Death and homelessness on the streets of Aotearoa New Zealand: Sustaining life

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Ko Larrun toku maunga

Ko Adour toku awa

Ko Urt toku iwi

Ko Sandrine toku ingoa no Euskal Herria ahau

He hono tāngata e kore e motu

Connections between people cannot be severed

kā pā he taura waka e motu

whereas those of a canoe-rope can

Abstract

In high-income countries, homeless people die 20 to 35 years earlier than domiciled populations. Despite this enduring reality, the issue of death inequality remains underexplored, especially in indigenous homeless contexts, facing the ongoing effects of colonisation. This study centres on the perspectives and aspirations of a Māori street homeless community, known as the "Peeps". Its objective is twofold: to spotlight to unjust, untimely, and avoidable mortality impacting homeless communities in Aotearoa New Zealand, and to understand how life can be sustained against the adversity of street life. The thesis diverges from conventional public health approaches, which often dichotomise early deaths prevention through improved healthcare access during homelessness, and palliative care provision at the end of life of homeless people. This thesis explores "the temporal space of life prior to death". Within that temporal realm, the omnipresent "risk of dying" that infiltrates the lives of homeless people, disrupting the linear progression toward death observed in domiciled populations, is recognised. This temporal space is understood as a zone of uncertainty and potentiality, wherein complex life-death dynamics operate, revealing broader political, societal and cultural tensions. This study encountered significant challenges, including the dearth of prior death-related research in Māori homeless contexts, and my non-Māori identity. In response, an indeterminate approach, rooted in relational ethics and complexity and systems thinking — aligned with Māori worldviews — was adopted.

Part I of the thesis is conceptual and contextual. Part II invites the readers into the fragile "temporal space of life prior to death" and the cyclical research process. Cycle 1 focuses on understanding the local context of death inequality, through relational fieldwork and statistical analysis of coroners' reports. This analysis uncovers a 30-year life expectancy disparity with domiciled populations, exacerbated by three-quarters of avoidable mortality, mainly due to chronic conditions and suicide. Subsequent cycles sustain relational fieldwork, using collaborative and critical performance ethnography. Cycle 2 reveals the Peeps' resistance to access healthcare, rooted in experiences of transgenerational trauma and marginalisation of Māori beliefs and values in relation to death and dying within mainstream healthcare institutions. Collaboration with the Peeps leads to the co-creation of a drama, intended to initiate conversations with health professionals from the Peeps' perspectives and aspirations, to improve the quality of care. This cycle also highlights the impact of disconnection processes with whānau (family, extended family) experienced by the Peeps. Progressing further, cycle 3

illuminates healing processes with whānau using Advance Care Planning, envisioned as a relational space, providing the Peeps with a sense of belonging, and spiritual continuity in the perspective of death and dying.

In addition to shedding light on the profound death inequality that affect Māori homeless people, this thesis argues for homelessness to be recognised as "complex life-threatening conditions associated with serious-related health suffering". Accordingly, the thesis advocates the shift toward comprehensive care, inclusive of a concurrent prevention and palliation approach over the course of homelessness, to mitigate its impact on the lives of Māori homeless people and enhance holistic wellbeing.

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Preface

Hegoak ebaki banizkio Neuria izango zen Ez zuen aldegingo Bain horrela

Ez zuen gehiago xoria izango Eta nik xoria nuen maite (Joxean Artze)[1]

Some life events alter and mark. The conjunction of early deaths and homelessness is among those experiences that have left life scars in my own journey. However, my trajectory took me on a privileged path. I became a doctor, anchoring my practice in relationships with people. I got involved with homeless persons and dying persons. I believe I have helped some with the modesty of a hope. However, I know they have helped and continue to help me so much more.

Near Paris (France) is "Nanterre", short for the former house of repression and begging which opened at the end of the 19th century. In 1887, "the house sheltered nearly 5,000 vagrants and indigents, who were divided into three categories: those sentenced to light imprisonment, released beggars and individuals under surveillance, and people in hospitality" (Declerk, 2001). At the end of the 1990s, I worked in "Nanterre". Repression, coercion and the will to help still intersected at Nanterre, which had become a "public hospital", notwithstanding, remaining under police authority. Thursday is pay day. The inhabitants of Nanterre escape the institutional frame, in every sense of the word. They cross the paved courtyard to reach the "other side": the public bus shelter to escape and drink the pay, pushing and dragging, as best they can, the infusion stands that connect them to the frame. For years, I have provided care to homeless people directly on the streets, despite disapproval from my hierarchy, who did not favourably view my crossing the boundaries of the institutional frame.

Meanwhile in France, palliative care struggled to develop, late behind the hospice movement that was initiated in England from the 1960s. "Palliative care is not real medicine": In a few words, some of my colleagues openly expressed what many thought to themselves. In the 1990s, palliative care in France appeared as an active minority spreading counter norms within the medical arena. Reintroducing the "unthinkable prospect of death" (Jankélévitch, 1993) into the discourse and practices of healthcare professionals meant one came up against the biomedical "crusade" to push ever further the limits of life. Resistance did not arise from strict opposition between cure and care as both dimensions have always been part of medical ethos. Essentially, developing palliative care required a genuine and democratic

[1] The poem Txoria Txori (song of the bird) became the anthem of resistance in 1968 to preserve Euskara, my native language, alive.

shift around death and dying to build a more humane and democratic society, and acknowledge, with modesty and humility, that dying is a unique experience that we are all come to share. It was thus a matter of reintroducing the question of the meaning of life and death, which are largely abandoned by healthcare institutions. This is where instrumental, financial and bureaucratic logics often prevail. A decade later, the first palliative care act went into force. Personally, beyond a mere biologic "truth", I consider death as a mystery — "a mysterious time that still remains" (Lévinas, 1961/1990) — where the sacred stakes of living together, living and dead, concentrate, and for which I have a deep respect.

My journey leading to this PhD with and for Māori experiencing homelessness and confronting death in their lives, has been a deep, interconnected, relational one of growth and learning. It began in my home country — Euskal Herria (the Basque country) — a cross-border land of seven regions, spanning Northwest Spain and Southwest France. Our motto " zazpiak bat" meaning the "seven regions are one", embodies the unity of my people, anchored in Euskara (the non-Indo-European Basque language) and visceral attachment to our land, culture, and traditions. Our motto also speaks of the resistance of my people against cultural and political repression enforced by France and Spain, especially marked during Franco's dictatorship (1936-1975). The aim of the Franco regime was the total suppression of Euskara language and Basque cultural heritage. The Basque university was closed, books in Euskara were burnt. Our language was prohibited in all schools, public and private spaces. My grandfather was beaten at school for speaking Euskara instead of French. Basque names could not be used in baptism, and all inscriptions in Euskara were ordered to be removed from tombstones and public buildings. Sixty years of armed conflict ensued (1959-2016) against Francoism and for Basque independence, marking the trauma of our collective memory. Though Spanish and French repression persists, we have saved our language and reclaimed our rights to speak Euskara, which is now taught in our own schools. This history of repression, violence and resistance has given me a rich understanding of the struggles faced by Māori people and claims for justice, preservation of their *taonga* (treasures) such as *te reo Māori* (the Māori language), and *Tino Rangatiratanga* (self-determination, sovereignty).

My steps to care for fellow human beings led me from Euskal Herria to "Nanterre" and the streets of Paris, to work in disadvantaged suburbs where the conditions surrounding the death of refugees and migrants where neither equal nor dignified. This path led me to palliative care, where I worked in various settings such as hospitals and paediatrics oncology. However, my true calling was to establish connections with the most isolated persons in society. Thus, I developed palliative care networks for the dying persons who were being deprived the possibility of a dignified end-of-life. Despite

the promise of palliative care to build a more humane and caring society around death and dying, it typically fell short for such marginalised people. The institutionalisation of death and dying through specialisation and privileges to access to palliative care, predominantly benefiting white, middle-class people with cancers, became the norm. Managing pain and physical symptoms took precedence, over a holistic approach of care, overshadowing the dying process and its meaning for all people. I made the decision to resign. I then moved to the South Indian Ocean area where I lived and practiced, as a General Practitioner, for many years alongside poor populations in multi-cultural settings, and indigenous communities in Madagascar.

Moving to Aotearoa New Zealand in 2016 with my husband and our two daughters marked the beginning of the next chapter of my engagement with homeless people. This new step resulted from a significant encounter and my decision to pursue a PhD, driven by the need to address the complex issues arising from the ever-presence of death in the lives of homeless people. While I was working on my PhD proposal around prevention of premature mortality, palliative care and homelessness, I met June (pseudonym), through personal relationships. June told me how, as Māori, she firstly responded to homelessness in the form of a community response centred around the values of inclusiveness, *whanaungatanga* (trusting relationships building and connections), *manaakitanga* (kindness, care and respect), and *aroha* (love and compassion) to uplift *mana*, the authority and prestige of Māori people in homelessness who dwelled on the streets of Seed Town (fictional name)[2]. I shared with June, my home country, my *whakapapa* (genealogical ties) and the life events that have led me, to this time and place, with my research project. June was leading "Cuppa Connection" (fictional name), a not-for-profit organization that provided human and material resources to homeless people. Jude invited me to join the organization as a volunteer. I become involved as an informal doctor. This study has come from an enduring and transformative journey, that has started with my own story and my engagement as a doctor. However, this study has truly grown and flourished with and for the men and women who live and face the harsh realities of life and death on the streets of Aotearoa New Zealand.

[2] Given the sensitive nature of certain information contained in this study, all identified information remains confidential.

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ACM	Auckland City Mission
ACP	Advance Care Planning
CaST	Complexity and Systems Thinking
ED	Emergency Department
GP	General Practitioner
PC	Palliative Care
PHO	Primary Health Organisation
PMH	Primary Mental Health
SHS	Serious Health-related Suffering

Chapter 1: Introducing the study

Framing the study within relational ethics

In 2015, the United Nations called for homelessness to be recognised as an urgent challenge of global proportions, and a profound assault on dignity, social inclusion, and extreme violations of a set of fundamental human rights, including the right to life (United Nations [UN], 2015). The right to life concerns "the entitlement of individuals to be free from acts and omissions that are intended or may be expected to cause their unnatural or premature death, as well as to enjoy a life with dignity" (UN, 2019, p.1). Yet, in high incomes countries, the differential in life expectancy between homeless and housed populations is on average 20 to 30 years (Bush-Geerstema et al., 2010; Fazel et al., 2014; Hwang et al., 2009; O'Connell, 2005; Office for National Statistics, 2018; Stenius-Ayoade et al., 2017). Over the last three decades, this differential has remained dramatically static (Aldridge et al., 2019; Baggett et al., 2010; Hwang et al., 2009; O'Connell, 2005). The landscape of premature mortality associated with homelessness endures as a combination of high rates of preventable and avoidable death, suicide and poorly treated multiple morbidities (Aldridge et al., 2019; Fazel et al., 2014; Funk et al., 2022). As a crude marker, the disparity in life expectancy of homeless people reflects considerable inequalities in the face of death. It also reveals moral and political evaluations of lives, that are constructed as being unequal in value and quality, affecting marginalised communities worldwide (Fassin, 2009), and for whom the right to life is not a given. Inequalities in the face of death, intertwined with the devaluation of the lives of homeless people, constitute the backdrop against which this study developed.

In Aotearoa New Zealand, homelessness is a pressing issue. On census night 2018, the prevalence of homelessness in the general population has been estimated, and likely underestimated, at around 2.2 %, or affecting 102,123 people (Amore et al., 2021). Census data is based on situations of "severe housing deprivation" where people live "in severely inadequate housing due to a lack of access to minimally adequate housing" (Amore et al., 2013, p.7). Reflecting entrenched disparities through colonisation and its lingering impacts, Māori (Indigenous people of Aotearoa New Zealand) are disproportionally affected (Amore et al., 2021; Groot & Peters, 2016; Lawson-Te Aho et al., 2019). In the 2018 census, the prevalence rate of homelessness was four times higher within Māori than Pākehā (New Zealanders of European descent) populations, while Māori account for only 16.5% of the general population and Pākehā 70.2% (Amore et al., 2021; Statistics New Zealand, 2018). The true level of

inequity is likely to be greater (Amore et al., 2021). Long standing issues including the social determinants of health, lack of affordable housing, land and cultural alienation, and marked discrimination in all sectors of social wellbeing contribute to the disparity in the prevalence of homelessness within Māori communities (Lawson-Te Aho et al., 2019).

Research about homelessness in Aotearoa New Zealand is growing (Groot et al., 2013; McMinn, 2021). Health care research studies tied to homelessness are scant. The challenges surrounding the end of life of homeless people and issues of premature mortality have received little attention. From my knowledge, there is only one longitudinal study, led in a New Zealand (NZ) district hospital, that has showed a disparity of life expectancy of around fifteen years between the general population and a group of 106 homeless people (Thornley & Marshall, 2016).

Addressing the multifaceted and complex field of unequal lives and deaths for people in homelessness in the specific context of Aotearoa NZ was not an easy task. Starting this study, and given the high prevalence rate of Māori impacted by homelessness, I was aware of the need to navigate slowly, carefully and with humility into a "field" of suffering, conflict and resistance, politically charged, forged by colonisation and its ongoing impact. The challenge was to navigate a smooth pathway across multiple zones of cultural, political and ethical tensions and contradictions to address a topic that is concerned with death and dying, at the margins of society.

Te ao Māori (the Māori world)[3] is holistic, relational and interconnected, echoing in Māori values, beliefs, and *Tikanga Māori* (Māori ways of doing, being and knowing). *Hauora* (holistic health and well-being), life and death, dying and grieving are centred upon notions of unity, harmony, balance (Durie, 1998; Ngata, 2005), and the continuity between the natural and spiritual world (Marsden & Royal, 2003). Hauora is thus also relational and inclusive of the physical, emotional, familial, environmental and spiritual dimensions that stand in balance and interconnection (Durie, 1998). In continuity with life, death and dying is a relational, spiritual, and transitional journey, primarily cared for by *whānau* (family and extended family) within *whakapapa* (genealogical ties) and honoured through *tangihanga* (death rituals and customs) (Moeke-Maxwell, Mason, Toohey, & Dudley, 2019; Moeke-Maxwell, Mason, Toohey, Wharemate, & Gott, 2019; Moeke-Maxwell et al., 2020). Tangihanga is one of the last Māori institutions that has survived colonisation (Ngata, 2005), and is considered the "pinnacle" of Māori cultural expression, of deep spiritual significance (Moeke-Maxwell, Mason, Toohey,

[3] Appendix A includes a Te reo Māori glossary as a reminder of the meanings of Māori words used throughout the thesis.

Wharemate, & Gott, 2019; Ngata, 2005; Nikora, et al., 2010). Paratene Ngata (2005) states that through tangihanga, "the spiritual dimensions of humanity strengthen the delicate relationships between the living, ancestral and spiritual worlds" (p.31).

In this PhD study, a context-sensitive approach had to acknowledge and account for the transgenerational disruptions and trauma stemming from colonisation, as well as Māori resistance and adaptability that shape the diversity of Māori cultural identities, socioeconomic realities, and ways of relating to te ao Māori in contemporary Aotearoa New Zealand. Colonisation has also shaped Māori homelessness in a distinct way, leading to multifaceted disconnection processes, among which, for many people, the loss of support and cultural resources from whānau stands pre-eminent (King et al., 2016). Even though the approach of death and dying for Māori people has changed by necessity in contemporary Aotearoa New Zealand (Reid, 2005), I reflected that the perspective of dying could be an all-encompassing devastation for Māori people in homelessness, as many are alienated from whānau, and set apart from a cultural nourishing framework of care. Lastly, a critical approach also required me to account for my position, role, privilege and limitation as a non-Māori, migrant doctoral student undertaking this study with marginalised people in the "post" colonial context of Aotearoa New Zealand.

To begin, there were few previous studies to guide me regarding concerns and priorities surrounding the dying experience of indigenous people in homelessness who share deep spiritual end of life perspectives (Duggleby et al., 2015), as well as features of homelessness (Bingham et al., 2019; Memmott et al., 2003). Intersectoral research on my topic were also scant. This study fell thus into a paucity of research that would account for the unique perspectives of Indigenous homeless people with regards to their own aspirations, values, and worldviews, at a confronting moment of their lives.

As a migrant to Aotearoa New Zealand, I asked myself how can I work, as an ally, on the land that hosts me? Which starting point do I privilege that may be relevant and responsive to communities' concerns and may ultimately contribute with positive difference to the lives of homeless people according to their aspirations, and in accordance with their rights? How to proceed in the face of an unexplored and highly sensitive topic that concerns marginalised groups? This questioning engaged my responsibility toward people experiencing homelessness and Māori communities in general, and was a crucial commitment for this study.

This ethical questioning was overarching and pivotal for and throughout the study, in line with a relational ethics principle whereby ethical deliberations rooted within the community concerns take

precedence over epistemology (Hodgetts et al., 2021; Hopner & Liu, 2021). This ethical questioning guided me into the labyrinth of uncertainty and complexity arising from the unknown. It shaped my engagement and relationships with Māori people living on the streets of "Seed Town" (fictional name), as most of this study developed, over time, in this specific Māori context. Relational ethics also led me to adopt a research approach that is open, dynamic, pluralist, non-reductionist, uncertain and aware of its own limitations, referred to as Complexity and Systems Thinking (CaST).

A CaST approach favours understanding the complexity of contemporary issues involving multiple interacting systems in terms of interconnected relationships among systems. Thus, CaST invites us to consider a range of viewpoints, interactions and levels of understanding, resulting in a unique mode of inquiry process (Alhadeff-Jones, 2013; Greenhalgh & Papoutsi, 2018; Hetherington, 2013). Engaging and working with uncertainty and complexity leads to exploring multiple perspectives and pathways of meaning, and to enlarge the horizon of inquiry to larger possibilities and linkages, so that new ways of addressing issues emerge as the inquiry progresses (Adam, 2014; Caveleri, 2005; Dixon-Woods et al., 2006; Flood & Jackson, 1991; Kurtz & Snowden, 2003; Mitroff & Linstone, 1995; Rwashana et al., 2014; Sturmberg, 2021). Coherence into the whole inquiry process intervenes *retrospectively* (Alhadeff-Jones, 2013; Dixon-Woods et al., 2006; Kurtz & Snowden, 2003). Moreover, a CaST perspective was consistent with the understandings of the world developed by Māori over centuries that emphasise holism, relationships and connections between levels, institutions, systems, and people (Oetzel et al., 2017; Peet, 2006; Taurima & Cash, 1999). Māori have their own aspirations, priorities and ways of knowing and working. A CaST lens offered thus a potential platform to address this study with care, responsibility and humility. CaST also is the ontological and epistemological position that is the closest to my ways of thinking, apprehending and being in the world.

The temporal space of life prior to death: background

Using a CaST line of inquiry, I sought to explore what I have retrospectively termed *"the temporal space of life prior to death"* occupied by homeless people in Aotearoa New Zealand. Within that temporal space, life is apprehended both in its biological and relational dimensions, or more exactly in the conjunction of these two dimensions. Given the indeterminate and non-linear approach of this study, the conceptualisation of this temporal space of life as well as the challenges at play, did not become apparent until late in the inquiry process.

Before conceptualising briefly the temporal space of life prior to death (see chapter 3) and clarifying the purpose of this study, I provide a brief overview of the trends in current health-based research engaged with premature mortality and the end of life of homeless people to situate the study. Alongside an increasingly medicalized view of population health over the last decades (Lantz et al., 2007), two poles of research — usually considered as mutually exclusive in their aims — have emerged at an international level. Both poles, however, attempt to provide an immediate response to death inequalities impacting homeless populations.

The first research area has focused on preventable and avoidable mortality, as a way to reduce the life expectancy differential. Preventable mortality refers to death that could have been avoided through public health measures focused on determinants of health and primary health care prevention strategy (e.g., vaccination) (Barber et al.,2017). Avoidable mortality concerns death that could have been prevented through timely and effective health care interventions (Barber et al., 2017). Within this research area, disparity in life expectancy has been mainly considered as a measure of unfulfilled *quantity* of life. Significant attention has thus been focused on understanding the factors that impede and/or facilitate the access[4] to mainstream healthcare systems and health care provision for homeless people (Canavan et al., 2012; Clifford et al., 2019; Elwett-Sutton et al., 2017; Frankish et al., 2005; Gelberg et al., 1997; Omerov et al., 2020; Siersbaek et al., 2021; White & Newman, 2015).

