic illness on the information sheet.

The issue of the scope of chronic illness was not the concern of this study, which was focused on the lived experiences of people with chronic illnesses rather than on numbers and trends. What mattered was the value of their experiences. While the tellers are categorised medically as chronically ill, their experience is likely to be relevant to people more broadly including people with disabilities and other vulnerable persons. Therefore, there is opportunity for further study and discussion about the ways in which the tellers' experiences can be utilised to benefit others.

This study had a small sample size which was sufficient for qualitative research and a critical narrative analysis. However, the sample size did not enable analysis of any demographic characteristics, which is significant as research shows that age, gender, culture, ethnicity, and socio-economic backgrounds influence people's experiences of health, and illness (Bolin & Kurtz, 2018; Bury & Gabe, 2004). Such a consideration would further improve knowledge of how living in a hazard zone matters to chronically ill people's health and wellbeing.

Seven of the eight tellers owned their homes, all had strong social connections, seven were financially independent, all were of European decent and, along with living in Petone, access to such resources afforded the tellers a certain amount of privilege that enabled them to manage their lives independently despite having chronic illnesses and living in a hazard zone. Such privilege is important to recognise because, if not viewed critically, it affirms emergency management narratives that promote strong social capital. On the other hand, chronically ill people like the tellers, who have a certain level of privilege, are still ill and this

means that they are still vulnerable due to their ongoing need for medical treatment. This vulnerability is real and significant regardless of comparative privilege.

Chronic illnesses are conditions that develop slowly and are degenerative which means the tellers will become increasingly more ill and less able to live independently due to an increased need for medical treatment (Lyons & Chamberlain, 2006). This study considered tellers at a point in time when they were all relatively well and still able to live independently in the community. The limitation of narratives is they are told from one vantage point and therefore not the entire story. A focus on the life stories of tellers would provide a more in depth understanding of the long-term impact of chronic illness.

Implications for Future Research and Emergency Management

Several have argued (Bethel et al., 2011; Blake, Marlowe, et al., 2017b; Blake, Miller, et al., 2017; Bolin & Kurtz, 2018; Gowan et al., 2014; Naser-Hall, 2013; D. Paton & Johnston, 2001; Pfeifer & Pfeifer, 2013) that the bulk of research carried out to date does not recognise that disaster preparedness and recovery plans only lessen adverse health outcomes for vulnerable groups when their vulnerabilities are considered and addressed. This results in an inadequate understanding of the situation for groups with vulnerabilities and an exacerbation of their social inequalities and consequential adverse health outcomes (Bolin & Kurtz, 2018; Coburn, 2000; Naser-Hall, 2013).

The issue of vulnerability is complex as vulnerability occurs at varying levels which is indicative of the social gradient effect where environmental, economic, and social influences shape people's health outcomes (Lyons & Chamberlain, 2006; Tuohy & Stephens, 2012; Wisner, 2004). Several of the tellers were in their eighties and required mobility aids to

walk; some lived alone which adds to their level of vulnerability compared with those living with family members. As such there is the need for critical research that considers disaster vulnerability in terms of layers, and how the social gradient of health may influence the vulnerability of chronically ill people in a disaster.

More alternative approaches to research (like this study) that take into account political, environmental, and social context are needed to better understand how to address the health disparities experienced by those living with chronic illness when a disaster occurs. The limited narrative based research conducted to date has shown that there is a story beyond the physical outcomes experienced by groups with vulnerabilities like chronic illness, and that personal and social context play a major role in people's health experiences (Baumeister & Newman, 1994; Hydén, 1997; Tuohy, 2014; Tuohy & Stephens, 2012).

An invaluable source of knowledge of the situation of the chronically ill is the chronically ill themselves. Giving them a voice in disaster preparedness gives people agency and privileges their knowledge about managing such illnesses, which in turn enables their proven practical solutions to be considered and utilised as a resource for everyone in the disaster context. The absence of the voice of the chronically ill is unjust to those people and denies the community the benefit of their knowledge and experience. The silence of the chronically ill needs to be addressed, and the critical narrative approach to research literally enables their voice to be heard.

"Hearing the voices" of the chronically ill is not important only for its own sake, but as a response to dominant discourses which create narrow and inflexible preparedness requirements. Exploration into the impact of dominant discourses on the actions of the chronically ill in disaster contexts is limited. What has been found is that adherence to social norms (individual responsibility, self-management, self-efficacy and the high value of health)

may skew risk perception resulting in risky actions such as not evacuating (Fox et al., 2009; Rushton et al., 2020). This is supported by the present study which found the need of some people with chronic illness to be independent (in order to adhere to that social norm) skews their perception of risk increasing adverse health outcomes. Future research is needed to increase understanding about how having a chronic illness may impact on people's perception of hazard risk.

The independence of experience and the expert knowledge the tellers have of their chronic illness leads to a range of effective disaster responses. If acknowledged by the emergency management sector, these responses can inform more flexible and effective preparedness requirements. Incorporating the knowledge and experience of the chronically ill will require the emergency sector to develop a relationship with this group in accordance with the Sendai Framework and the National Disaster Resilience Strategy so that the sector can better understand the complexities of living with a chronic illness and the impact of unusable preparedness strategies.

Also, given the varying levels of vulnerability among the chronically ill, the emergency management sector could consider the strategy of "protecting the most vulnerable…to protect all" (Lichtveld, 2018), which would enable the development of plans flexible enough to meet varying needs, so that other vulnerable people as well as the chronically ill could also benefit. For example, addressing the physical mobility needs of the chronically ill will also benefit those without chronic illnesses but who have mobility issues.

The dialogue between the chronically ill and the emergency sector needs to appreciate the progressive nature of chronic illness so that preparedness requirements can evolve with illnesses. This could be supported by longitudinal studies that enable follow-up interviews

and analysis resulting in a more comprehensive understanding of the long-term and evolving impact of chronic illness within a disaster context.

In addition, the educational strategies provided by the emergency management sector would benefit from a greater understanding of reasons why people (especially people with vulnerabilities such as the chronically ill) make decisions about how to respond in disaster situations. This study indicates that these reasons include place attachment, and the potential for independent thinking to be counter-productive and lead to risky decisions. This confirms Bonaiuto et al. (2016) assertion about the complexity of hazard risk perception. This is an area that needs a critical narrative approach to research.

In Closing

This thesis provides a better understanding of what it means to be chronically ill and living in a hazard prone environment, such as Petone, Lower Hutt, Aotearoa New Zealand. This study confirms that a ‘one size fits all’ approach to disaster preparedness is inadequate as it fails to recognise the different needs of different groups, especially groups with vulnerabilities (in the present case, the chronically ill). It also confirms that taking a critical stance towards research and research design, thereby centring the experiences of the people with chronic illness is an effective way of discovering how vulnerable groups are over looked, how members of those groups respond, and how this knowledge can inform better emergency management. This aligns with the Sendai framework and the National Disaster Risk Reduction Strategy which is necessary to the development of inclusive disaster policies and strategies for all.

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Appendices

Appendix 1: Example of Consecutive Segments in Teller Narrative

Episodes Making Up Teller One's Earthquake Story

Episodes	Name	Outline
Episode 1	The Shaking	The experience of earthquake event
Episode 2	Lessons	Things to have in place before the next quake
Episode 3	The Plan	Meeting with friend and evacuate
Episode 4	Evacuation	Driving to evacuation site
Episode 5	Didn't Wait for the Siren	Leaving after the quake, before any siren
Episode 6	The Route	The decision to use a particular route to get up the hill
Episode 7	Provisions	What things were taken
Episode 8	A Good Four Hours	The wait before returning home
Episode 9	Next Time	Things to prepare before the next quake
Episode 10	The Next Day	What the next day was like

Appendix 2: Information Sheet

MASSEY UNIVERSITY

SCHOOL OF PSYCHOLOGY

TE KURA HINENGARO TANGATA

Information Sheet

Stories from a hazardscape: Peoples experiences of living with chronic illness and natural hazards in Petone, Aotearoa New Zealand

Kia ora,

My name is Nardia Kearns and I am a post graduate student enrolled with Massey University's School of Psychology. I am conducting a research project as part of a Master's thesis and would like to invite you to take part in my research.

The aims of the research are to better understand the experiences of people with chronic illnesses living in Petone which is an area prone to natural hazards (e.g. earthquakes, tsunamis, flooding etc.), and how these hazards might matter to health and wellbeing.

I am looking for people who live in Petone and have a chronic illness (e.g. diabetes, cancer, cardiovascular diseases, respiratory diseases, neurological diseases, kidney disease, or chronic pain). Before participating you will need to sign a consent form. You would participate in one interview which will be approximately one hour long. We will discuss your thoughts, feelings and experiences about living in Petone, while there is risk of a hazard event and having an illness. The interview would take place at a time and location that best suits you. Support people are welcome to be present during the interview.