Considerable obstacles of access to healthcare have been evidenced, involving a myriad of structural, political, economic, cultural, relational and individual factors that interact in a non-linear way, according to changing and complex needs, and over time (Siersbaek et al., 2021). Well recognized factors include, for example: a) the gaps induced by the organisations of mainstream health systems (e.g., partition of medical and social services, bureaucratic procedures, primary care design); b) the hierarchisation of basic survival priorities (e.g., food, shelter) over getting health care; c) the mistrust toward institutions due to previous experiences of stigmatisation, discrimination and racism. As a result, unmet health care needs, fractioned care, delayed diagnosis and treatment, and avoidable mortality epitomize early death of homeless people (Aldridge et al., 2019; Canavan et al., 2012; Davis-Berman, 2016; De Veer et al., 2018; Gelberg et al., 1997; McNeil, et al., 2012; Moore et al., 2011; O'Donnell et al., 2016; Omerov et al., 2020; Siersbaek et al., 2021; Stajduhar et al., 2019; White & Newman, 2015).

[4] Access to health care is understood in terms of avoidability, affordability, continuity, connectivity and acceptability (Giesbrecht et al., 2018).

A second and burgeoning corpus of research has focused on the access to palliative care. Palliative care has various meanings (Pastrana et al., 2008). Within the body of research, palliative care refers to holistic care intended to improve the *quality* of life until death once the risk of dying has been recognised and identified. However, meeting the palliative care needs of homeless people has proven to be frequently undermined by the extreme difficulty in identifying the end-of-life period and anticipating death trajectories (Hudson et al., 2016; Shulman et al., 2018; Stajduhar et al., 2019). Indeed, the deaths afflicting people who live on the streets do not fit the norms and assumptions of the deaths of mainstream domiciled society. Emergency Departments (EDs), and general health and social services assume a domiciled reality and have little understanding of their realities, experiences and needs. As a result, the omni-presence of death in the lives of homeless people who live on the streets (Song, Bartels et al., 2007), or the increased "risk of dying"(Stajduhar et al., 2020) are unrecognised. For example, ED staff lack the training to engage in appropriate ways, and a young age has often been reported as a factor leading to misassumptions regarding the risk of dying. Similarly, frontline social/community workers also lack skills/experiences about the reality of dying, especially since they are trained to work within a recovery model, not in a mindset that integrates the ubiquity of death (De Veer et al., 2018; Hudson et al., 2017; Shulman et al., 2018; Webb, 2015). For example, the uncertainty about the course of alcohol-induced chronic liver disease leads to focus on harm reduction interventions and to miss early recognition of the dying process (De Veer et al., 2018). As a result, homeless people are often alienated from early identification of palliative care needs and quality end of life care provision. Within a system that is not designed for homeless people, nor tailored to meet their needs over the course of homelessness, death trajectories are thus rarely linear and predictable (De Veer et al., 2018 ; Page et al., 2012 ; Podymow et al., 2006; Shulman et al., 2018; Stajduhar et al., 2019).

The temporal space of life prior to death: overview

In contrast to housed populations, the unpredictability of death trajectories tied to homelessness reflects that their deaths respond to a complex and specific dynamic, which modifies the temporality in which death can be anticipated. This singular temporality, with ill-defined contours in time and space, that I have imperfectly named "the temporal space of life prior to death" is governed by high levels of contingency and uncertainty. Within this tenuous and fragile "interval" of life, the existences of homeless people may be exposed to rapid variations between two contradictory poles: living or dying. In the latter, the existences tip more often than not into brutal and sudden deaths (e.g. suicide, heart

attack) or directly into end-of-life or terminal situations that could have been avoided (Aldridge et al., 2019; Hwang et al., 2009; De Veer et al., 2018; Podymow et al., 2006; Shulman et al., 2018; Stajduhar et al., 2020). The temporal space of life preceding death constitutes thus a highly dynamic interface that force us to reconsider the linearity that characterizes the deaths of mainstream domiciled populations, and thus how issues are framed.

At the core of this study is the proposition that preventing premature mortality requires one to *concomitantly* consider the "risk of dying", as death is an ever-present potentiality that threatens the life of homeless people. The person-centred and holistic approach of care underlying palliative care philosophy should not be limited to the end-of-life period, or to the identification of life-limiting illnesses. Rather "palliative care" should be considered over homelessness conditions where physical, social, emotional, cultural and spiritual wellbeing are to various degrees compromised. A shift in scope and focus is necessary so that "palliative care" may be proactive, supportive, reaching people over their life in homelessness and to explore what "living well" means to each person in their uniqueness and context. In other words, in order to balance high rates of avoidable mortality, suicide and unmet needs, as well as a trend toward a respectful end of life, it is critical to consider "cure" and "care about" as overlapping and implying each other (Sarradon et al., 2014).

In chapter 3 I return to the conceptualisation of the temporal space of life and the need to rethink the notion of palliative care in homeless contexts. Suffice to say, the proposition underlying this study considers homelessness as "complex life-threatening conditions associated with serious health-related suffering (SHS)", aligned with the recommendation of the Lancet Commission (Knaul et al., 2018) and of the International Association for Hospice and Palliative Care (Radbruch et al., 2020). These recommendations stress the need to shift the scope of palliative care from life-limiting illnesses to life-threatening conditions of suffering, and to move from the dichotomy curative-palliative to synchronic, shared, and combined care, adapted to each person in their own cultural contexts. Research with homeless people in Canada and the United Kingdom (Hudson et al., 2016; Stajduhar et al., 2020) or with prisoners support similar positions (Shaw et al., 2020). For example, the authors of recent review of the deaths and avoidable mortality in prison custody in England from 2009 to 2019 have concluded the need to implement supportive care alongside incarceration given the system failure to recognise the severity of illness and/or deteriorating conditions for people in custody (Shaw et al., 2020).

Aim of the study

In a conventional approach to research, researchers define and determine solely the aim of their studies. Attempting to respond to death inequality, my initial aim was to explore the barriers that impede access to general healthcare and palliative care services for homeless people. However, I soon realised that the unknown requires pre-determined objectives to be abandoned, especially in marginalisation and indigenous contexts where the risks of misassumptions and Western dominance is high. Alongside my volunteering at "Cuppa Connection", much of this study unfolded with, for, and under the guidance of a group of Māori men and women living on the streets, for a long time, and who, for many, were disconnected from the healthcare system. They call themselves the "Peeps", short for "People", in resistance to stigmatising terms such as "the streeties" or "the homeless". The term "Peeps" will hence be retained in the thesis as a term of reference. This study is the result of long-term and mutual relationships of trust, respect, sharing and learning, collaboration and dialogue that have been built over time with the Peeps in alignment with the core principles and values of *Tikanga Māori* (ethical ways of being, doing, knowing) (Mead, 2016). Central to tikanga Māori, especially while working with homeless people, are the values of *whakawhanaungatanga* (building trusting relationships and connections), *manaakitanga* (caring with respect), *aroha* (love and compassion), *kōtahitanga* (collective action, togetherness) and *whakaiti* (acting towards all people with humility) that all provide a sense of mutual engagement, obligations and responsibility (Hodgetts et al., 2021; Mead, 2016)

This study began by being committed to the Peeps' community[5], centred within their reference frame, transformative in spirit and actions, and thereby aimed to raise awareness on the inequalities surrounding the death of homeless people in Aotearoa New Zealand. In response to these inequalities, I tried to understand how, within the contexts and circumstances of the Peeps' lives, with regard to distinct worldviews, and their own aspirations, their lives and existences could be meaningfully preserved and flourish. This broad questioning is at the heart of this inquiry and extends into the temporal space of uncertainty and contingence preceding death and until death.

In that purpose, I undertook:

- A quantitative analysis of the coroners' reports related to the mortality and circumstances surrounding the death of homeless people in Aotearoa New Zealand (published article).

[5] June, the Māori woman leading Cuppa Connection, the Peeps and I decided together to conceal all identifying details, including the name of the town. This was done deliberately to keep the Peeps safe and to protect the community of care we have built together.

- A long-term ethnographic study with the Peeps (2019-2022), leading to a collaborative performance project directed towards sensibilizing professionals to "hidden realities" of the everyday life of the Peeps, and what "living well and dying well" means from the Peeps' perspectives (published article). Processes of disconnections from whānau were stressed.
- A relational and collaborative autoethnographic account of a reconnection process with whānau through reconsidering and extending the Western notion of "Advance Care Planning" that traditionally focuses on healthcare preferences at the end of life. This ethnographic account has been written with Daniel (pseudonym), one of the Peeps (published article).

Critical interfaces

This study entails critical interfaces that are important to highlight here as they also led me to write and present the thesis in quite an unconventional way.

First, the study embraced not only marginalized people but, more broadly, a context of historic and ongoing Western domination and marginalization of Māori communities, Te ao Māori, and ongoing resistance to this domination by Māori communities (Bishop, 1998; Smith, 2012). From the 1960s, *kaupapa Māori theor*y has emerged as a form of resistance to literally reconstruct a "Māori way" (Cram, 2019, p.1507) that asserts the validity and legitimacy of "being Māori "(Smith, as cited in Bishop, 1996, p.12), and of Māori-led research agenda and methods. In health care research, kaupapa Māori theory extends well beyond Western biomedical cultures and promotes hauora alongside challenging Māori health disparities and empowering Māori communities (Cram, 2019). Rejecting deficit oriented and victim theory, I posited my study within Māori perspectives, as much as it was possible for a non-Māori migrant researcher.

Second, addressing the experience of death and dying is an eminently sensitive topic that concerns each of us. However, for many Māori this moment of life belongs to the domain of *tapu*, 'that stems from its association with the spiritual domain; it covers the realm of the sacred, prohibited and restricted" (Moeke-Maxwell, Mason, Toohey, Wharemate, & Gott, 2019, p.297). Consequently, addressing the interrelated domains of tapu, *wairuatanga* (spirituality), and death and dying raises significant issues for a non-Māori researcher. These issues relate to Māori intellectual property, and restrictions in the understanding and utilisation of knowledge (Valentine et al., 2017). Further, despite increasing recognition within Western research that spirituality is a core component of wellbeing,

especially at the end-of-life (Dyson et al., 1998), spirituality poses significant challenges in research given the Western tradition of scientific rationale and "secular rationalism" (Spalek & Imtoual, 2008, p.2). Yet, *wairua* (spirit) is of primary importance for the health and wellbeing of Māori (Nikora et al., 2013), and critical in coping with the end-of-life journey (Moeke-Maxwell, Mason, Toohey, Wharemate, & Gott, 2019, p.300). Marsden (2003) states that wairua is the "ultimate reality" (p.33) that bonds and unifies the essence of the Māori universe (Marsden & Royal, 2003). Accordingly, with care and humility, I positioned myself in an attitude of listening, learning, and belief (Lassiter, 2001, p.140), outside the secular/sacred dichotomy. I respect the reality and validity of wairua for Māori and I tried to honour it as much as it was possible for a non-Māori researcher.

Third, a CaST-based approach provided the methodological flexibility needed to critically address the complexity of a topic that has received little attention. However, this flexibility was accompanied by a non-linear progression of my inquiry that developed following three cycles, close to the modalities of development of research-actions (Davis, 2007; Honan & Bright, 2016). Each cycle overlaps with the preceding one, and forms the image of a spiral (Alhadeff-Jones, 2013). As some researchers have pointed out, this spiralling evolution is rarely highly structured, and does not fit well with a conventional thesis presentation in "five chapters" (introduction, literature review, methodology, analysis, conclusion) (Davis, 2007; Dick, 1993; Fisher & Phelps, 2006). Working with death and dying requires care and time. People in homelessness require care and time. "Understanding" a topic is not a straightforward process, you can rush into. You need to understand some prerequisites that allow you to move forward.

The structure and writing of this thesis attempts to respond to these critical interfaces by opening up the flow of inquiry as much as possible, in order to assist with the way knowledge has been gathered and interpreted. I posit as an allyship in Aotearoa New Zealand, trying to work with and for Māori people in homelessness and to contribute to positive change in their lives. Saying that, I am aware of the power imbalance at play in this study, by subjecting this differential to the possibility of critical evaluations, necessary for the construction of horizontal solidarities. Accordingly, I present my thesis in three interconnected narrative cycles, which aim to locate, share and communicate the paths taken through my inquiry, and the emergence of the points of tension, dilemmas, uncertainty and contradictions I have been confronted with. Each cycle has been underpinned by deep critical reflection in response to the relationships forged with the Peeps, to the lived realities on the ground, and by a considerable mass of reading emanating from various disciplines and traditions. The dynamics of each

cycle led to a reconceptualization of the issues at stake, and induced a shift in my inquiry purpose and focus, as well as in the methods I have used and the actions and inactions undertaken. In other words, the writing and structure of this thesis reflects the natural development of the study that evolved at the pace of street life and companionship with the Peeps, without the constraints of predefined research questions. This approach eventually gave rise to the conceptualisation of the temporal space of life prior to death, a notion that emerged late in the study process and which embodies both the constant risk of death and the enduring potential for life. It was within this intricate, fragile and nuanced space that this study progressively took shape, centering on life until death and in death, as central concerns.

Structure of the thesis

This thesis has been structured within a CaST research approach and in response to critical interfaces that challenge the conventions of research reporting. The study also unfolded on a trajectory from death to life, from the coroners' reports to the life on the streets with the Peeps, in a reverse order from more conventional end of life research that usually proceed from the dying experiences to death and bereavement. This reverse order also had implications for how I addressed questions of death inequalities. Thus, much of the structure of the thesis follows a *chronological order* that presents the narrative of the study, and critical, ethical, methodological and theoretical concerns underpinning this study as it developed. The use of narrative in the health sector is recent (Greenhalgh, 2016), although stories have long fuelled interactions and care practices between clinicians and people, as a key element of clinical medicine. Using a narrative tone for reporting this study is underpinned by the assertion that a CaST approach is also a story of change in research practices, beliefs and assumptions, resulting from the complexity of interactions between intersubjective experiences, social environments and cultural contexts. As noted by Charon (2006): "Narrative makes its own paths, breaks its own constraints, undercuts its own patterns. … [It] can make new out of old, creating chaos out of linearity while, subversively, exposing underlying fresh connections among the seemingly unrelated" (Charon, 2006, as cited in Greenhalgh, 2016, p.7). Equally important, the use of narrative in this thesis recognises and honours the oral tradition of Māori people and story-telling as relational practices of sharing life experiences, meanings, and holistic knowledge and connections (Lee, 2015; Rieger et al., 2020). In this process, the readers are actively invited as co-producers of the narrative for collective actions (Briggs & Mantini-Briggs, 2016; Ricoeur, 1994).

The complexity of homelessness and the challenges surrounding premature mortality and the end of life cannot be captured in an introductory chapter even though the notion of the "temporal space of life prior to death" presented to this point sets the stage for my study. The thesis is structured in two-inter-related parts. **Part I** encompasses **chapters 2, 3 and 4**, which are conceptual chapters and provide further context for this study. In **chapter 2**, I present and discuss the cultural, relational and human rights perspectives on homelessness that have informed this study, beyond the sole aspect of "lacking housing". The distinct aspect of Māori homelessness is highlighted. **Chapter 3** centers on mortality and healthcare. In this chapter, I provide an overview of the New Zealand healthcare system, spanning from primary care to palliative care. I discuss some of the systemic "gaps", mismatches, and relational and cultural tensions and challenges that hinder equitable access to healthcare, effective prevention of premature and avoidable mortality, and the provision of quality end-of-life care. The chapter concludes with a discussion about the necessity to reconsider the definition and perspective of palliative care in the context of homelessness, leading to the proposition of considering homelessness as complex life-threatening conditions associated with SHS. In so doing, I advance the conceptualisation of the temporal space of life prior to death. **Chapter 4** explains the weaving of relational ethics and my CaST approach, as a comprehensive methodology to explore a complex and undetermined topic. I discuss the relevance of this approach in relation to distinct worldviews, values, beliefs, systems of knowledge and a topic politically and emotionally charged.

Part II indicates a break with conventional PhD thesis presentation, and invites the reader into the temporal space of life prior to death and the research process itself. Part II encompasses **chapters 5, 6 and 7.** Each of these chapters corresponds to a cycle of development of my study. Each of these three chapters follow a similar structure in order to contribute to the overarching relational ethics and purpose of this PhD study. The chapters start with a narrative prelude that grounds the dialogue and events that occurred, the reflexive movements these engendered, and the corpus of literature I read in response. Each of these three chapters end with a published manuscript. **Chapter 5** acts for the first cycle and concentrates on mortality features, preventable and avoidable mortality of homeless people in Aotearoa New Zealand. The second cycle is reported in **Chapter 6** in response to the first one. In this chapter, I focus on the lived experiences and perspectives of the Peeps in regard to life, death, health and wellbeing, and access to healthcare through three years of ethnographic "research" and my long-term commitment as an informal doctor, and companion of the Peeps. The chapter ends with a publication that includes a performance text (drama) and the impetus behind a wider performance project. In response to chapters 5 and 6, **Chapter 7** is *a* proposition about the disconnection processes at stake in

Māori homelessness that may interfere dramatically at the end of life. **Chapter 8** concludes the thesis, by critically revisiting my PhD journey, and the propositions that my thesis makes to the intersectoral field of homelessness, premature mortality prevention, palliative care, and CaST in a Māori context.

Chapter 2: Perspectives on homelessness in Aotearoa New Zealand

This chapter presents the three key perspectives on homelessness that informed the study and contextualized the topic. These intertwined perspectives encompass human rights-based, relational, and cultural approaches to homelessness. The chapter is divided into four sections. The first section examines the New Zealand definition of homelessness as applied to a population level. The second section presents a human rights-based approach and discusses the limits of this approach within the study context. A relational approach that complements a human rights-based perspective is presented in the third section. The distinct dimension of Māori homelessness is the subject of the last section. This chapter does not intend to provide a detailed discussion about homelessness in Aotearoa New Zealand, which would go beyond the scope of this thesis. References are provided for the readers interested in further detailed discussion.

New Zealand definition of homelessness

As widely discussed by the literature, the term homelessness resists any adequate definition given its multidimensional aspects – that span the social, political, economic, legal, cultural, emotional, physical, relational – and which are further encapsulated in a broad context of inequalities, injustice and violation of human rights. Nonetheless, at a State level, the administrative definitions are based on the notion of lack of housing. In 2009, against the backdrop of neo-liberal policies prevailing since the 1980s (Barnett & Bagshaw, 2020), a persistent decline in housing affordability, and prevalent issues such as overcrowding and substandard housing (Leggatt-Cook & Chamberlain, 2015), New Zealand adopted a broad definition of homelessness. This official definition, established by Statistics New Zealand in 2009 is "living situations where people with no other options to acquire safe and secure housing" (Statistics New Zealand, 2009, p.5). Yet, this short definition encompasses a range of living situations including:

- "living without shelter (living on the streets, and inhabiting improvised shelters, such as living in a shack or a car);
- in temporary accommodation (hostels for the homeless, transitional supported housing for the homeless, women's refuges, and people staying long-term in motor camps and boarding houses);

- sharing accommodation with a household;
- living in uninhabitable housing (people residing in dilapidated dwellings) ” (Statistics New Zealand, 2009, p.5).

The development of the 2009 Statistics New Zealand definition reflected increased concern about homelessness as a potentially growing problem in the country that needed to be addressed (Groot, 2010). Since then, the prevalence of homelessness has still accelerated, with an average rate of 2% per year between the 2006 and 2013 censuses (Amore, 2016), and a further increase between 2013 and 2018 censuses. In 2020, in the face of the so-called “housing crisis” that could be broadly described as “a dark shadow that hangs over the country” according to the special rapporteur of the United Nations (Farha, 2020), the New Zealand government adopted the first national coordinated homeless strategy. Known as the “Aotearoa New Zealand Homeless Action Plan 2020-2023”, it focuses on four key areas of action: prevention, supply, support, and system enablers (Ministry of Housing, 2020). The preferred approach within this plan is the “Housing First” model, which is an international approach premised on placing clients without preconditions of entry such as sobriety (Tsemberis, 2013). Housing First Services are informed by the notions of harm reduction, consumer choices and community integration (Tsemberis et al., 2004). However, the homeless plan including Housing First model, predominantly relies on reactive strategies that fail to effectively challenge the current statu quo, such as addressing poverty, and improving access to education and employment opportunities. Moreover, as highlighted by Lawson-Te Aho et al. (2019), the Housing First approach does not fully consider the aspirations of Māori people, and their rights to Tino Rangatiratanga (Māori self-determination and authority) in shaping a cultural informed response to homelessness. Homelessness is, however, not simply about the presence or absence of standard forms of shelter. It is a multi-dimensional and complex process whose consequences are devastating. For some, their only escape is through dying 20 to 30 years prematurely. Studies have shown that how homelessness is conceptualized can significantly impact the political and societal responses to it (Chamberlain & McKenzie, 2002; Neale, 1997; Pleace & Quilgars, 2003). Often, explanations for homelessness are used to identify “risk factors” and “populations at risk” to respond to homelessness at a broader population level. For a comprehensive explanation of homelessness in Aotearoa New Zealand, at a population level, the reader can refer, for example, to McMinn (2020).

Briefly, individualistic and structural explanations of homelessness have traditionally dominated the literature. Individualised explanations hold homelessness as the result of personal failings (e.g.,

addictions) or so-called “life choices”, which leads to minimal services and punitive responses (Hodgetts & Stolte, 2017; Leggatt-Cook & Chamberlain, 2015). The issuance of city bylaws to “clean” the public space of homeless people is an ever-present illustration of penalizing responses to homelessness. Structural explanations focus on macro socio-economic forces and stress recommendations for broad social interventions, together with housing provisions (Hodgetts & Stolte, 2017; Leggatt-Cook & Chamberlain, 2015).

Currently, there is a broad consensus among commentators that complex combinations of structural factors (e.g., adverse housing and labour markets, poverty, racism and system failure) and individual circumstances create conditions within which homelessness may occur (Fitzpatrick et al, 2002; Fitzpatrick et al., 2013; Groot et al., 2008; Rua et al., 2019; Stafford & Wood, 2017). Individual circumstances include a range of adverse and trauma life events such as domestic violence, early death and compounding loss and grief, job loss, relationships breakdowns, adverse childhood experiences (e.g., abuse), experience of institutions (e.g., foster care, prison), mental illnesses and substance misuse (Fitzpatrick et al., 2002; Fitzpatrick et al., 2013; Hodgetts & Stolte, 2017; Morrell-Bellai et al., 2000).

While acknowledging the significance of research that focuses on explanatory models to address homelessness, this study aimed to explore the vulnerable period of life prior to death for people who are homeless and face challenges, including high levels of unmet needs, violence, loneliness, stigma, racism, and inequitable access to healthcare, as well as stark disparities in death rates (see chapters 3 and 5). I will thus present the perspectives on homelessness that have informed this study to address the challenges of life and death.

A human rights-based approach

The right to adequate housing was first recognized as part of the rights persons have to an adequate standard of living in the 1948 Universal Declaration of Human rights (UN, 1948). It has since been reaffirmed in diverse covenants and many international treaties, resolutions, and declarations. According to the United Nations (1991, 1997), in order to be adequate, a person’s housing requires to be affordable, habitable, accessible, secure in tenure and culturally appropriate. Aiming to protect and enhance the health and wellbeing of people and their families, the right to an adequate standard of living also includes food, clothing, housing, medical care and social services, and security in case of

adverse life events (UN, 1948), as well as the right to live in peace, security and dignity, and to experience equality and non-discrimination (UN, 1991, 1997).

In 2015, the special rapporteur of United Nations on the right to adequate housing proposed a tri-dimensional approach of homelessness. These three dimensions encompass: 1) the absence of a home as a material and social harm, given that the absence of home prevents the establishment of familial and social relationships, and the ability to participate in community life; 2) homelessness as a form of systemic discrimination against persons who have become a "social category", exposed to marginalisation, stigma, social exclusion and criminalization based on characteristics attributed to them; 3) the agency, dignity and rights of homeless people in the face of systems that deny them their rights (UN, 2015).

As a signatory to various international human rights laws and covenants, the New Zealand government is legally obligated to protect the right of individuals to enjoy adequate housing. This obligation includes the responsibility to provide remedies for homelessness, ensuring that individuals have access to safe, secure, and affordable housing. However, homelessness in Aotearoa New Zealand must be understood and recognised within the principle of equal rights and expectations enshrined in Te Tiriti o Waitangi (Treaty of Waitangi) — New Zealand's founding document (Orange, 2015). Te Tiriti o Waitangi (1840) established a partnership between Māori and the British Crown that affirmed Tino Rangatiratanga as *tangata whenua* (the people of the land) and guarantees equal citizenships and rights for all (Orange, 2015; Waitangi Tribunal, 2020). As the cornerstone of Aotearoa New Zealand's governance, Te Tiriti o Waitangi underscores the significant breaches against the principles of equal citizenship, dramatically exemplified by the disproportionate representation of Māori within the homeless population. In 2019, the Waitangi Tribunal [6] initiated the Housing Policy and Services inquiry (WAI 2750) that will examine concerns about the regulation of the housing market, the provision of social housing, and the relationship between poor physical and mental health and housing issues for Māori (Waitangi Tribunal, 2019).

Human rights are indivisible, interdependent and interrelated. This means that violating the right to adequate housing impairs the enjoyment of other human rights, such as the right to health or the right to life, and vice versa. First articulated in the 1946 Constitution of the World Health

[6] The Treaty of Waitangi Act 1975 established the Tribunal of Waitangi to examine claims related to Te Tiriti o Waitangi principles.

Organisation (WHO), the right to health has been defined as the right to "the enjoyment of the highest attainable standard of health" (WHO, 1946, p.1), health being described there as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (WHO, 1946, p.1). Health is tied to the factors and conditions that promote and contribute to health, referred to as social determinants of health, such as housing, water and sanitation, access to goods and resources, education, employment, or non-discrimination on the basis of sex, ethnicity, religion, disability or social status. Positioning homelessness as a matter of human rights is thus important for advancing the pernicious injustice it entails, and for reiterating the multiple embroiled ramifications that lead to poor health and wellbeing, and the considerable life expectancy differential. The current state of affairs reveals a significant misalignment between domestic policies and the commitments outlined in the United Nations declarations on the right to housing (UN, 1991, 1997) as well as the principles of Te Tiriti o Waitangi. Notably, the right to adequate housing is not legally established (Farha, 2020). As a result, homelessness tends to be predominantly perceived as a housing provision issue, disregarding its broader implications for the progressive realization of all human rights, equity and justice. This narrow framing has severe consequences for people experiencing homelessness, as it creates a stark contrast in how their rights to life, health, and non-discrimination, among others, are addressed. In the light of Te Tiriti o Waitangi principles, the absence of legal recognition of the right to housing perpetuates the rejection of homeless persons from the sphere of citizenship, denying them equal status as members of society.

The relevance of human rights to the field of public health is not new. Nonetheless, it was the HIV/AIDS pandemic from the 1980s that highlighted the importance of upholding and ensuring accountability for the realization of all human rights (Mann et al., 1994; Marks, 2002). While human rights primarily applied to states, it is important to recognize that accountability extends beyond states to include non-state actors (London, 2008). Indeed, accountability also means that agency plays a critical role to a human rights approach. Homeless people are not needy victims nor passive recipients of assistance, but they have voices to participate in shaping decisions that affect their lives, as active and equal citizens. This brings attention to power dynamics and raises critical questions about who define rights and how, and who "give" voices and how.

In the context of Aotearoa New Zealand, and of this study in particular that developed in the Peeps' contexts, it is important to remember that the language of human rights remains rooted in Western philosophy. This philosophy is underpinned by defining human nature and the relationships between individuals with each other and with the state in ways that are marked by individualism and the

principle of autonomy (Panikkar, 1982; Ten Have, 2016). Accordingly, a human-rights perspective requires one to pay attention to "the conditions under which individuals adopt a sense of self that includes the entitlements and rights offered in the human rights system" (Merry, 2017, p.141). It is not overstressed in the "post" colonial context of Aotearoa New Zealand to reiterate Te Tiriti o Waitangi principles and the Declaration of Rights of Indigenous Peoples (UN, 2007) for freedom, equality, Tino Rangatiratanga, and participation. How Māori experiencing homelessness own the diversity of their culture and identity and their human rights is important in understanding the challenges of life and death at the margins. For example, the Western concept of autonomy does not fit well with a Māori sense of belonging that emphasises the individual within the collective. Further, the Western concept of health as defined by WHO (1946) does not account for the familial, spiritual and balanced dimensions of hauora (Durie, 1985). Given the overly individualised Western framings of human rights and health, in this research, a relational approach of homelessness complemented the human-rights based perspective.

A relational approach

A relational lens apprehends homelessness as a dynamic, non-linear and *experiential* process, situated and understood within the socio-economic, cultural and human environments in which people find themselves (Hodgetts & Stolte, 2017; Lancione & Calafate-Feria, 2016; Sommerville, 2013). Consistent with a CaST approach, the stressor is put on the relationships and interactions between structure, contexts, and individuals whether they are homeless or housed. A relational lens encourages a holistic perspective of homelessness, integrating considerations of a range of aspects of people's lives in which multiple dimensions (physical, emotional, social, cultural and spiritual) "come into play" over the life span (Groot et al., 2015; May, 2020; Robinson, 2008; Sommerville, 2013).

Importantly, emphasis on the relational dimension highlights that homelessness is not independent of people's experiences of homelessness and the various interpretations people make of their own situations. As with the experience of dying, experiences of homelessness remain unique to each person and each story, even though homeless populations are described using broad collective terms according to housing status or duration of homelessness (e.g., chronic homelessness). Diversity within homeless people in terms of their origins, aspirations, greater or lesser degrees of adaptability to social norms, and engagement with street culture are important to recognise to understand life and death at the margins.

A relational perspective invites thus a genuine encounter and long-term commitment with homeless people on a daily basis (Hodgetts et al., 2021; Lancione & Calafate-Feria, 2016) to apprehend the multiple interactions that fuel the creativeness, adaptability, and agency of homeless people in their struggle for dignity and affirmation against adversity. Although homelessness is fuelled with marginalisation, exclusion and disconnection processes, fear, shame, violence, isolation and death, it is also important to recognise the strengths that homeless people develop over time to survive and adapt to their homeless' life situations, such as friendship, mutual support, partnership, or social networks with housed people (Cloke et al., 2008; Farrington & Robinson, 1999; Hodgetts et al., 2007; Hodgetts et al., 2008; King et al., 2016; Rowe & Wolch, 1990). Scholars have adopted the term "culture of resistance", to highlight the skills, strengths and strategies through which homeless people work to construct alternative meanings and ways of being that foster dignity, identity, and wellbeing (Groot et al., 2008). For example, Groot et al. (2015) have accounted how Maia, a Māori woman living on the streets of Auckland (NZ) retained her Māori identity through cultural practice of homemaking, acting according to ancestral practice of *whanaungatanga* (trusting relationships and connections) and *manaakitanga* (unconditional caring relationships) towards the new arrivals and younger people on the streets. Maia's mentoring of other "streeties" taught them the necessary skills for survive, whilst providing Maia with feelings of belonging and connections central to being "at home" (Groot et al., 2015).

Adaptation to street life and responses to homelessness may also take the form of substance misuse. Even though the prevalence of addiction within homeless populations is significantly higher than that within housed populations, this does not mean that homeless people are all "addicts". Conceptualisations of, and responses to, homelessness are largely influenced by assumptions, worldviews, beliefs, values and social norms of domiciled people. Criminalization (e.g., incarceration), increased stigma from members of the public, and recovery models from a public health perspective (e.g., harm reduction strategies) constitute various responses to substance misuse within homeless populations. However, the relationships forged around addiction practices have an important social function. These relationships are part of the relational life on the streets, or may act as coping strategies against adversity or pain, yet they can also lead to violence and death (Bourgeois, 1998; Briggs, 2018; Neale & Brown, 2016). Bourgeois (1998), for example, has cast new light, in non-stigmatizing terms, on the so called "individual health risk behaviour" of a group of homeless "addict" people, for whom respect, identity and meaning are shaped by structuring strong relationships between them that over precedes the risk of HIV transmission through syringes' exchange (Bourgeois, 1998). Without arguing for substance misuse, the complexity of homelessness also requires moving beyond decontextualised and

pathologizing assumptions to understand what matters for those whose lives are at the margins including meaningful relationships around substance use practices. Lastly, as the following section will explain, a relational approach is congruent with working with Māori as *whakawhanaungatanga* (the process of building relationships and connections) is a foundational value for Māori and for Māori health and wellbeing (Cram, 2019; Mead, 2016).

Māori homelessness

Homelessness is not the same as Māori homelessness. The latter is rooted into the colonisation of Aotearoa, its lingering effects, and the historical trauma inherited from colonisation (Anderson & Collins, 2014; Brown, 2016; Groot & Peters, 2016; Lawson-Te Aho et al., 2019). Understanding the distinction is important in addressing the issues at stake in this study.

As Durie (2004) has pointed out, all indigenous peoples share a deep and sacred sense of unity with the land, which is reflected in, for example, rituals associated with healing, birthing, and death. Previous to the broken promises of Te Tiriti o Waitangi that guaranteed Māori continued possession of their resources and sovereignty, around 80,000 Māori (Pool & Kukutai, 2018) lived on their *whenua* (land), within their tribal areas. People were aware of their *turangawaewae* that is "a place of strength and belonging, a place to stand" (Groot et al., 2010, p.125) through *whakapapa*, the genealogical ties that connect and bind people with people, the ancestors, the natural and spiritual world (Brown, 2016; Cram, 2019; Groot et al., 2010; Mahuika, 2019). Whakapapa means "to lay one thing upon another" (Cram, 2019, p.1512) and "has always been considered the explanatory framework for the world and everything in it" (Mahuika, 2019, p.10). Known through whakawhanaungatanga — the process of building relationships and connections (Cram, 2019) — whakapapa "encompasses everything that is passed from one generation to the next, from one ancestor to the next and from the deceased to the living" (Rameka, 2018, p.369). The importance of whakapapa is paramount as it is considered crucial to assertions of Māori identity and belonging, with which come obligations, responsibilities, and reciprocity as ways of honouring these relationships (Cram, 2019; Mahuika, 2019; McIntosh, 2006).

From 1840, enforced land dispossession allowed large-scale acquisition of Māori lands by the Pākehā new comers and the Crown. By the end of the 19th century, less than 12% of the lands still belonged to Māori (Durie, 1998). Combined with the spoliation of lands and resources, exposure to new imported diseases, wars and malnutrition, Māori health declined dramatically. By 1887, settler numbers

reached 770,000, yet the Māori population plummeted to only 42,000 (Moewaka Barnes & McCreanor, 2019). The difference in life expectancy between Māori and settlers was about 30 years (Pool & Kukutai, 2018). Alongside active policies of assimilation, Māori land dispossession led to the loss of an economic base and source of identity, destabilizing whānau, *hapū* (sub-tribes) and *iwi* (tribes) in their sovereignty, eroding long established knowledge-practice systems and the fabric of Māori society (Cram, 2019; Moewaka Barnes & McCreanor, 2019).

From the 1930s onwards, the erosion of land-based resources resulted in rapid and massive migration of Māori to urban areas (Boulton, et al., 2022; Brown, 2016; Durie, 1998; Poata-Smith, 2013). Most of urbanised Māori people met severe levels of discrimination in all domains of social wellbeing resulting in widespread hardship and poverty (Boulton and al., 2022; Brown, 2016; Williams, 2015). By the mid-1950s, as issues of urban overcrowding became urgent, a government assimilation agenda intensified to promote Western ways of living. The model of nuclear-family and the notion of «home as housing», were deemed a means of successful Māori integration within the Western economic system (Boulton et al., 2022; Brown, 2016). As stated by Moewaka Barnes & McCreanor (2019):

…"colonisation has deeply harmed Māori communities, […] has had profound negative consequences for the health, wellbeing and indeed the very existence of Māori populations in Aotearoa.[…]Through land alienation, economic impoverishment, mass settler immigration, warfare, cultural marginalisation, forced social change and multi-level hegemonic racism, Indigenous cultures, economies, populations and rights have been diminished and degraded over more than seven generations" (p.19).

Resistance and adaptation to the impact arising from colonisation have shaped the diversity of Māori identities in contemporary Aotearoa New Zealand (McIntosh, 2006; Poata-Smith, 2013), as well as indigenous perceptions of what it means to feel "at home" (Memmott & Nash, 2016). Māori perspectives on homelessness, which are aligned with those of other colonised indigenous people, extend well beyond the Western notion of homelessness (Bingham et al., 2019; Groot, et al., 2015; Memmott & Nash, 2016; Thistle, 2012). The later fails to recognize the historical, cultural and socio-economic contexts in which many indigenous people find themselves. Indigenous perspectives are directly linked to the persistent effects of colonization which have created and maintain inequities in many areas (health, housing, employment, education, criminal system). Furthermore, systemic racism and discrimination shape Māori homelessness in a very real way (Harris et al., 2018; Health Quality and Safety Commission [HQSC], 2019; Lawson-Te Aho et al., 2019). Cultural dispossession shapes yet another

form of homelessness. The concept of "spiritual homelessness" (Memmott et al., 2003) encompasses the aspects of loss of connections and relationships to land, whānau, hapū and iwi kinships, rituals, language and knowledge (King et al., 2016; McIntosh, 2006; Thistle, 2012). As stated by McIntosh (2006), for many Māori, "homelessness begins as a symbolic state and transforms into an actual state" (p.75).

Disconnection processes, especially being separated from whānau, are key points in understanding Māori homelessness and the impact that these processes may have for the health and wellbeing of homeless people, and for the experiences surrounding death and dying. Indeed, whānau are at the core of the Māori world, as a key cultural and social unit (Lawson-Te Aho, 2010). Although traditionally whānau means family and extended family as kin tied by whakapapa, a wide diversity of whānau are represented within Māori communities (Durie, 2001). Importantly, whānau reflects cultural values and practices that enforce mutuality, reciprocity, and shared responsibilities within a Māori context (Durie, 2001). Whanaungatanga or whānau "working to support each other" is an important contributing factor for building strength, resiliency and wellbeing (Lawson-Te Aho, 2010, p.14), especially in caring for a loved one at the end of life (Moeke-Maxwell et al., 2014). However, the dynamics of whānau as a collective enterprise has been impacted by major processes of colonisation and urbanisation that have led to considerable variations in the degree of connections within whānau, in the complexity of the social environment that whānau experience, or in the depth of involvement with te ao Māori (Te Ohu Rata o Aotearoa, 2019).

Whilst experiences of homelessness are diverse and complex, many Māori homeless people undergo patterns of disconnection from whānau, which results in cultural and spiritual disconnection to varying degrees (King et al., 2016; Lawson-Te Aho et al., 2019). It is important here to put in perspective the long-term effects of historical trauma on individuals and whānau in the occurrence of Māori homelessness and disconnection processes (Anderson & Collins, 2014; Bingham et al., 2019; Lawson-Te Aho et al., 2019). Historic trauma has been defined, in Indigenous contexts, as "cumulative and psychological wounding over the lifespan and across generations, emanating from massive group trauma experiences; the historical trauma response is the constellation of features in reaction to this trauma" (Brave Heart, 2003, as cited in Wirihana & Smith, 2014, p.198).

Transgenerational trauma often manifests as adverse childhood events resulting from domestic violence, removal of children into state care, physical, mental, and sexual abuse that may have occurred in state care settings (Royal Commission of Inquiry into Abuse in Care, 2020), early deaths, and compounded loss and grief. These recurring features frequently lead to disruptions in early life and

increase the risk of homelessness (Johnson et al., 2013; McMinn, 2020; Pihama et al., 2014; Pihama et al., 2019). Domestic violence, or more exactly "violence within whānau" (Gear, 2019, p.15), for example, does not exist in isolation, but rather are interwoven in complex ways with the collective and transgenerational trauma resulting from the impact of colonization, undermining the social and cultural resources to protect children and whānau (Johnson, 2009; Johnson et al., 2013; Menzies, 2006; Pihama et al., 2019; Treolar & Jackson, 2015). Those who find themselves forced onto the streets as a result of escaping violence, often carry with them the burden of trauma and intricate connections, whether symbolic or tangible, with their whānau (Groot et al., 2015). In such circumstances, the perspective of death and dying can intensify or rekindle these experiences (Te Ohu Rata o Aotearoa, 2019).