I will record the interview so that I can transcribe our conversation which I will then analyse. You will be given the opportunity to read and edit the transcript if you wish. Your name will not be included in the transcript as it will be replaced with a false name that you have chosen. Your personal information will be secured on a password protected system that will only be accessible to myself and my supervisor. As the research findings will be published your confidentiality is ensured and will be maintained. Your information will only used for this research unless you provide consent for it to be used in other research.

It is not expected that you will experience any distress but at any time during the interview we can stop, reschedule or you can withdraw from the research. You will have the absolute right to withdraw from the research at any time. If you do experience any distress you will be provided with contact information for groups that can support or assist you as required.

You have been given this information sheet because you may be interested in this research as you live in Petone and possibly have a chronic illness. There is no obligation for you to take part in this research but if you participate you have the right to:

- not answer any of the questions;
- request that the interview or recording of an interview be stopped;
- withdraw at any time;
- ask any questions about the research;
- privacy and confidentiality.

Your information will enable me to develop knowledge about how living with a chronic illness and natural hazards might matter to your health and wellbeing. The research findings may also help health and emergency managers prepare better for future events by being able to address the specific needs of people with chronic illnesses based on the experiences of those living with a chronic illness.

If you participate in this research you will be given a $40 supermarket voucher to thank you for your time. If you have any questions please do not hesitate to contact me. Thank you, for taking the time to read this information sheet and, if you would like to participate in this research, I look forward to hearing from you.

Kind regards/ Nga mihi

Nardia Kearns

Contact Details:

Researcher: Nardia Kearns [redacted]	Supervisor: Dr Denise Blake d.blake@massey.ac.nz (04) 979 3412 or [redacted]

This project has been reviewed and approved by the Massey University Human Ethics Committee: Southern B, Application 19/17. If you have any concerns about the conduct of this research, please contact Dr Rochelle Stewart-Withers, Chair, Massey University Human Ethics Committee: Southern B, telephone 06 356 9099 x 83657, email humanethicsouthb@massey.ac.nz.

Appendix 3: Participant Consent Form

MASSEY UNIVERSITY

SCHOOL OF PSYCHOLOGY

TE KURA HINENGARO TANGATA

Stories from a hazardscape: Peoples experiences of living with chronic illness and natural hazards in Petone, Aotearoa New Zealand

PARTICIPANT CONSENT FORM - INDIVIDUAL

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

1. I agree/do not agree to the interview being sound recorded.
2. I wish/do not wish to have my recordings in the form of a transcript returned to me.
3. I agree to participate in this study under the conditions set out in the Information Sheet.

Declaration by Participant:

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

Signature: _____ Date: _____

Appendix 4: Interview Guide

Interview Guide

Themes:

Environment

Tell me the story of how you became a resident of Petone and whether you intend to keep living there?

What is it about Petone that makes you want to stay or leave?

Tell me about the types of natural hazards that you have experienced while living in Petone

Tell me what it was like for you when the earthquake struck on 16 November 2016

Did you hear the siren, and if you did what did you do? How did you feel when you heard the evacuation siren?

The day after the earthquake parts of Petone were flooded. How were you effected by the flooding?

What types of support do you have in Petone?

Preparedness

Tell me how would you define a natural hazard and the influence such an event may have on you

Have you thought how you would prepare should a natural hazard strike?

What would you need to do in relation to your chronic illness to be prepared for an emergency resulting from a natural hazard?

Have you thought about how you would get water if a natural hazard cut Petone's water supply off?

Tell me how you would manage if toilet facilities were not available due to damage from a natural hazard

Have you thought about how you would access medication / healthcare if Petone is cut off by a natural hazard?

Tell me what you would do if you are injured during a natural hazard and need medical treatment

Tell me about actions you would take to keep yourself safe if a natural hazard strikes Petone

Health

Tell me about your general health and wellbeing

Tell me about the kinds of things to you do for your health and wellbeing

Tell me about a recent time when you had trouble with your health

Tell me the story of how you first became diagnosed with a chronic illness?

What do you have to do to manage your illness? Do you require support, if so is help available locally?

Have you thought about the how you would manage your illness if Petone was cut off due to damage from a natural hazard?