Chapter summary

Homelessness in Aotearoa New Zealand is a pressing issue with a constant increase in prevalence. Yet the complexity of the issue is usually reduced to housing provision problems, eluding broader societal and cultural challenges, as well as the voices of homeless people, on their own rights. Through the perspectives that have informed this study, I contend that homelessness is first a deprivation of rights and equal citizenship that flies in the face of Te Tiriti o Waitangi principles, and second a relational, experiential and cultural process marked, for Māori, by colonization, transgenerational trauma, loss and cultural disconnections. This chapter provides a context to address nuanced questions surrounding death inequalities and to begin exploring the temporal space of life prior to death. In **chapter 3**, I describe mortality features and the gaps that exist within the New Zealand healthcare system. My commitment towards more effective and adequate responses to premature and avoidable mortality, as well as to provide quality end of life care has led me to conceptualise the temporal space of life prior to death on a continuum of care and attention alongside any homeless conditions.

Chapter 3: The New Zealand healthcare system and homelessness: locating points of disconnection

In this chapter, I provide an overview of the New Zealand healthcare system, from primary care to palliative care, to advance the conceptualisation of the temporal space of life prior to death and to provide context for the study. This chapter does not aim to review the international literature on barriers and/or facilitators to access to healthcare for homeless people. Rather, it aims to highlight the major points of disconnection —systemic, cultural and relational —which, over the course of homelessness, merge and blur the dichotomy between life, in comparison with the end of life, and death. Relying on international[7] and New Zealand research and policy documents, I discuss tensions and contradictions that stem from a system that is not designed for homeless people, contributing to or even exacerbating precarious health conditions and death inequalities. I also draw on my appreciation of, and experiences with, the Peeps to orient my analysis and discussion. This way of proceeding is directly related to a CaST approach and will become clearer from the next chapter and throughout the thesis. As this study developed with the Peeps who, are mostly Māori, unsheltered, experiencing long-term homelessness and disengagement from healthcare, I intersect research findings to the extent of available literature. An essential understanding for that study is that long-term homelessness is strongly associated with chronic health conditions, at a degree of severity that would normally occur with housed people who are 15-30 years older (Ku et al., 2014; Rogans-Watson et al., 2020).

The chapter entails four sections. In the first section, I provide a brief overview of homeless mortality features that put into perspective the magnitude of disparities in death. Further findings and discussion in the New Zealand context are presented in chapter 5 (published article). The second section relates to the organisation of primary care in Aotearoa New Zealand, as a pivotal site of increasing relevance for marginalised populations, and highlight key points of disconnection. Advancing toward death and dying, the third section provides a snapshot of the New Zealand palliative care system. I also highlight the importance of spirituality at the time of death for Māori whānau. In the fourth section, I discuss the need to expand a narrow definition of "palliative care" in the context of homelessness, and to consider homelessness as complex life-threatening conditions associated with SHS.

[7] Mainly from Australia, Canada, the United Kingdom, Ireland, the USA and Scandinavia.

Mortality features

Homelessness is a key driver of poor health, accelerating aging, multimorbidity[8], and of excess, premature and avoidable mortality (Aldridge et al., 2018; Aldridge et al., 2019; Brown et al., 2022; Fazel et al, 2014; Funk et al., 2022; Morrisson, 2009; Queen et al., 2017; Seastres et al., 2020; Stenius-Ayoade et al., 2017). Premature mortality is especially marked for people dwelling on the streets for longer periods of time (Auerswald et al., 2016; Fazel et al., 2014; Munoz et al., 2005; Roncarati et al., 2021; White et al., 2021). Reasons are multifactorial. Research focusing on street homelessness points towards a complex interplay between competing survival priorities, harsh living environments, issues affecting the relational, emotional, cognitive and physical domains, and increased barriers to access to healthcare. I have compiled Table 1 to recapitulate key factors influencing premature mortality for long term unsheltered homeless people.

Table 1: FACTORS INFLUENCING PREMATURE MORTALITY FOR LONG-TERM UNSHELTERED HOMELESS PEOPLE

Competing priority on a day-to-day basis	Seeking food, water, shelter, safety, warmth over healthcare
Living environments	Exposure to communicable disease (e.g., tuberculosis) Exposure to stressful events and violence (e.g., fights, assaults, robberies, rape)
Relational	Increased stigma, stereotypes, social isolation
Mental health issues and cognitive impairment	Increased difficulty to access to healthcare (e.g., depression, trauma, cognitive alteration of self-perceived physical symptoms)
Multimorbidity	High prevalence of physical, mental health and addiction issues
Adherence to treatment	Issues of refrigeration and stockage of medications
Poorer access to regular sources of care	Increased multifactorial barriers including lack of transportation, addresses, and telephone, stigma stemming from mental health issues, substance misuse, and "dirt" (difficulty to access to showers)

Sources: Davies & Wood, 2018; Fazel et al., 2014; Linton & Shafer, 2014; Munoz et al., 2005; Nyamati et al., 2000; Paudyal et al., 2017; Roncarati et al., 2020.

[8] Multimorbidity is defined as the presence of two or more long term conditions.

Death inequalities manifest through a wide range of health conditions that significantly differ in prevalence from housed populations, including the most deprived neighbourhoods (Aldridge et al., 2019; Fazel et al., 2014; Lewer et al., 2019). For example, in a recent meta-analysis, Standardised Mortality Ratios[9] have been reported to be 11.9 and 7.9 amongst women and men respectively who were homeless at time of their death, and evidenced across all International Classification of Diseases-10 categories (Aldridge et al., 2018).

In the table below (Table 2), I have highlighted the leading causes of mortality drawing from international literature based on death certificates and/or medical and coronial reports. The percentages are broad intervals I report from research, while acknowledging the disparity in research methodologies, demographic factors, definitions of homelessness, subgroups of homeless people, duration of homelessness, differences in healthcare systems, and individual circumstances in which has death occurred. Although little research has specifically focused on avoidable mortality, most of the studies have reported high rates of treatable and undiagnosed conditions and underlying risk factors of mortality (Brown et al., 2022; Fazel et al., 2014).

Table 2: LEADING CAUSES OF PREMATURE MORTALITY WITHIN HOMELESS POPULATIONS

Natural causes	• Chronic heart conditions (15-33%), cancers (19-30%), chronic respiratory diseases (e.g., asthma, COPD) (10%), digestive disease (e.g., liver disease) (9 -19%), infectious diseases
Unnatural causes (16-30%)	• Unintentional injuries (e.g., traumatic brain injuries), assaults • Unintended poisoning (overdose), up to 30% of all death (Thomas, 2012) • Suicide
Suicide	• Up to 14 times the rate within general populations (Nielsen et al., 2011; Slockers et al., 2018) • Leading cause of death within homeless youth (Auerswald et al., 2016; Kidd, 2007; Roy et al., 2004). • High prevalence of associated mental health issues and substance misuse
Avoidable mortality	• 30 % vs. 23% in the most deprived quintile (Aldridge and al., 2019) • 40 % of unreported cancers as the primary cause of death (Brown et al., 2022) • High prevalence of treatable conditions across studies (Fazel et al., 2014).

Sources: Aldridge et al., 2019; Auerswald et al., 2016; Baggett et al., 2013, 2018; Brown et al., 2022; Fazel et al., 2014; Funk et al., 2022; Henkind et al., 2023; Lewer et al., 2019; Nielsen et al., 2011; Office for National Statistics, 2018; Page et al., 2012; Slockers et al., 2018; Stenius-Ayoade et al., 2017; Thomas, 2012.

[9] Standardized Mortality Ratio (SMR) is a crude marker that describes whether a specific population are more, less or equally (SMR=1) likely to die than a standard/reference population.

As shown in Table 2, the burden of health and death inequalities across homeless populations are profound, compounding and sobering. Having access to high-quality healthcare is a human right and may improve health inequities (Marmot, 2013). Whilst healthcare may not be necessarily curative, given the abysmal death inequalities impacting homeless populations, greater access to healthcare and continuity of care may improve health outcomes, increase life expectancy and alleviate suffering (Craig et al., 2006; Pereira et al., 2018). Nonetheless, it is important to keep in sight that neither life nor death at the margins of society can be reduced to the sole aspects of clinical conditions or a housing status. Instead, such situations of adversity must be understood in broader historical, political, cultural, relational, and individual contexts. For clarity, I have divided systemic, and relational and cultural tensions into separate sub-sections. However, they are interwoven and shape the dynamics of the whole.

The New Zealand healthcare system: challenges and tensions

In 2022, the New Zealand health care system was significantly reformed to respond to persistent inequities within the population, and institutional racism (Health and Disability Services Review, 2020; Waitangi Tribunal, 2019). The Pae Ora (Healthy Futures) Act 2022 disestablished the previous District Health Boards (DHBs), and established a partnership between the Ministry of Health-Manatū Hauora and two news entities: 1)Te Whatu Ora-Health New Zealand, as a Crown agent, and 2) Te Aka Whai Ora-Māori Health Authority, as an independent statutory entity (Pae Ora (Healthy Futures) Act 2022). Indeed, the differential in life expectancy at birth is still an average of seven years between Māori and non-Māori (Statistics New Zealand, 2015b) with an avoidable mortality rate two and a half times higher (Walsh & Grey, 2019).

Healthcare systems have become increasingly complex and compartmentalised. Partition between sectors (social welfare, mental health, and medical services) and levels of care (community/ primary care and specialised care) is a consequence of specialisation and funding arrangements. Unfortunately, such partitions create a fragmented health and social services system. To avoid “falling through the cracks”, service users need to adopt the skills in what is usually termed as “navigation”. Navigating fragmented systems requires support, resource, capabilities, and time. For homeless people with complex needs, accessing the healthcare system is a major challenge, including in New Zealand

(Pierse et al., 2019) that is further complicated when associated with mental health issues (Canavan et al., 2012; Trick et al., 2021).

The Primary Care system

The New Zealand healthcare system is predominantly tax-funded. In 2001, the primary care sector was reformed in an effort to address some of the deleterious impacts of neoliberalism (Barnett & Bagshaw, 2020; Ministry of Health, 2001b). Community-based Primary Health Organisations (PHOs) were established to work with the main sector in supporting general practices including, private general practices and not-for-profit clinics (Downs, 2017; Foley, 2018). PHOs are funded through Te Whatu Ora based on their enrolment populations and through agreed management fees. General practices receive a capitation payment for each enrolled patient and fee-for-service from the patient (Chin et al., 2018). Additionally, general practices can receive additional revenue for specific services such as immunisations or for ACC[10] work (Chin et al., 2018). In order to receive general practices services, citizens are required to enrol with a PHO but still incur co-payments for primary care services including general practitioner and nurse consultations, and up to July 2023, prescribed medications. To be enrolled, people are required to provide proof of eligibility for public funding such as evidence of identity and address, and to commit with the PHO, through signing a binding agreement form. Depending on complex capitation fundings schemes, the cost of co-payment varies (Downs, 2017; Foley, 2018). For low-incomes groups who hold a community services card, for example, a consultation with a General Practitioner (GP) still costs $19.50 for 15 minutes, and additional charges may apply (Te Whatu Ora-Health New Zealand, 2023a).

For disadvantaged and/or marginalised groups, financial constraints remain a salient obstacle to being able to access healthcare on a regular basis (Campbell et al., 2015; HQSR, 2019; Kertesz et al., 2013; O'Donell et al., 2016; White & Newman, 2015). The burden of unmet healthcare needs due to affordability issues affects 29% of people in New Zealand low-income groups (Organization for Economic Co-operation and Development [OECD], 2017). Research suggests that free access to community care increases the use of GP clinics and the rates of negative self-reported healthcare needs, and decreases the use of Emergency Departments (Keogh et al., 2015).

[10] ACC stands for Accident Compensation Corporation, which is the government organisation that manages the accident compensation scheme.

Continuity of care is recognised as being crucial for fostering trusting care environments and quality healthcare provision, and decreasing mortality (Baker et al., 2020; Pereira et al., 2018). Yet, the absence of a "fixed abode" has been identified by homeless people as the largest barrier to preventing access to primary care, given that providing proof of address or identity is systematically requested by frontline staff in general practices (Gunner et al., 2019; O'Donnell et al., 2016). In England, Elwell-Sutton and al. (2017) evidenced that within an enrolment to GP driven system similar to the New Zealand system, homeless people were approximately 40 times less likely to be registered with a GP than the housed population. Not having the writing and reading skills to complete enrolment forms, a lack and/or cost of material resources (e.g., transportation, phones), appointment system, limited consultations times, or feelings of embarrassment and judgmental attitudes are some additional "difficulties" for gaining access to general practices (Gunner et al., 2019; O'Connell et al., 2016). While theoretically people can change general practices at any time, the enrolment procedures are also unlikely to provide adequate flexibility for people whose mobility is sometimes dictated by survival imperatives such as escaping domestic violence or abuse, or responding to employment/housing opportunities.

The mental healthcare system, in Aotearoa New Zealand, has become particularly fragmented and difficult to access. The two decades (1980-2000), which where the height of the neoliberal reforms, resulted in the privileging of financial thresholds over healthcare needs (Barnett & Bagshaw, 2020). This led to the creation of a complex system of rationing criteria for the allocation of secondary care and mental healthcare (Barnett & Bagshaw, 2020). Access to specialist mental health care is criteria-based and conditional to assessment and referral by GPs (Ministry of Health, 2022). Primary Mental Health (PMH) is aimed at people with mild to moderate mental health issues and/or addictions, and is mainly provided through general practices (HQSR, 2021). However, people who are "not unwell enough" to access specialist mental health services and "too unwell" to receive care in general practice are left in the shadows, as is the case for many homeless people (Nikora et al., 2016). Since 2019, a progressive implementation of an integrated primary mental health and addictions services model (IPMHA) has been underway, with the aim of providing a pathway beyond the narrow remit (Te Whatu Ora-Health New Zealand, 2023b). However, this service is not universally implemented and its effectiveness is still untested. For homeless people with mental health issues and complex needs, the issues surrounding GP registration, cost, navigation, and stigma persist and result in barriers to them receiving the specialist care many need.

Moreover, two other significant concerns also need to be highlighted. The first concerns the threat of compulsory treatment allowed under the Mental Health (Community Assessment and Treatment) Act 1992 (Government Inquiry into Mental Health and Addiction [GIMHA], 2018; Johnson et al., 2013). The second concerns cultural "dissonances" and prejudices marked by the predominance of the biomedical model over Kaupapa Māori approaches towards mental health, assessment and healing Māori practices (Bennett & Liu, 2018; GIMHA, 2018; Johnson et al., 2013; Pitama et al., 2007; Rangihuna et al., 2018). The combination of the aforementioned factors reinforces unmet needs and disengagement from PMH/IPMHA for homeless people and Māori communities (Bingham et al., 2019; Gunner et al., 2019; GIMHA, 2018). Yet, suicide remains a major public health issue in Aotearoa New Zealand that disproportionally affects Māori communities as with other indigenous people worldwide (Durie, 2017; Te Whatu Ora-Health New Zealand, 2022a). Given the strong association between mental health issues, stressful life events, trauma, self-harm attempts, suicide and homelessness (Knipe et al., 2022), disconnections with the mental health sector are concerning. In the few reviews of death by suicide among homeless people, authors have reported a higher prevalence of unprocessed mental health issues and people lost from services than in the general population (Arnautovska et al., 2014; Bickley et al., 2006). Further, in Canada, Bingham et al. (2019) have highlighted the higher prevalence of transgenerational trauma and higher level of needs amongst Indigenous homeless people compared with non-indigenous homeless people, which is consistent with the legacy of colonization. These authors recommend developing culturally safe practices that address transgenerational trauma, family separations, and restore cultural and social power to indigenous communities (Bingham et al., 2019).

Furthermore, the criteria-based system has led to a two-tiered system and the purchasing of private insurance (by around one third of the New Zealand population). This two-tiered system results in a queue-jumping by the wealthiest who can bypass waiting lists in public hospitals and access specialists in private hospitals. Thus, scarce health resources can end up being monopolised by more wealthy and healthy citizens, leading to concerning unmet needs within the most disadvantaged communities in New Zealand (Barnett & Bagshaw, 2020; Chin et al., 2018). Inequitable access to secondary care, due to similar two-tiered system was stressed by homeless people in Ireland for contributing to poor health outcomes (O'Donnell et al., 2016).

Failures in continuity of care within the primary care sector are widely recognised to have a knock-on effect on hospital presentations and admissions. Homeless people often use emergency departments (EDs), which are free in New Zealand, as the last and only source of healthcare (Vohra et

al., 2022). High rates of ED visit, ED re-presentation within a month after discharge, hospital admission and readmissions and longer lengths of stay are consistent patterns across international studies (Bowen et al., 2019; Khatana et al., 2020; Ku et al., 2014; Miyawaki, et al., 2020; Moore, et al., 2011; Racine et al., 2019; Raven et al., 2017; Trick et al., 2021; Vohra et al., 2022). Moreover, the lack of integration in discharge practices among health, housing and social sectors contributes to the burden of unmet needs, exacerbations of poor health outcomes, hospital re-entry, and premature mortality (Aldridge, 2020; Gunner et al., 2019; Martineau et al., 2019; Vohra et al., 2022). This issue is particularly salient for people being directly discharged back on the streets without follow-up, or into shelters that are not appropriate to receive people with high levels of care (Martineau et al., 2019). The New Zealand Homelessness Action Plan 2020-2023 has highlighted the need to improve discharge planning for homeless people leaving hospitals, mental health wards and prisons (Ministry of Housing, 2020).

To sum up, the most visible systemic failures (cost, enrolment procedures, criteria-based access, lack of discharge policies and partition of sectors) contribute to fragmented and irregular care, lack of follow up, and ineffective support to prevent premature and avoidable mortality among homeless people. Nevertheless, systemic failures are only one aspect of what is referred to as "structural violence", a term coined by Galtung (1969) to describe social structures — economic, political, legal, religious, and cultural — that avoidably harm individuals and communities, restrict them reaching their full potential, and impair human life (Farmer et al., 2006). Normalised by institutions, embedded into everyday life experiences, structural violence "remains a high-ranking cause of premature death" (Farmer et al., 2006, p.1690). Stigma, discrimination, racism are words that speak of structural violence and create marked cultural and relational tensions and challenges for homeless people and Māori communities to access to quality healthcare provision.

Cultural and relational tensions and challenges in healthcare provision

Stigma, discrimination, stereotypes, disrespect, judgments, presumptions and misunderstandings are acutely and sorely part of the everyday life of homeless people dealing with society and healthcare services in particular. Research focusing on homeless people has stressed the impact that such forms of structural violence, whether intended or not, has in their decisions to engage or to not engage with health services. It has long been identified that dehumanising attitudes and practices in healthcare settings contribute to homeless people delaying seeking care until a severe crisis occurs, and to rely on underground resources and strategies to alleviate symptoms (e.g., medication sharing; substance use), or to not seek care at all even when dying (Davis-Berman, 2016; Håkanson &

Öhlén, 2016; Hudson et al., 2017; Hwang et al., 2001; Krakowsky et al., 2013; Martins, 2008; Medcalf & Russell, 2014; Purkey & McKenzie, 2019; Song, Bartels et al., 2007; Song, Ratner et al., 2007; Stajduhar et al., 2019; Tobey et al., 2017). Disparity in healthcare provision according to the "social value" granted to individuals by healthcare institutions is not a new phenomenon (Sudnow, 1967). This disparity is enshrined in society, whose contemporary healthcare institutions are not spared. For example, Wadhera et al. (2020) in the USA, have shown that, differences in decision-making related to cardio-vascular procedures for cardiac arrests, led to increased mortality amongst homeless persons (76.1%) compared to housed people (57.4%). Repeated, reiterated and redeployed over time, structural violence harms, and amplifies mistrust toward institutions and people, low self-esteem, shame, fear, distress, trauma that all impede and complexify the possibilities of effective and respectful quality of care provision.

In Aotearoa New Zealand, further tensions and challenges arise from the disregard of Māori beliefs, values and practices coupled with racial discrimination, deeply embedded into the colonial history of the country (Harris et al., 2018; Graham & Masters-Awatere, 2020; Wilson et al., 2018). The notion of *cultural safety* has been developed from the 1990s to foster reflexivity amongst health professionals and organizations to acknowledge and address cultural biases, stereotypes, prejudices and power relationships affecting clinical interactions and healthcare delivery (Papps & Ramsden, 1996). Nonetheless, healthcare services can still be experienced as foreign and hostile environments by marginalised people. Many Māori, whether they subscribe to traditional beliefs or not, feel uncomfortable within healthcare settings (Graham & Masters-Awatere, 2020; Wilson, 2018, p. 3814). Lack of trusting and meaningful connections with professionals, domination of the biomedical approach to health, devaluation of the importance of wairua and whānau for hauora, or disregard for cultural practices such as rongoā (natural healing medicine) are widely reported by whānau (Graham & Masters-Awatere, 2020). Thus, it is not unusual for Māori to "avoid" or to delay access to healthcare services, and/or to request for earlier discharge from hospitals (Graham & Masters-Awatere, 2020).

Repeated exposure to experiences of perceived discrimination and racism at an interpersonal and/or systemic level is corelated to negative mental and physical outcomes amongst marginalised populations (Harris et al., 2018; Pascoe & Richman, 2009; Pascoe et al., 2022). Ultimately, reducing premature suffering and death demands placing the burden of so-called "non-compliance" or "care-avoidance" of marginalised populations back onto the healthcare system and providers. This requires a concerted effort at all levels of the healthcare system. Some barriers may be removed and others may be attuned. Institutional racism is "often evident as inaction in the face of need" (Jones, 2000, p.1212). For

example, the importance of building meaningful relationships with homeless people or first "engaging" health professionals rather than expecting homeless people "re-engage" with the health sector has been widely highlighted in the literature, both locally and internationally. Research suggests that educating and training staff about the unique challenges faced by homeless people is another important area to consider for tackling the stigma and discrimination homeless people face within the healthcare sector, and to "close the gap" of patient and health professional estrangement (Drury, 2008).

The palliative care system

The Western notion of the "good death"

Death holds foundational significance within any culture, influencing the values and practices that govern the living. The manner by which a culture organises the bonds, the distance and the dynamic exchange with those who have passed away shapes the daily foundation of social links (Baudry, 2005; Kaufman & Morgan, 2005; Ngata, 2005). From a Western contemporary view, death is understood as a kind of termination of existences or a closure, restricting the grieving and memorialization processes in time and to the private sphere (Klass et al., 1996). Palliative care (PC), a relationally driven and holistic concept, has developed within Western perspectives on illness, death and dying, oriented toward the "good death" (Clark, 2002). Originating from the hospice philosophy initially developed in cancerology, where death trajectories are relatively predictable, the Western notion of the "good death" places control and autonomy as central components of the experience of "dying well" (Cottrell & Duggleby, 2016; McNamara et al., 1994). However, since death is seen as a termination of existences, the notion of a "good death" should also reflect this closure by encouraging the dying persons to be aware of their impending death, resolve conflicts to find peace in the process of dying. A "good death" is thus achieved when a dying person accepts the impending death, and the dying process becomes predictable and manageable in controlling, for example, physical symptoms, timing and place of death (Clark, 2002; Cottrell & Duggleby, 2016). The notion of the "good death" is considered central to the theoretical framework of palliative care (Hart et al., 1998), shaped by the values, discourses and practices of palliative care professionals, as well as societal expectations (Broom, 2012; Cottrell & Duggleby, 2016). However, the ideology of a predictable, controlled, autonomous death is challenged by the experiences of the dying persons who may not wish to align with the awareness and acceptation of death, or who may face the complexity of chronical conditions and/or dementia among aging populations (Cottrell &

Duggleby, 2016; Gott et al., 2008). Importantly, although various cultures have expectations about what constitutes the experience of "dying well", Māori perspectives on death and dying challenge the Western "good death" ideology by prioritizing collective values and practices of care over individuality, as well as giving precedence to the spiritual aspects of the dying journey (Moeke-Maxwell, Mason, Toohey, & Dudley, 2019; Moeke-Maxwell, Mason, Toohey, Wharemate, & Gott, 2019; Moeke-Maxwell & Nikora, 2019).

Definition and design of palliative care in Aotearoa New Zealand

Palliative care is defined as a care "approach that improves the quality of life of patients and their families facing the problem associated with life-threatening *illness*[11] through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual" (WHO, 2002, p.84).

In Aotearoa New Zealand, the Ministry of Health has adopted its own definition of palliative care to take into account the rights of Māori under Te Tiriti o Waitangi principles, and to reflect the cultural diversity of the population (Ministry of Health, 2007). Accordingly, "all people who are dying and their family/whānau who could benefit from palliative care have timely access to quality palliative care services that are culturally appropriate and are provided in a co-ordinated way" (Ministry of Health, 2001a, p.7). Emphasis has been put on optimising the quality of life of an individual with a life-limiting *illness* by addressing the person's physical, psycho-social, spiritual and cultural needs, and by supporting family/whānau in such a way as to meet the unique needs of individuals from particular communities or groups (Ministry of health, 2007).

Importantly for this study, two points need to be noticed that are developed further in the last sections of this chapter. First, the WHO and New Zealand definitions both associate conventional PC with "life-threatening illness" which implies a diagnosis. Second, the language of PC is intertwined with what is usually referred to as the "*end of life*" — a period defined in terms of time and knowledge limits. The New Zealand definition of the end of life covers a period where people with "unstable and deteriorating conditions are at risk of dying in the year ahead" (Ministry of Health, 2015, p.4).The risk of dying is identified and recognised, inducing a shift from curative treatment to palliative care. Thereupon the

[11] Emphasis added

"place, level and goals of care" are modified to enhance the quality of life until death (Ministry of Health, 2015, p.4), aligning with the notion of the "good death" as a controlled, predictable and linear process. Figure 1 visually illustrates the current and conventional model of palliative care, showing how the dying process follows a linear progression after a curative phase of a diagnosed life-threatening illness. Palliative care is provided through the end-of-life period, which typically spans around one year.

Figure 1: CONVENTIONAL MODEL OF PALLIATIVE CARE

Modified from source: Ministry of Health, 2015.

Aligned with other high-income countries, in Aotearoa New Zealand, palliative care provision has been modelled according to two levels of intervention, one general and the other specialized. In Table 3, I have summarized the organization of PC, the providers implied, their specifications, as well as the conditions of access and use of specialised palliative care in the case of complex needs.

Table 3: ORGANISATION OF PALLIATIVE CARE IN AOTEAROA NEW ZEALAND

Levels of palliative care	Providers	Specifications
General palliative care level	GPs, district nurses, Māori health providers, residential care, EDs, hospital wards, social welfare	Should meet the palliative care needs of 80 % of the population
Specialised palliative care level	Hospices, hospitals and community palliative care services	• Assessment and co-ordination • Clinical care • Support care for patients referred for **complex needs** exceeding general palliative care resources • Free of charge

Complex needs	Specialized PC services in coordination with general providers	• Uncontrolled physical and psychological symptoms • Specialised nursing (e.g., mobility issues) • Patients experiencing financial issues or distress in their human environment • Referral by GPs, conditional on acceptance by patients/families/whānau

Sources: Ministry of Health, 2001a, 2012; Palliative Care Council New Zealand, 2014.

From a policy perspective, homeless people who experience complex needs, have no housing, little social and financial support, regularly face the aforementioned barriers within primary care and/or in hospital settings, should be thus "eligible" to specialised palliative care. Yet, the same upstream structural barriers that obstruct homeless persons' access to primary care are amplified in the palliative care space. These barriers include: (a) General Practitioner registration that is conditional on providing an address, (b) being able to afford the financial cost of medical visits and transportation in order to be diagnosed with a life-limiting illness, (c) to have sufficient health literacy for access to free palliative care services provided whilst also needing to meet the criteria of complex needs, and (d) to be in a position to accept that one is dying. Throughout my study, I was unable to find data related to palliative care provision by hospices to homeless people. Informal insights from palliative care providers in two regional hospices estimated that over a ten-year period homeless people accessing hospices ranged between zero to five patients.

Cultural and relational challenges and tensions in palliative care provision

Palliative care is a recent notion for Māori whānau whose views and practices surrounding illness, death and dying contrast with a Western model (Moeke-Maxwell, Mason, Toohey, & Dudley, 2019). As for other indigenous people, the land and the spirit are of deep significance in journeying toward death and dying, and preparing the spirit to transit into the afterlife (Duggleby et al., 2015; Moeke-Maxwell, Mason, Toohey, Wharemate, & Gott, 2019; Moeke-Maxwell & Nikora, 2019; Nikora et al., 2013). Despite colonial disruptions, death and dying remain deeply anchored in "spiritual landscapes" (Nikora et al., 2013, p.3). For many Māori, *whenua tapu* (the sacred land) is the home place where the tūpāpaku, as an embodied spirit, return to be mourned and interred amongst their own, enabling the spirit to participate in a broader cosmological story of ongoing renewal (Nikora et al., 2013). Unified by spirit, life and death deploy on a continuum, neither interrupted nor divided (Marsden & Royal, 2003; Moeke-Maxwell, Mason, Toohey, Wharemate, & Gott, 2019; Nikora et al., 2013). Moeke-Maxwell, Mason, Toohey and Dudley (2019) state: "For indigenous people then, the purpose of palliative

care is to provide physical, emotional, and spiritual comfort to support the ill and dying person and their family; when combined, the activation of these health domains helps to prepare the dying person's spirit to transition through the ārai (the veil between the physical and metaphysical realms) at time of death" (p.1251-52).

Māori whānau prefer to care for their loved ones, drawing on Māori knowledge, spiritual practices and rituals (Gott et al., 2015; Moeke-Maxwell et al., 2014; Moeke-Maxwell, Mason, Toohey, Wharemate, & Gott, 2019; Moeke-Maxwell et al., 2020; Moeke-Maxwell et al., 2021). This assertion needs, however, to be nuanced as whānau are diverse, experience different socio-economic and cultural realities and distress, and have diverse capacities and resources to provide care to the dying person (Te Ohu Rata o Aotearoa, 2019). Responding to palliative care needs is thus a matter of providing culturally safe and whānau-centred support (e.g., good communication, access to cultural and spiritual resources when needed such as cultural liaison workers), while maintaining high clinical standards, so that whānau may fulfil the emotional, familial and importantly spiritual needs of the dying person (Gott et al., 2015; Moeke-Maxwell, Mason, Toohey, & Dudley, 2019; Te Ohu Rata o Aotearoa, 2019).

Nonetheless, research suggests that access to and use of palliative care, whatever the settings, is frequently undermined by "cultural differences between the communities served and the suppliers of health services" (Frey et al., 2013, p.522), the latter operating mainly from Western biomedical perspectives. Indeed, for many Māori, hospices are often associated as a "place to come and die" and previous experiences of discrimination within the health sector fuel fears that prevent Māori from using palliative care services (Frey et al., 2013). Further issues stem from an increasing medicalization of palliative care as a "medical speciality". Despite palliative care commitment to holism, there is growing evidence of the predominance of physical care (e.g., pain management) in routine practices over spiritual care that remain the least developed and most neglected dimension of palliative care (Gisjberts et al., 2019), including in Aotearoa New Zealand (Egan et al., 2017).

Moreover, at the general palliative care level which is increasingly required to provide "hospices type care", research suggests a lack of effective integration of palliative care into current practices. For example, a New Zealand cross-sectional study found significant deficits that challenge the assumption that GPs are willing and/or able to play a key role in palliative care provision in the community (Robinson et al., 2022). Indeed, findings have indicated that 18% of bereaved whānau/family felt they received no support from community services in the last three months preceding the death of their loved ones, only 50% felt they have received enough support at home (mostly people diagnosed

with cancers), and 35 % highlighted a lack of coordinated approach with specialist palliative care services when involved. The strongest predictor of having services involved was corelated to satisfaction with GP care (Robinson et al., 2022). This echoes recent surveys of New Zealand's medical and nursing schools that highlight a lack of education and training in palliative care (Heath et al., 2021; Heath et al., 2022). Accordingly, these authors have recommended that palliative care competencies be mandatory and further developed to equip health professionals with adequate knowledge, skills and attitudes to provide optimal and culturally safe palliative care. With regard to homelessness, deficiencies in PC training amongst health and allied professionals, coupled with naivety of the unique challenges faced by homeless people, have been stressed in much international research as important factors impeding early recognition of the dying process (Davis-Brenan, 2011, 2016; De Veer et al., 2018; Hudson et al., 2017; Klop et al., 2018; Krakovsky et al., 2013; McNeil et al., 2012; Petruik, 2018; Traynor, 2019; Shulman et al., 2018; Stajduhar et al., 2019; Webb, 2015).

Under the principles of Te Tiriti o Waitangi and the Universal Declaration of the Rights of Indigenous Peoples (UN, 2007), access to culturally safe palliative care is a right. Within Māori homeless contexts where whānau disconnection processes prevail, what "palliative care" means or might look like is yet to be understood or invented. Largely unknown questions are: What are the priorities, aspirations and wishes of homeless people? How spiritual needs at the time of death may be met? What are the needs beyond physical pain relief and symptom management? So far, I have shown that in the face of ever-present death and ongoing deficits at all levels of the healthcare system, opportunities for the prevention of premature and avoidable mortality are severely compromised. The corollary is that opportunities to provide timely, effective, appropriate "end-of-life" care that would be based on early identifications of "life-threatening illnesses" are also missed. When care provision are inadequate, health conditions that would or should not be life-threatening become so (Knaul et al., 2018). Life and the end of life collapse then, more often than not, into the same reality. In other words, the convergence of life and end-of-life experiences, often leaves little room and time for anticipating death and opportunities for homeless people to engage in dying experiences that may be meaningful for them. For many of the Peeps, who are no longer connected with whānau and who yearn to reconnect, not having enough time before dying may be experienced as an all-encompassing devastation. These circumstances could also lead to more trauma for bereaved whānau. Therefore, I took *a pause*.

In the course of this study, I decided not focus on the conventional notion of palliative care as the ultimate response to death and suffering. Instead, I stopped at a place and a time where life may still

be possible, where potentialities still exist, and where time is of utmost importance, even vital. I halted within the temporal space of life prior to death, within this fragile and uncertain interval, particularly in the contexts of homeless people's lives. In other words, I did not consider prevention and palliative care as dichotomous approaches, nor did I view the pursuit of "quantity and quality" of life as mutually exclusive goals. This perspective challenges the conventional division between preventing premature mortality and providing palliative care, compelling a shift towards a comprehensive and integrated approach of care. Such an approach recognises and endeavours to respond to the intricacy of life and end-of-life experiences associated with homelessness, where boundaries become blurred in the face of the ever-present "risk" of dying. This perspective acknowledges the complexity and challenges posed by homelessness, a condition of constant uncertainty where people are persistently confronted with the omnipresent risk of dying. In the subsequent section, I will further elaborate and delve into this shift of perspective.

Homelessness as complex life-threatening conditions: towards a comprehensive care approach

The aim of this section is twofold: to discuss homelessness as complex life-threatening conditions associated with SHS and to present the corresponding shift in the approach of care, in alignment with the current international recommendations for modifying the 2002 WHO definition of palliative care. In 2018, in the face of abysmal inequalities in PC delivery worldwide, the *Lancet Commission on Global Access to Palliative Care and Pain Relief* recommended to adopt a ground-breaking view that:

> "explicitly rejects any time or prognostic limitation on access to palliative care, includes complex chronic or acute, life-threatening, or life-limiting *health conditions*, and considers all levels of the healthcare system from primary to specialised care and in all settings where palliative care can be delivered" (Knaul et al., 2018, p. 1400).

The recommendations of the *Lancet commission* reject the prevailing notion that palliative care should be restricted to time limit or prognosis resulting from life-threatening illnesses, as established by WHO in 2002. Instead, the focus is shifted towards complex, acute or chronic complex health conditions that are life-threatening or life-limiting. Furthermore, the *Lancet Commission* advocates for a

comprehensive approach of care that encompasses all levels of the healthcare system, from primary to specialised care, and is applicable in all settings where PC can be provided.

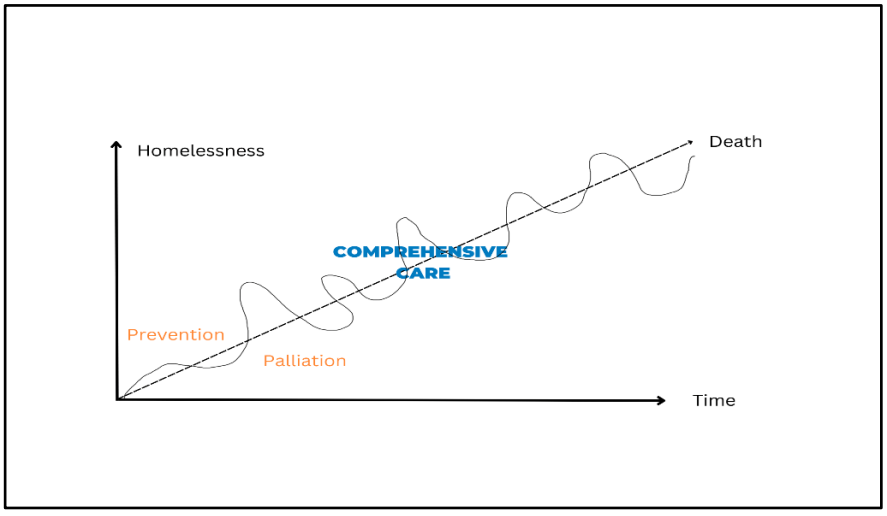
Unlike solely focusing on life-threatening illnesses, the *Lancet Commission* further introduced the notion of *serious health-related suffering* (SHS) (Knaul et al., 2018, p. 1392). Suffering is defined as health related when it compromises physical, social, spiritual, and/or emotional functioning and serious when it cannot be relieved without health professional interventions (Knaul et al., 2018). The notion of SHS applies to all patients regardless of diagnosis, prognosis and socio-economic level (Radbruch et al., 2020). From the *Lancet Commission* perspective, PC is regarded as an essential component of comprehensive care, implemented within the care continuum for people with complex health conditions (Knaul et al., 2018). Accordingly, the focus of PC should be on relieving SHS that is associated with life-threatening or life-limiting conditions, or the end of life (Knaul et al., 2018).

The *International Association for Hospice and Palliative Care* (IAHPC) echoed the view of the *Lancet Commission*, and undertook to work toward redefining PC and modifying the applicability of PC throughout the course of complex health conditions associated with SHS, in all care sittings, by any caregivers including families as the unit of care (Radbruch et al., 2020). IAHPC argued that emphasizing complex health conditions and suffering as a mainstay for PC would allow a shift from an illness-centred conceptualisation to a more person-centred approach (Radbruch et al., 2020). It also would enable PC to be delivered based on complex needs rather than on prognosis and limited end-of-life period, and to shift from the dichotomy cure-care or curative-palliative model to comprehensive and synchronic care, implemented throughout complex health conditions in all settings of health and social care (Radbruch et al., 2020).

So far, I have highlighted the profound death inequalities associated with homelessness that encompass higher rates of excess, premature, avoidable mortality, multimorbidity and accelerating aging, underpinned by unmet healthcare needs. I have also pointed out the unpredictability of death trajectories and the ever-present risk of dying resulting from unmet healthcare needs and harsh living conditions as inherent aspects of homelessness. Therefore, aligned with the *Lancet Commission* and *IAPHPC*'s recommendations, this study proposes to consider homelessness as complex health conditions associated with SHS (but not only) which significantly compromise physical, social, spiritual, and/or emotional functioning and wellbeing, to various degrees and dependant on persons. More precisely, a crucial aspect of this study has been to address *homelessness as complex life-threatening conditions associated with SHS*, taking into serious account the omnipresence of the risk of dying into the lives of

homeless people, especially for those living on the streets. Drawing from my experience on the streets of Nanterre, with the Peeps, and in accordance with the recommendations of the Lancet Commission and IAPHPC, addressing homelessness as complex life-threatening conditions associated with SHS, necessitates a shift in the approach of care. This requires moving towards a comprehensive and integrated care approach that accompanies the persons throughout their experiences of homelessness. In other words, the traditional dichotomy between "prevention OR palliation" transforms into a synchronic, supportive and integrated approach of care that focuses on "preventing AND palliating". This approach aims to respond to the uncertainty of death trajectories induced by homelessness. Figure 2 visually illustrates this proposition, illustrating alternative and non-linear movements between prevention and palliation, in contrast to the conventional and linear approach of palliative care depicted in Figure 1.

Figure 2: COMPREHENSIVE CARE AND HOMELESSNESS AS COMPLEX LIFE-THREATENING CONDITIONS



Modified from source: Knaul et al., 2014.

Variations between preventive and palliative care, and vice versa, may co-exist throughout the course of homelessness. However, unlike many other chronic health conditions, the effects of homelessness are particularly severe, as evidenced by the extreme death inequalities experienced by homeless populations. Recognising the pervasive nature of human suffering throughout processes of marginalization, alienation and exclusion in homelessness, it is thus crucial not to confine the addressing of emotional distress, social and familial disconnections, spiritual needs or physical symptoms solely to

the "end-of-life period". This argument aligns with the proposition of the Lancet commission, which stresses that palliative care should focus on alleviating suffering throughout the course of any life-threatening conditions or life-limiting conditions, not just at the "end of life". Thus, recognising homeless as complex life-threatening conditions associated with SHS, and adopting a comprehensive care approach may provide a "time of life" and support that are desperately lacking in many homeless situations. This is crucial for effectively preventing premature and avoidable deaths, and vital to offer some respite to homeless people, allowing the dying process to occur in accordance with their wishes, priorities, aspirations and rights, within their unique life stories. For many of the Peeps, however, allowing for a space of care and support in the course of time had distinct significance. It meant having the possibility of reconnecting with whānau, to be honoured and recalled as an ancestor through whakapapa, and being able to return to their spiritual homelands at the time of death to be buried, so that their wairua can participate in the broad cosmological story (see chapter 7).

Proposing a shift towards a comprehensive care approach does not intend to enforce standardised rules of healthcare and palliative care within biomedical models. It is important to note that what palliative care could mean for Māori people who experience homelessness, is still to be understood or invented, as already stated. Embracing an integrated, supportive and synchronic approach implies adopting a caring stance that acknowledges the constant presence of the risk of death in the lives of homeless people, and strives to respond effectively in their unique cultural contexts. Nonetheless, while addressing the root causes of death inequalities affecting homeless populations remains beyond the control of health professionals, the health community, to which I belong, has the duty of relieving suffering as much as possible, in appropriate and culturally safe ways. In addressing homelessness as, but not only, complex life-threatening conditions associated with SHS, health and allied professionals have an important role to play. Small acts can make a huge difference and contribute to a comprehensive care approach. For example, GPs have the authority to register homeless people without requiring evidence of an address and can offer free healthcare through the Care Plus[12] scheme. Some GPs I met during the study, took such actions once they recognised that homelessness is also associated with life-threatening conditions that lead to premature, avoidable and unjust deaths. In my personal experience with the Peeps, I took various small acts to embody Māori values such as whanaungatanga, manaakitanga and aroha. A few examples included providing informal care that prioritized their well-

[12] Care Plus provides free healthcare access for people with one or more health chronic conditions that encompass a "significant burden of morbidity" (Te Whatu Ora-Health New Zealand, 2022b).

being based on their own reference frames, or sharing my contact information (e.g., phone number) with both the Peeps and health institutions to maintain ongoing connections and communication.

Through small acts, the temporal space of life prior to death may become less tenuous and fragile. Perhaps, some deaths may be avoided, distress will be reversed which may prevent some people from self-harm, and a meaningful time prior to death may be found in accordance with the wishes, aspirations and priorities of each homeless person. Lastly, embracing a comprehensive care approach means (re)placing homeless people at the centre of care, included in life and death as agents, citizens, women and men, mothers and fathers, sons and daughters and relational beings, in their uniqueness and cultural contexts. This approach goes beyond addressing physical needs; it acknowledges the person as a whole, encompassing their emotional, social, familial, and spiritual wellbeing in the intricate web of relationships, connections and mutual influences Māori homeless people are part of. This shift of perspective is the proposition that has supported my study and has led me to explore the temporal space of time prior to death, as a "zone" of potentiality, where life and death intimately coexist. Within that space, life may flourish as death may abruptly intrude, revealing the profound significance of complex life-threatening conditions associated with SHS as manifested in homelessness.

Chapter summary

Death inequalities affecting homeless people are profound. By way of systemic failures in healthcare provision, racism, discrimination, stigma, and cultural prejudices, structural violence fuels unequal access to healthcare, premature and avoidable mortality, untimely and unjust deaths, and for the living amplifies an ever-present risk of dying. In this chapter, I have located key points of disconnection between homeless people and the healthcare sector, including at the end of life that undermine prevention of premature mortality and respectful palliative care provision. This has led me to firstly, describe homelessness as complex life-threatening conditions associated with SHS; secondly, to call for a shift in care perspective; and thirdly, to apprehend the temporal space of life as a "zone" of potentiality. In **chapter 4**, I describe how the overarching relational ethics principle and a critical CaST approach have shaped this study, including my approach to exploring the temporal space of life prior to death within the unique Māori contexts of the Peeps, as well as the methods, actions and inactions undertaken throughout this study.

Chapter 4: Working with death and homelessness in Aotearoa New Zealand: a Complexity and Systems Thinking (CaST) approach

Working with death is not neutral. Working with death at the margins of society, in a context in which cultural, social and political factors channelled through power structures are pervasive, is even less neutral. As argued by Borgstrom and Ellis (2017), the field of "death studies" — an umbrella term for research spanning all aspects of death, dying and bereavement — is both multi-disciplinary and specific. Further, the "universal reach" of death, carries emotional and ethical tensions, that are particular to doing "death research". In the absence of specific methodological and practical guidance, researchers tend to draw on the work published in their own disciplines to study death-related topics and to rely heavily on reflexive practice and their own ethical sensibilities (Borgstrom & Ellis, 2017). This PhD study, however, required crossing the boundaries of my own discipline. The cultural, political and epistemological conditions of the study, its sensitivity and indeterminacy, my own presence as non-Māori and the ever risk of Western dominance and misinterpretations this implied, required more than a methodology to simply gain data/information. It required an approach that honours and foregrounds Māori realities, ways of knowing, and the agency of homeless people to define for themselves their aspirations and priorities in the face of death in their own reference frames.

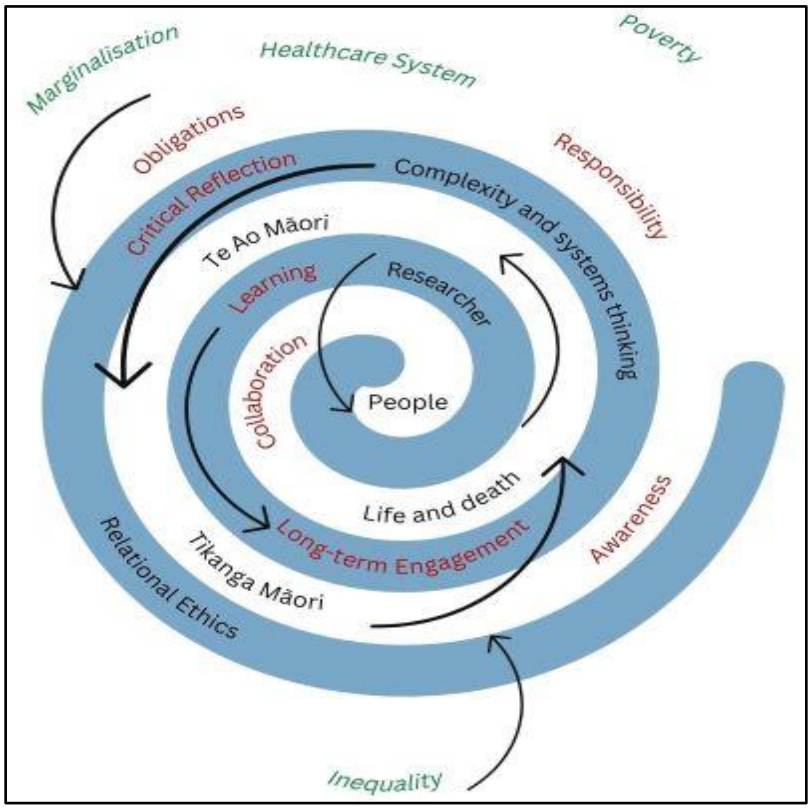
In this chapter, I present a critical CaST approach intertwined with relational ethics, as the theoretical and practical stance I adopted to respond with sensitivity, careful attention, and cultural humility[13] (Danso, 2018) to the conditions of this study. This chapter is organised in three sections. The first section presents relational ethics, as my "ethical sensibility" which operated as a guiding thread throughout the whole research process. I also discuss the resonance of relational ethics with Tikanga Māori. The second section briefly explains (see chapters 5, 6 and 7 for detailed narratives) how I came to choose a CaST-oriented approach and provides an overview of the field of CaST in health research. In the last section, I present the critical trend in CaST methodologies within which I locate my study, and the resonance between critical CaST and Māori knowledge systems. I also explain my positioning in regard to my presence as a non-Māori researcher in this study. The section concludes with an overview of the

[13] Cultural humility (Danso, 2018) aims to: a) Understand self and other; b) Recognize one's prejudices and cultural misperceptions; c) Engage in continuous self-critique; d) Challenge power differentials in working relationships and in organizations; e) Develop an attitude of not knowing and learn from people who are affected.

quantitative and qualitative methods I used, as the methods will be presented and discussed in the corresponding chapters (chapters 5, 6 and 7).

The schema illustrated in Figure 3 provides an overview of the methodological stance and interrelated practice I adopted that shows the spiralling dynamic of the study and the influences of the main vectors, which encompass the people at the centre of the study inserted within a web of connections to wider influences, life and death, Tikanga Māori and relational ethics, te ao Māori in its diversity of perspectives and CaST. Important elements of research practice such as critical reflection, learning, genuine and long-term engagement, trusting relationships building, collaboration, responsibility and obligations to the Peeps and Māori communities, critical awareness, are highlighted in red. The broader context of inequities and structural forces such as racism, socio-cultural marginalisation or inequitable access to health care and social services are highlighted in green.

Figure 3: OVERVIEW OF THE STUDY APPROACH



Relational ethics and Tikanga Māori

Knowledge, in most Western research, tends traditionally to derive from a lineage that goes from ontology to epistemology to methodology. Ontology is concerned with the nature of reality and entails the philosophical foundations from which researchers engage in inquiry (Schwandt, 2007). Epistemology relates to the nature of knowledge and is traditionally constrained by ontological considerations, while methodology governs the principles of conducting research and grows out of researchers' ontological and epistemological stances (Guba & Lincoln, 2005). However, as noted by some (Christians, 2005; Guba & Lincoln, 2005; Mertens & Ginsberg, 2009; Morgan, 2007), whatever the "ontological paradigms" within which researchers work (objectivism, constructionism or critical realism), axiology — the branch of philosophy concerned with ethics, religion and spirituality, and aesthetics — has been externalised from processes of knowing. As a result, vast areas of human experiences such as spirituality have been obscured from Western epistemology, and ethics is often restricted to instrumental research endeavours (Hopner & Liu, 2021; Mertens & Ginsberg, 2009).

In contrast, when *relational ethics* is the overarching consideration, then research, epistemology and ethics became inter-related and cannot be separated. At the roots of relational ethics is the acknowledgment of our human finitude, of our primary corporeal vulnerability of being born naked without defences other than our inter-relationality and inter-dependence to preserve and sustain life, and the responsibility that stem from this acknowledgment (Butler, 2004; Lévinas, 1961/1990, 1995). Responding to this acknowledgment is an ethical act that asserts our fundamental nature as relational human beings (Lévinas, 1961/1990, 1995), and calls for "doing something to act" (Ellis & Bochner, 2006). This is the deep meaning of relational ethics that the vicinity of death and suffering conveyed through homelessness urgently reminds us. Researching from the dying space in the light of relational ethics, Ellis (2007) states that we should "hold relational concerns as high as research and […] strive to leave the communities, participants, and [ourselves] better off at the end of the research than they were at the beginning" (p. 25).

Positioning relational ethics and epistemology on an equal plan of concern challenges the mainstream Western research tradition by overturning the paradigmatic lineage between ontology, epistemology and methodology. Rather than privileging knowledge as an end in itself, relational ethics requires us to question what the value and utility of knowledge is as a consequence of research, whose interests are being served and how, and to act accordingly (Hodgetts et al., 2021; Hopner & Liu, 2021). Hodgetts et al. (2021) argue that foregrounding relational ethics when working in Māori homeless

contexts is essential for culturally informed research practices that seek to produce actionable knowledge that is aligned with homeless people's concerns and experiences. Foundational to relational ethics is the recognition of our shared humanity as relational beings and how this recognition is reflected in practices of engagement with people through core Māori concepts such as whakawhanaungatanga (building trusting relationships and connections), manaakitanga (the duty to care for and to value all people) or whakaiti (acting towards people with humility) (Hodgetts et al., 2021).

Holding relational ethics as the first research principle commits us to respect, dignity, solidarity, human rights, justice, and responsibility that comes with the declaration of being relational beings. Even though relational ethics forms the core of my "ethical sensibility" which has always guided my professional practice, in the context of this study, relational ethics was essential to engage the inquiry in a way that supports homeless people's agency, aspirations and priorities while retaining their identities. Equally important, relational ethics articulates that knowledge processes, and research practices and endeavours are intrinsically inter-related. This resonates with the concept of Tikanga Māori. As highlighted by Mead (2016), the relationships between knowledge, ways of knowing, and knowledge practices form an inseparable triad that reflect the relational essence of Māori worldviews. *Mātauranga Māori* (Māori philosophy and system knowledge) holds in its core lineage connections or whakapapa between people, events, place, time, the metaphysical and physical, life and death, the living and the dead (Nepe, 1991), which is shaped as both a set of ideas and ethical practices (Mead, 2016; Smith, 2012). As stated by Mead (2016) "while mātauranga Māori might be carried in the minds, tikanga Māori puts that knowledge into practice and adds the aspect of correctness and ritual support […] Tikanga Māori might be described as Māori philosophy in practice and as the practical face of Māori knowledge" (p.15). This means that for knowledge to be experienced by people as right and true, ways of knowing must concord with the ethical values and principles carried out by Tikanga Māori (Mead, 2016). In other words, ways of knowing or culturally informed research practices are an integral part of what constitutes valid knowledge. An important "methodological" aspect of this PhD study was thus to find, as much as possible, an appropriate place for this study so it could develop in a way that would honour Māori ways of understanding, knowing, doing, and being while retaining distinctiveness and uniqueness. Saying that, it is not simply a matter of smoothing over the tensions and complexities resulting from cultural interfaces.

Toward a complexity and systems thinking (CaST) approach

On the ground

At the outset of this study, the scarcity of research about death and dying in homeless indigenous contexts led me to opt for a mixed methods methodology to explore the healthcare barriers to effective prevention of premature mortality and palliative care provision. At that stage, these two poles of inquiry were loosely related. Defined simply, a mixed methodology combines both qualitative and quantitative methods so that the combined strengths of each approach provides a deeper understanding of a research problem rather than if using only one approach (Creswell, 2007).

As the study progressed on the ground, challenges and tensions at various levels became more distinctly apparent. Briefly (see chapters 5, 6, and 7 for the narrative), the more I advanced into my research, the more I ventured into indeterminacy and "messiness". My "topic" was not only sensitive and quite on the fringes of the literature, but also had limited recognition in practical settings. In my reading of academic literature, the topics of death and dying seemed often invisible, as were cultural aspects of Māori homelessness. No data were available, and most of the health and allied professionals I met did not seem aware of and/or expressing a need for research connecting death, dying and homelessness. In the professional discourses, homeless people tended to be referred to as a homogenous group, and issues were reduced to a 'lack of housing" that is often combined with substance misuse/mental health problems requiring urgent and normative responses. Being a new migrant to the country also meant I was not part of an established network of relationships in social and professional spheres of life. Hence, I could not utilise typical avenues to gather stakeholders around the topic. Meanwhile, alongside my volunteering at Cuppa Connection as an informal doctor, I became even more involved with the Peeps. Over time, this PhD study progressed exclusively within this specific Māori context. As a result, I was also a witness to the ever-presence of death and risk of dying in Peeps' lives. Prevention of premature mortality increasingly merged with palliative care provision, which led me to locate this study within the temporal space of life prior to death and to conceptualise homelessness as complex chronic life-threatening conditions associated with SHS, calling for comprehensive care.

Consequently, cultural and sensitive responsiveness to these evolving and fuzzy conditions of the study, required me not to foreclose what should be investigated, and to retain assumptions about the type of care responses required in the face of cultural disconnections and suffering. These questions and considerations resulted in a shift from mixed methods to another methodological approach. From a

relational ethical perspective, an appropriate approach would tend towards ethical, epistemological and spiritual dialogue with Māori worldviews in their contemporary diversity, and to see the world in terms of connections, relationships, and a web of mutual influences. Therefore, I turned to a CaST approach that locates interrelatedness, interrelationships, and interactions at the core of the research process and views of the world, while offering enough flexibility and openness to accommodate indeterminacy, uncertainty, and complexity.

Theoretical background of CaST

Simply put, CaST is "a general conceptual orientation concerned with the inter-relationships between parts and their relationships to a functioning whole, often understood within the context of an even greater whole" (Trochim et al., 2006, p. 539). It is thus a way of organising our thoughts or ways of thinking (but also of doing and being) about the complexity of the world by developing an understanding of the interrelationships and interconnections between the whole and the parts, the whole being more than the sum of the parts. Committed to holism and pluralism, CaST is about seeing both "the forest and the trees (one eye on each)" (Richmond, 1994, p.140). Saying that, and in line with a constructivist orientation, I ally with some theorists such as Le Moigne (2001) who stated that "the complexity of a system is not in the nature of things […], and is not necessary a property of such system, […], it is rather a property of the representation currently available of such a system" (Le Moigne, 2001, as cited in Alhadeff-Jones, 2013, p.22). Given the daunting literature about CaST, Table 4 below sums up some key ideas useful for this study.

Table 4: KEY IDEAS IN COMPLEXITY AND SYSTEMS THINKING

Characteristics of complex systems	Interrelated ideas
Systems are constituted relationally	Interdependency, interrelationships, interconnections
Systems are constituted contextually	Importance of the ecological, socio-cultural, economic, political and historical environment
Systems evolve according to dynamic processes	Interactive components Non-linearity, no single cause nor single explanation Unpredictability, uncertainty, constant evolution Importance of feedback loop
The whole is more than the sum of the parts	Holism, theoretical and methodological pluralism, trans-disciplinarity

Sources: Preiser et al., 2018; Rajagopalan, 2020

CaST approaches aim to deal with "messy" and complex situations that cannot be addressed by establishing linear cause and effect relationships. Instead, CaST offers a way to view issues in terms of interrelationships and interactions between parts and with the whole instead of isolating and breaking problems down, and to address contexts as an integral part of the research process.

CaST in health research

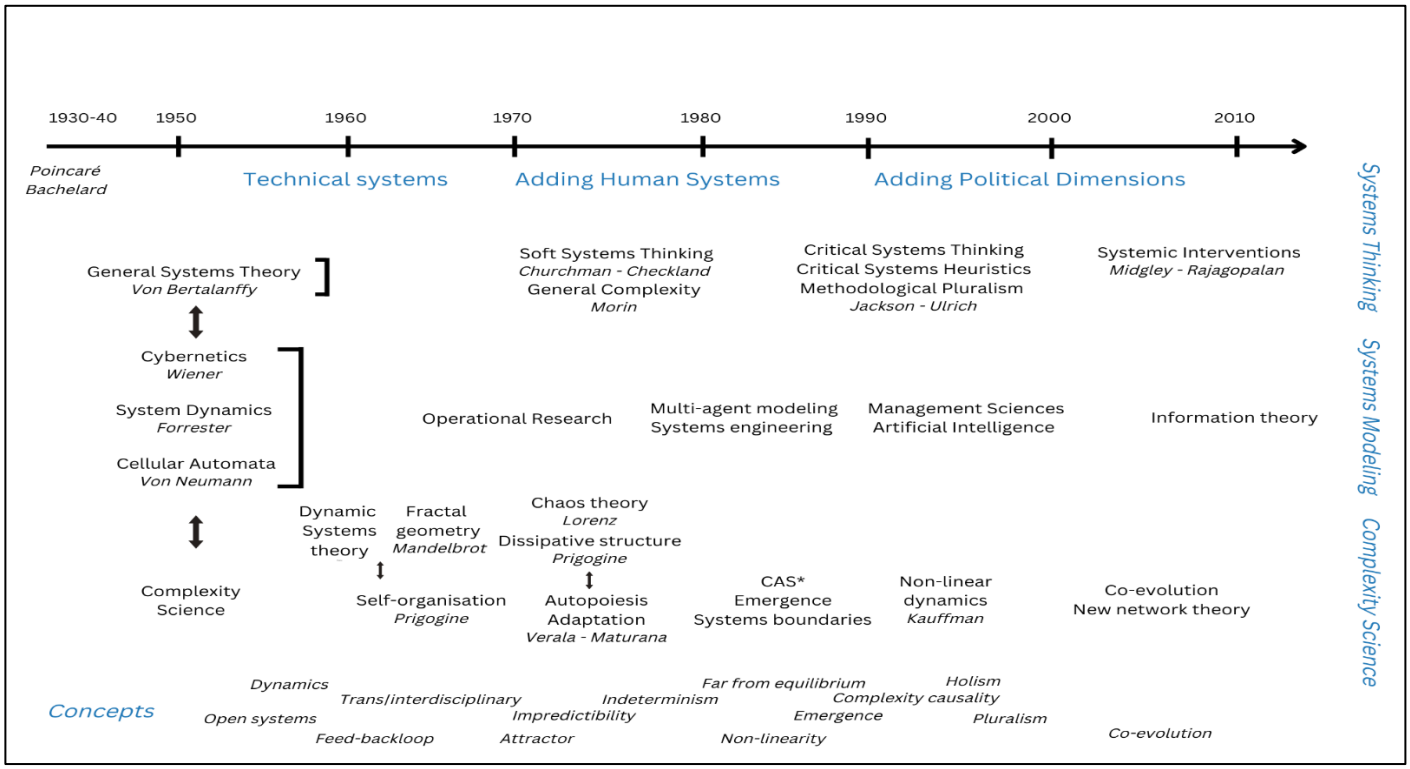
The last 25 years have seen a growing interest in the use of CaST in health research (Carey et al., 2015; Carroll et al., 2023; Jackson & Sambo, 2020; Rusoja et al., 2018; Thompson et al., 2016). Across the globe, health and social care organisations struggle in several topic areas including inequality, poverty, inequity of access to healthcare, suboptimal care quality and complexity. "Wicked problems" simply defined are problems that have no definitive formulation and are particularly complex, multifaceted, urgent, intractable, and stubborn (Rittel & Webber, 1973), such as homelessness or health inequalities that remain a challenge. It has thus been argued that such complexity implying multiple factors and levels of interactions would be better understood, when researching for optimal solutions, through a systemic and complexity lens, rather than more reductionist linear approaches (Adam & de Savigny, 2012; Fowler et al., 2019; Jackson & Sambo, 2019; Martin & Félix-Bortolotti, 2014; Midgley, 2003; Plsek & Greenhalgh, 2001; Richardson & Cilliers, 2001). CaST has been applied to various public health issues such as chronic diseases (Ansah et al., 2018; Hirsch et al., 2010), intimate partner violence (Gear et al., 2018), neonatal mortality (Rwashana et al., 2014), homelessness (Fowler et al., 2019; Marçal et al., 2021), indigenous health inequity (Hernandez et al., 2017), or in various healthcare settings (Carroll et al., 2023; Thompson et al., 2016) including palliative care (Hodiamont et al., 2019).

Nonetheless, a CaST-based approach is not without challenges. For instance, the wide range of epistemological traditions, disciplines, and approaches from which the field has evolved, has generated heterogeneous meanings, methodologies and methods (Carey et al., 2015; Carroll et al., 2023; Rusoja et al., 2018; Thompson et al., 2016), making it less likely to offer a clear research roadmap to follow. The figure below (Figure 4) provides an overview of the field of CaST theories[14] as it developed over time. Diverse influences emanating from complexity sciences, systems modelling and engineering, and systems thinking, encapsulated in their own epistemic traditions have shaped the field of CaST. For

[14] I use "theories" at the plural form to emphasise the absence of a unified approach within the field of "complexity and systems thinking", showcasing the diversity of perspectives and methodologies used (Alhadeff-Jones, 2008).

example, complexity theories tend to derive from post-positivism orientations, while systems thinking exhibit interpretivist/constructivist and emancipatory perspectives provided by the social sciences (Alhadeff-Jones, 2008; Jackson & Sambo, 2020; Leleur; 2014). As shown in Figure 4, the field of CaST is diverse.

Figure 4: OVERVIEW OF THE FIELD OF COMPLEXITY AND SYSTEMS THINKING



CAS: Complex adaptive systems

Sources: Alhadeff-Jones 2008; Chowdhury, 2022; Flood, 2010; Leleur, 2014; Sturmberg et al., 2014.

Modified from source: Sturmberg et al., 2014.

As highlighted by Jackson and Sambo (2020), systems dynamics and the concept of "complex adaptive systems" dominate health systems research. Health, healthcare systems and services, or identified issues tend to be designated as "complex adaptive systems" (Jackson & Sambo, 2020; Sturmberg & Martin, 2013). Accordingly, systems dynamics and related concepts are applied to look for "patterns of behaviours" in order to supply insights on their inner working (e.g., modelling) for improvement and intervention endeavours (Best et al., 2016; Jackson & Sambo, 2020; Sturmberg & Martin, 2013). These CaST concepts frequently function as metaphors used as "ways of imagining and

understanding the world and events within it" (Heath, 2013, p.19). They include interconnected agents, emergence, non-linearity, attractors, open systems, feedback loops, far from equilibrium, unpredictability, boundary conditions, inherent patterns, self-organisation, complex causality, and edge of chaos to cite a few. Given that my methodological approach did not follow systems dynamic, the readers could refer, for example, to Braithwaite and al. (2017) or Sturmberg and Martin (2013) for a description of CaST-related concepts. As highlighted by many (Carey et al., 2015; Carroll et al., 2023; Rusoja et al., 2018; Thompson et al., 2016), there are wide variations in theoretical approaches, often generating a lack of clarity and transparency about the meaning, use, and purpose of a CaST approach. The next section will explain the specific ways in which CaST is drawn on and applied in this study.

A CaST approach for working with death and homeless people in Aotearoa New Zealand

Critical and transformational CaST: theoretical background

Without dismissing the importance of health research using systems dynamics/complex adaptive systems and associated methods, I did not follow that path since it does not fit well with human activity (Flood, 2010). Rather, I directed my reading towards critical and transformational trends in systems thinking, namely "critical systems thinking" (Flood & Jackson, 1991; Jackson, 2020), "critical systems heuristics" (Ulrich, 2005) and "systemic intervention" (Midgley, 1995; Rajagopalan, 2020), since these areas provided an appropriate theoretical and practical framework in regard to the political, cultural, and epistemological conditions of this study. Indeed, the key theorists (Flood, 2010; Flood & Jackson, 1991; Jackson, 2020; Midgley, 1995; Rajagopalan, 2020; Ulrich, 2005), argue that critical CaST oriented research is committed to the following priorities:

- *Critical awareness* meaning examining and challenging dominant assumptions and values (including those of researchers), along with the conditions that give rise to them.
- *Social awareness* meaning appreciating and taking account of the uniqueness of local contexts and the impact of structural power on shaping these contexts (e.g., social and cultural disruptions resulting from colonisation; marginalization of the spiritual realm).
- *Human emancipation* meaning that research is directed toward people's wellbeing and the development of their potential within their own reference frames (e.g., considering hau ora

and the spiritual aspect of death and dying for Māori rather than focusing on the Western notion of health and biomedical perspectives on dying).

- *Theoretical complementarity/pluralism* meaning creating room for distinct knowledge systems and worldviews.
- *Methodological complementarity/pluralism* emphasizing a need for various sets of methodological principles and research practices sitting side by side with theoretical complementarity.

Moreover, although CaST is committed to holism, we must acknowledge that no view of the world can ever be comprehensive. The boundaries of what is included in, and therefore also excluded from our understanding and actions, become crucial. As pointed out by Midgley (2000) "where exactly boundaries are constructed, and what the values are that guide the construction, will determine how issues are seen and what actions will be taken" (Midgley, 2000, p.36). Seeking appropriate boundaries is thus an important aspect of critical systems thinking (Jackson, 2020; Midgley, 2000; Ulrich & Reynolds, 2010). *Who* is to be consulted or involved and *what* issues are to be included/excluded or marginalized into a system become essential questions to engage holistically and critically toward relevant actions (Ulrich, 2005; Ulrich & Reynolds, 2010). The process of exploring taken-for-granted boundaries, also called "boundary critique" (Ulrich, 2005), rests on the understanding that judgments and values are closely connected (Ulrich, 2005). Boundary critique focuses thus on working with tensions between conflicting perspectives, values, interests, stakeholders as they arise typically in coercive and marginalization contexts where "those affected are not involved" (Ulrich & Reynolds, 2010, p.244). Boundary critique provides a framework for critical reflexive practice to assist with the "who and what questions" in identifying and exploring relevant problem aspects, assumptions, questions, that usually stem from ill-defined issues and unequal power relationships (Ulrich, 2005).

In sum, critical CaST facilitates alternative ways of knowing and doing research by engaging with relationality, holism, boundary critique, pluralism, and uncertainty leading to critical forms of questioning and understanding. For example, what a meaningful death means for Māori homeless people is not necessarily related to the assumption that one needs to access palliative care services. For Māori, there may instead be a desire for the expressions of healing processes such as reconnecting with whānau, and be part of a cultural and spiritual system of care that gives a sense of belonging and togetherness. Core commitments in critical CaST are to foster research developed from within communities of interest, relationship building, partnership, co-creation of knowledge and actions, and

accountability. Community participatory-based research is thus often associated with (albeit not limited to) critical CaST approaches (Flood, 2010; Oetzel et al., 2017). Indeed, CaST advocates learning from a range of theoretical and methodological viewpoints to foster wider understanding (Flood, 2010; Jackson, 2020; Midgley, 2000; Rajagopalan, 2020; Ulrich & Reynolds, 2010).

Critical CaST has conceptual overlaps with Māori system knowledge and worldviews (Heke et al., 2019) and has sometimes been used complementarily in health-based research (Heke et al., 2019) and "death studies" (Taurima et al., 1999). For example, Heke et al. (2019) used the notion of feedback loops to help with understanding cultural factors that might influence Māori people in engaging with physical activity/improved nutrition in regard to obesity. The concept of boundary critique was essential in a bicultural research involving Māori funeral directors (Taurima et al., 1999). Both bodies of knowledge stress the importance of considering the interrelations and interactions resulting from a wider context and at multiple levels, to engage holistically and to put webs of relationships and interconnections at the centre of our understandings, research practices, and engagement with people (Heke et al., 2019; Vigliano Relva & Jung, 2021). Further, both approaches highlight the importance of critical self-reflection as a crucial part of the inquiry process and to adaptively engage with a learning mindset (Vigliano Relva & Jung, 2021; Smith, 2012). Last, but not least, CaST stresses the imperative of explicitly creating a space for distinct perspectives, worldviews, and the "diversity of truth" (Smith, 2012, p.146).

Instead of being driven by a step-by-step framework, research from a critical CaST perspective fosters an open, flexible, and non-linear process. This means that the researcher needs to relinquish being in full control. Accordingly, research development considers how respect, responsibility, and reciprocity relate to the relationships between the researcher, the community of interest, the local context, and the "topic", and how these relationships and emerging understandings shape research issues and the direction of an inquiry (Heke et al., 2019; Vigliano Relva & Jung, 2021). The research process therefore becomes just as important as knowledge arising from the research. In other words, how knowledge is "gained" is part of what constitutes valid knowledge, which is aligned with Tikanga Māori principles and values. This also means that research is not something fixed, or necessarily predetermined. Rather, CaST favours uncertainty and retrospective meaning-making because the research process is in constant flux and transformation as new understandings emerge from relationships, interactions, experiences, encounters and events, evolving local circumstances, critical self-reflection, and learning processes. As stated by Morin (1977) "at the beginning the word method

signified advancing along a path. Here we must accept to advance without a path, to make the path by advancing" (Morin, 1977, as cited in Alhadeff-Jones, 2013, p.21). The researcher is thus an integral part of a web of relationships and interactions, rather than being an external observer of the system.

From theory to practice

I would not argue that the complexity entailed in homelessness and/or in complex life-threatening conditions associated with SHS would justify on its own a CaST-based approach. Rather, working with death and in a Māori context, meant engaging holistically and working against the backdrop of deep death inequalities, injustices and power imbalances, comprising my own presence in this study. As highlighted by Daellenbach and Flood (2002), "boundary choices always involve some degree of arbitrariness [that] need to be challenged and justified by way of boundary critique" (Daellenbach & Flood, 2002, as cited in Oetzel et al., 2017, p.5). Although boundary critique operated throughout the whole research as part of a learning and self-reflection processes (Ulrich, 2005), some of my boundary decisions were consistent because they reflect my positioning in regard to my own presence in the study, and broader power and injustice issues. Transparency is needed.

Boundary choices

Acknowledging the power imbalance at play in this study or what had to be included in the system meant, from my perspective and values, the need to articulate the following interrelated key points:

- Actively acknowledging and respecting the validity and legitimacy of Māori worldviews and systems knowledge.
- Engaging with a learning mind-set, instead of working from an "expert" position.
- Engaging in critical self-reflection and awareness.
- Progressing from the strengths, concerns and aspirations of homeless people, as defined by and for themselves, through genuine and trusting relationships building, respect, dialogue, partnership, and long-term engagement.
- Working with death as an active agent in a more deliberate and holistic way. This means both challenging premature, avoidable, untimely and unjust death, and whilst equally acknowledging death and dying as a meaningful experience. The latter is too

often denied to homelessness people, without foreseeing what "meaningful" could mean for Māori homeless people.

- Being responsible to the Peeps and Māori communities.
- Being humble in my claims and goals.

My boundary choices reflect, in part, the ever-present and ongoing ethical, political, and epistemological tensions that arose from my own presence in this study, that developed over time with the Peeps. I am aware of my whakapapa, history, education, and privilege. I am also aware of the colonial practices of domination, and ongoing risk of perpetuation in research, as highlighted by Bishop (1998):

> "[…]Traditional research has misrepresented Māori understandings and ways of knowing by simplifying, conglomerating, and commodifying Māori knowledge for "consumption" by the colonizers. These processes have consequently misrepresented Māori experiences, thereby denying Māori authenticity and voice. Such research has displaced Māori lived experiences and the meanings that these experiences have with the "authoritative" voice of the methodological "expert". Moreover, many misconstrued Māori cultural practices and meanings are now part of our everyday myths of Aotearoa/New Zealand, believed by Māori and non-Māori alike"(p.200).

I recognise that my own presence in this study is not a right, but rather carries significant ethical, political, and epistemological obligations and responsibilities. As argued by Crawford and Langridge (2022), the "paralysis"[15] that non-Māori researchers may feel when working with Māori communities is a form of power that maintains the statu quo and upholds inequitable racist systems. Power, unbalance of power, and identities form a triad, to which there is no straightforward, comfortable, and definitive response. This study entails considerable injustices, extreme inequalities, and suffering that the ever-presence of death in the lives of homeless persons may render definitive. In this death-related context, the cultural interfaces I have highlighted in the introduction become even more sensitive and complex to address, as they also carry a form of ethical responsibility that can be understood as ontological. As stated by Lévinas (1999) :

> "The death of the other man puts me on the spot, calls me into question, as if I, by my possible indifference, became the accomplice of that death, invisible to the other who is exposed to it; as if even

[15] Pākehā paralysis can be described as "emotional and intellectual difficulties that Pākehā can experience when engaging in social, cultural, economic and political relations with Māori because of: a fear of getting it wrong; concern about perpetuating Māori cultural tokenism; negative previous experiences with Māori; a confusion about what the 'right' course of action may be" (Hotere-Barnes, 2015, p.41).

> before being condemned to it myself, I had to answer for that death of the other, and not leave the other alone to his deathly solitude[…] Death signifies in the concretization of what is for me the impossible abandonment of the other to his solitude, in the prohibition addressed to me regarding that abandonment. Its meaning begins in the interhuman" (pp.24-25).

Embracing these obligations and responsibilities, along with the inherent tensions they entail, influenced, in part, my boundary choices and the research approach I have adopted and described in this chapter, and largely influenced the whole research process (see part II). I firmly believe that as a non-Māori person, there are obligations and responsibilities to work towards Tino Rangatiratanga and equity which form the core of my positioning as an "ally" in Aotearoa. Furthermore, while I am not Māori and did not seek to use kaupapa Māori theory, I recognise my responsibility and obligations to learn from it, to reflect on its significance in contexts of colonial practices of research. Indeed, kaupapa Māori theory sets itself apart from, and in resistance to, hegemonic Western tradition and involves significant distinct dimensions, highlighted by Bishop (1998):

> "One main focus of a Kaupapa Māori approach to research is the operationalization of self-determination (tino Rangatiratanga) by Māori people […]. Such an approach challenges the locus of power and control over the research issues of initiation, benefits, representation, legitimization, and accountability […], with the latter being located in another cultural frame of reference/world-view. Kaupapa Māori is, therefore, challenging the dominance of traditional, individualistic research which primarily, at least in its present form, benefits the researchers and their agenda. In contrast, Kaupapa Māori research is collectivistic and is oriented toward benefiting all the research participants and their collectively determined agendas, defining and acknowledging Māori aspirations for research, while developing and implementing Māori theoretical and methodological preferences and practices for research"(p.201).

Therefore, my boundary choices and my research approach that aimed to honour Māori worldviews and systems knowledge, as well as foregrounding the Peeps' perspectives, also reflect the need to find a "*space of resonance*". This space is not a matter of combining, mixing or integrating distinct worldviews and systems of knowledge. Rather, it required me to find a space for distinct worldviews and knowledge systems that may accommodate and work toward Māori homeless people's aspirations and priorities, as defined by and for themselves. A useful metaphor may be those of walking in groups into a mountain cirque, — a bowl-shaped amphitheatre carved into mountains and valleys sidewalls. Each person produces a unique and distinct sound, which reflects on the sides of the cirque, in the form of an echo. Each echo is unique, but the set of echoes form a space of resonance that together, you listen to, you learn from, which transforms you, and directs the inquiry in a reciprocal way, as echoes

do. In this space of resonance, mutually constituted, this study has sought, with cultural humility (Danso, 2018), respect, and integrity, to explore the temporal space of life prior to death. This temporal space of life is, primarily relational, calling for heightened awareness, inclusivity, fairness, respect, and comprehensive care within the healthcare system and more broadly, within society at large.

Methods

As highlighted previously, pluralism of methodologies and methods is an important aspect of critical CaST. Given the scarcity of research related to the death of homeless people in indigenous contexts, enlarging the scope of inquiry was an important aspect of this study. Methods should also be flexible and open enough to not foreclose directions of inquiry by prematurely containing what should be explored. Last, but not least, the choice of methods also reflects boundary judgments (Midgley, 2006). Hence, methods had to accommodate cultural safety concerns, and allow time for building trusting relationships and connections with homeless people, for learning, understanding, reciprocating, so that inquiry can genuinely progress "from within", with and for people. Therefore, this study entails both quantitative and qualitative approaches.

The quantitative part relied on the analysis of 176 coroners' reports related to people with "no fixed abode" from which I derived sobering results in terms of mortality and avoidable mortality (see chapter 5). However, this analysis did not merely provide a kind of contextual background. It marked the starting point for me to shift the scope and focus of the study toward the temporal space of life prior to death.

The qualitative part of the PhD initially relied on ethnography and fieldwork that extended from September 2019 to December 2022, in "Seed Town", with the Peeps. However, as my understanding and trusting relationships with the Peeps grew, ethnographic approaches evolved to include the use of performance ethnography and relational and collaborative (auto)ethnography as the privileged methods for addressing the issues of concerns in this study.

Performance ethnography (Conquergood, 1991; Denzin, 2003; Madison, 2020) stands apart in the ethnographic field. As outlined by Messac and al. (2013), what the term "ethnography" means varies across disciplines. In public health research, ethnography tends to refer to standardized protocols based on formal structured interviews that limit access to shared experiences with people in their everyday lives. In anthropology, critical ethnography strives to document context, process, and meaning to contribute to a more complex understanding of unequal power that damage health (Messac et al.,

2013). In contrast to both of these traditions, *critical performance ethnography* sprang from interdisciplinary work in the social sciences, performance arts, cultural studies, and critical theories. According to main theorists such as Conquergood (1991), Denzin (2003), and Madison (2020), the alliance between performance and ethnography offers both a distinct practice of doing the fieldwork (see chapter 6) and a creative way of mobilising larger audiences around critical issues through performance texts (e.g., drama). Attention is paid to the performative nature of social life, meaning its inter-relational, transformative, and embodied dimensions, rather than prioritising just the informative dimension (Conquergood, 1991; Madison, 2020). However, a performance ethnographic project is not merely an alternative way of knowledge translation but inscribes into a broader critical and democratic perspective. The project can be seen as an attempt to bridge theory and practice, communities, researchers, artists, audiences, distinct world views, voices, value systems, and beliefs so that they can be in a conversation with one another (Conquergood, 1991). Critical performance ethnography projects seek to challenge issues of power and injustice in the production of socio-cultural systems, and to invite more voices, audiences, and citizens to join the human dialogue for positive change (Conquergood, 1991; Denzin, 2003). Accordingly, the ethical and relational stance I took in this research, led me to collaboratively co-create a drama with the Peeps, centred on their concerns and aspirations. This is discussed, detailed, and presented in chapter 6.

The conventional approach of autoethnography draws upon 'the personal experience of the author/researcher for the purposes of extending sociocultural understanding' (Sparkes, 2000, p. 21). In contrast, collaborative and relational (auto)ethnography gives priority to whanaungatanga to explore disruptive contexts such as those stemming from many Māori homeless experiences, by collaboratively and meaningfully creating sense-making and a shared narrative (Ellis & Rawicki, 2013). This has led to a published article written with Daniel (one of the Peeps) toward healing and reconnecting processes with whānau through a cultural revision of the Western notion of Advance Care Planning (see chapter 7).

Chapter summary

Relational ethics culturally informed by Tikanga Māori values and principles, and critical CaST-oriented approach committed to relationality, holism, pluralism, human wellbeing, boundary critique, and uncertainty form the theoretical framework for this study. Combined, they offered a potential platform to create a "space of resonance" between Western and Māori distinct worldviews and systems

knowledge, research practices, and people, from which this study could develop with cultural humility (Danso, 2018) and responsiveness. This chapter "closes" the conceptual first part of this thesis. The second part of the PhD invites the readers into the exploration of the temporal space of life prior to death and the inquiry process. An overview of this second part is provided in the following pages. **Chapter 5** accounts for the first inquiry cycle and ends up with a published article related to the avoidable mortality of homeless people in Aotearoa New Zealand.

Overview of part II

Part II of this PhD thesis invites the reader into the temporal space of life prior to death and the research process itself. As previously stated in chapter 1, this study developed according to spiralling dynamics, underpinned by three overlapping cycles of learning-dialogue-relationships building-reflection-action/inaction. Table 5 (next page) shows the evolution and development of the study that shifted from exploring the mortality landscape of homelessness in Aotearoa New Zealand with a focus on premature mortality prevention and palliative care provision to exploring the temporal space of life prior to death under the guidance of the Peeps. The main elements of research practice and areas of literature related to the content and conduct of the study are highlighted by these cycles.

The first cycle focused on understanding the local context of homelessness and death inequalities and finding starting points for this study. At that stage, the objective was pre-determined and was concerned with understanding the barriers to healthcare utilisation that impede effective premature/avoidable mortality and quality palliative care provision. These two poles of inquiry, prevention and palliation, were not yet conceptualised as part of a comprehensive approach to death inequalities associated with homelessness. However, aligned with a CaST approach, I did not separate them into two distinct problems, enabling a move towards the temporal space of life prior to death. Essentially, cycle 1 confronted the invisibility of the deaths of homeless people and ever-present risk of dying.

From cycle 2 then cycle 3, the study explored the temporal space of uncertainty and contingence preceding death and until death and sought to understand how, within the contexts and circumstances of the Peeps' lives and experiences, with regard to distinct worldviews, and their own aspirations, their lives and existences could be meaningfully preserved and flourish. These two later cycles developed from the temporal space of life prior to death considering homelessness as complex life-threatening conditions associated with SHS (but not only), requiring a comprehensive healthcare approach as developed in chapter 3. In line with the overarching relational ethics principle and CaST approach, these cycles unfolded under the guidance of the Peeps, with and for them, and according to their priorities.

Part II is organised in three chapters (5, 6, and 7) corresponding to each cycle of this study. Each cycle ended up with a published or submitted article. The areas of literature related to the content and

conduct of this study have so far been partially reviewed. Additional analysis of the literature is provided in the narrative preludes and related articles. An important point is that the areas of literature relevant to the study were not limited to specific cycles but remained ongoing, allowing for a deeper understanding of te ao Māori while I progressed in the study, and facilitating continual updates to the existing literature on the topic.

Table 5: OVERVIEW OF THE DEVELOPMENT OF THE STUDY

Cycles and objectives	**Study focus**	**Research practice**	**Areas of literature related to the study content**	**Areas of literature related to the conduct of the study**
CYCLE 1 (2019-2020) **Mortality-Barriers to access to healthcare for effective premature mortality prevention and palliative care provision**	Understanding the local context Finding starting points	Volunteering at Cuppa Connection Companionship with the Peeps Conversations with professionals Identifying mortality data bases Data analysis Writing journal Analysis of the literature Reflection, learning	Mortality and avoidable mortality in homelessness populations Barriers to access to healthcare and palliative care for homeless people Homelessness Māori contexts (history, inequalities, homelessness, Te ao Māori, hauora, death and dying, palliative care) Suicide and homelessness Suicide in Māori contexts	Research methodology (mixed methods-CaST- decolonizing methodologies) Relational ethics Reflexivity Feminist theories Critical theory Critical ethnography Death studies
Article 1: Avoidable mortality within the New Zealand homeless population: We can do better!				
CYCLE 2 (2020-2022) **Toward awareness among health/allied professionals**	Under the guidance of the Peeps	Volunteering at Cuppa Connection Companionship with the Peeps Developing ethnographic drama project Searching for drama professionals Writing journal Analysis of the literature Reflection, learning	Politics of life and necropolitics Structural/cultural violence Social death Performance-based ethnography in health, homelessness, and indigenous contexts	Critical CaST Kaupapa Māori theory Critical performance ethnography Narrative medicine Community participatory based research
Article 2: 'Before it is too late': Street performance, life, death and homelessness in Aotearoa New Zealand				
CYCLE 3 (2021-2022) **Toward reconnection processes with whānau**	Under the guidance of the Peeps	Volunteering at Cuppa Connection Companionship with the Peeps Writing collaboratively Writing journal Analysis of the literature Reflection, learning	Advance Care Planning (ACP) and homelessness	Relational auto-ethnography Collaborative/relational ethnography
Article 3: Can Advance Care Planning (ACP) be a relational healing place for Indigenous homeless people in Aotearoa New Zealand?				

Chapter 5: Toward the temporal space of life prior to death of homeless people (cycle 1)

Narrative prelude

Aligned with the overarching principle of relational ethics and recognizing my limited understanding and lack of experience of the local context, an important aspect of my research practice during the first year of study was to enlarge perspectives and engage in a continuous learning process. The analysis of relevant literature and the engagement with the "ground" were an integral part of my inquiry approach. Essentially, I maintained a constant back and forth movement, fostering an open dialogue between the examination of the literature pertaining to the study's content and methodology, and the ground itself, which allowed for flexibility within the study process.

The "ground" encompassed three interrelated activities and engagements that I conducted conjointly. Firstly, my engagement with the Peeps as an informal doctor through volunteering at Cuppa Connection allowed me to encounter them in their own realities, through genuine practice of whanaungatanga, manaakitanga, aroha and whakaiti. Secondly, the insights shared by healthcare and social professionals who worked closely with homeless people constituted another realm that also informed my learning process and approach with the study. Lastly, there was the undeniable presence of death itself, which I consider as an active "actor" in this study, and one I witnessed through my immersion into the 176 coroners' reports associated with the deaths of homeless people. This immersion brought forth a range of unpredictable emotions, turmoil and thought-provoking questions. In the following sections, I provide an overview of each activity on the ground to explain the transformative shift that occurred throughout the first cycle. It is important to note that although presented separately for clarity, these activities were conducted concurrently, each informing the others and shaping the dynamic of the whole inquiry process. The article compounding the methodology, analysis, and results of the coroners' reports is presented at the end of this first narrative prelude, and closes the chapter.

Being an informal doctor

My engagement with the Peeps is detailed in chapter 6. Suffice to say that, following June's invite (see preface), I joined the team of volunteers (around 10) who met once a week in an open-air public carpark of Seed Town with homeless people to provide human and material (e.g., tents, blankets, hot meals) resources. In mid-2019, around 40 to 60 persons met weekly in the carpark but this approximated figure increased to more than 120 persons in mid-2020 after the establishment of the first national lockdown in response to the Covid-19 pandemic. The human landscape of Cuppa Connection was constantly changing. However, a group of women and men who lived on the streets of Seed Town or in their cars, the Peeps, were the centre of Cuppa Connection since June created the organization in 2016. The incentive behind Cuppa Connection was not to *give to* homeless people — "the rich giving to the poor (without recognising what they have taken from the poor)" (Ahmed, 2000, p.149) — in a philanthropic perspective of serving the "needy" which is a frequent endeavour within charities dealing with homelessness (Hodgetts et al., 2005). Rather, operating according to Tikanga Māori values, the primary objective of Cuppa Connection was relational, centred on the wellbeing and mana of people. Being deeply present — emotionally, physically, spiritually — whatever the weather, sharing and "chatting", building trusting relationships and connections with people, was an essential aspect, if it is not the first of our public gathering.

I easily noticed, however, that many people suffered various ailments (e.g., foot/dermatological conditions) affecting their wellbeing and/or their bodily mobility which is an essential condition of safety and survival when living on the streets. As a man retells: "You can't just lie down because of this and you know, like now I can't walk cause I mean no one else is going to walk for me, but the fact is, if you can't walk you're gonna die out there" (Håkanson & Öhlén, 2016, p.6). Most of the Peeps were disconnected from the healthcare system and were not enrolled with a GP, meaning that many people did not see a doctor for years. ED was the only point of contact, if at all. I proposed to June to provide homeless people and the Peeps with basic care in the carpark if they wished. June, homeless people, and the Peeps welcomed my proposition, despite the obvious absence of privacy in the car park. I became thus involved as an informal doctor, providing first aid such as dressing wounds or checking healthcare issues as needed. The photo below (Figure 5) illustrates a moment of care at Cuppa Connection.

Figure 5: CARING AT CUPPA CONNECTION (30 SEPTEMBER 2019)

Caring for the Peeps at the margins of the healthcare system profoundly transformed the study, albeit I did not realize it immediately. Indeed, the realisation came with distinctive and unique forms of responsibilities, obligations, and long-term engagement, that diverged from those stemming from a pre-determined research agenda, even though the latter seeks to be accountable for the Peeps and Māori communities. Through accepting my offer, the Peeps and I have built and nourished deep reciprocal relationships of trust, which initially revolved around their bodily and healthcare issues but extended far beyond this over time (see chapters 6 and 7). This trust resulted in a form of *companionship*, and in some cases even friendship (see chapter 7), that developed outside the confines of a strict and bounded research setting, fostering relational forms of understandings and genuine commitments as those that exist in companionship and friendship (Ellis, 2007; Leeuw et al., 2012; Tillmann-Healy, 2003). It is important to acknowledge the asymmetry of power relationship within this companionship with the Peeps, as the use of this term may hint. I make no claims here to equalise "differences" and blur distance and singularities between the Peeps and myself. Instead, being involved in companionship means acknowledging our foundational human interdependence as relational human beings and acting accordingly (Lévinas, 1961/1990, 1995).

At a practical level, assuming a role of informal doctor meant, for example, going above and beyond to find some sort of "solutions" that would genuinely accommodate each person's unique situation, priorities, decisions, and preferences, especially when healthcare issues overpassed what I could offer on the carpark with limited means. While we have many times navigated the healthcare system together with the Peeps, I also took upon myself to identify PHOs that would be open and receptive to enrolling the Peeps if they wished, ensuring they would not be subjected to burdensome bureaucratic procedures (e.g., evidence of an address) and judgmental attitudes. I also explored alternative free healthcare options beyond ED such as establishing a partnership with a pharmacy of

Seed Town enabling the Peeps to access free first aid medications (see chapter 6). However, it has always been the Peeps who guided me. I came to understand that their so-called "disengagement" from the healthcare system reflected more complex resistance and priorities than those highlighted in the existing literature on "access to healthcare". These resistances and priorities were deeply intertwined with processes of cultural disconnection and intergenerational trauma, often tied to vivid memories of the death of their loved ones, and the conditions surrounding them (see chapter 6). Regarding the long-term engagement inherent to companionship, I did not simply "leave the field". The Peeps and I maintain regular contact, with my phone still ringing for sharing or for some kind of support, and we continue to meet around a coffee for chats, even though Cuppa Connection has ceased its activity and my "fieldwork" has ended. These sustained relationships reflect the prioritization of the Peeps' wellbeing and the enduring bond we have forged, extending beyond the confines of academic research. It signifies a commitment to long-term engagement and acknowledges the reciprocal nature of our relationships as companions of this ongoing journey.

Insights from professionals

To foster a comprehensive and nuanced understanding of the local context and facilitate meaningful learning, I also placed a significant emphasis on building relationships with professionals to gain insights into the intricacies of homelessness, healthcare and end-of-life issues. Of particular importance was my commitment to acknowledge and honour Māori worldviews, including distinct perspectives on homelessness, death and dying, and health and wellbeing. I aimed to ensure that the study embraced a broad and meaningful approach toward the wellbeing of Māori homeless people within their own contexts, priorities and aspirations. As part of this effort, I eventually worked to develop collaborations with agencies that would share an interest in the topic and my approach.

Through personal relationships, the connections and support from my supervisors, and the network of June's relationships, I had the opportunity of visiting numerous healthcare settings, as well as social agencies tailored to homelessness, where I met with a range of health and allied professionals. I engaged in approximatively 50 informal conversations, ranging from one to three hours in length, with professionals working both in Seed Town and other regions of the country. Professionals working in regional hospices included doctors, nurses, a regional Māori Advance Care Planning coordinator, a Māori cultural advisor, social workers and a volunteer. I also met with doctors and nurses working in PHOs in Seed town. Professionals working in the homeless sector included social workers and managers of housing services (e.g., Housing First, Salvation Army, Māori organisations), men's and women's shelters, women refuge and addiction service, as well as

volunteers of charities. Lastly, I spent five days at Auckland City Mission (ACM) which has an extensive experience of working with and supporting homeless people. ACM provides advocacy, social services (e.g., emergency and permanent housing, food bank, drop-in centre) and healthcare services as a PHO, for marginalized people in the Auckland region.

The literature on homelessness and healthcare consistently emphasizes the fragmentation of the health system and the disconnection between healthcare and social services as an important structural factor contributing to unmet healthcare needs. Research has highlighted the division between social services engaged with homeless people, and mainstream healthcare providers. The later often lack understanding of the complex challenges faced by homeless people, which leads to a lack of awareness regarding the end of life (De Veer et al., 2018; Klop et al., 2018; Krakowski et al., 2013; Shulman et al., 2018; Stajduhar et al., 2019). Further, discussing death and dying with sensitivity is difficult, and can even be considered taboo. The lack of medical information combined with social/community workers' limited experiences and skills in palliative care has also been highlighted (Davis-Berman, 2016; Hudson et al., 2017; Krakowski et al., 2013; Petruik, 2018; Shulman et al., 2018). Additionally, research informed by critical theory underscores the significance of underlying ideologies, beliefs, and practices that inform services policies and responses to homelessness (Bungay, 2013; Dej, 2016). These responses often align with normative, middle-class, white expectations, particularly regarding substance use. As a result, professionals are often trained to work within a recovery model that may not adequately facilitate the identification and provision of palliative care for homeless people (De Veer et al., 2018; Hudson et al., 2017).

The insights I gathered from the professionals I met, with notable exceptions, particularly those working at ACM, represented to various degrees a mix of perspectives found in the literature. Homelessness was often simplified as a "lack of housing" issue. The focus was primarily on substance and alcohol use as the major health concern, overshadowing other concerns. The urgency seemed to lie in recovery, rehabilitation, and housing provision. Many social/community workers in Seed Town did not seem to express significant concerns or acknowledge the broader issues of premature and avoidable mortality, and death of homeless people more generally. However, I understand the challenges that come with discussing death and dying, especially in the current situation where professionals were not familiar with me as a stranger and new migrant to Aotearoa New Zealand. Further, although there were exceptions, my conversations with professionals often did not reflect the processes of cultural disconnections from whānau, iwi and hapū, and spiritual resources, as distinct aspects of homelessness for many Māori people. It seems that homeless people tend to be homogenised in a single entity. Professionals in the palliative care sector had rarely, if ever, encountered persons experiencing homelessness facing the end of their lives. However, I was warmly

welcomed and given the opportunity to visit hospices, fostering reflection, as exemplified by the following excerpt, extracted from my fieldwork diary.

> " The hospice I visited today was a stark contrast to my previous experiences with palliative care and hospices in France. This one was housed in a vast, brightly lit building with large bay windows, yet it felt strangely empty and eerily quiet. The silence was deafening, and the "opulence" seemed out of place. I felt intimidated and disconnected from the world outside, the noise of everyday life and people. I wondered how the Peeps would feel if they were given the option to stay in a hospice like this. It seemed so disconnected from life, as if death was being tucked away in a box of silence. As I reflect on my visit, I'm not sure if I'm going in the right direction with my inquiry (excerpt of diary, 2019).

The Covid-19 pandemic and subsequent social distancing measures and lockdowns added additional difficulties to what seemed like a lack of awareness among professionals, making difficult to establish collaborative relationships on issues surrounding the death of homeless people.

The invisibility of death

Though the death of homeless people was often absent from professionals' awareness, so it also was when I sought to identify reliable sources of mortality data. The issue of invisibility and underrepresentation of homeless deaths in administrative databases is not unique to my research. It is a recurrent phenomenon experienced by many researchers in this field (Aldridge et al., 2019). I spent significant time in exchanges with the Ministry of Health, former DHBs and a funeral director, to understand how people experiencing homelessness could be identified in administrative mortality/health data sets. It was a puzzle. Clearly, I was navigating through obscurity. As the detailed article covering the methodology, analysis, and results of the coroners' reports is presented at the end of this chapter, I do not delve into the details here. Instead, my intention is to discuss the impact of that multiple reading of the coroners' reports, which revealed the stark reality of death among homeless people, and how this stark reality affected the development of the study. These readings brought to light tensions between the invisibility of death of homeless people and the urgent need to address sharp death inequalities, contributing to modify the trajectory and focus of the study.

Fincham et al. (2008), while conducting research on suicide, have discussed the emotional impact of working with coroners files as secondary sources of data, meaning data not collected directly by the researchers. A point these authors have discussed related to the strategies they adopted to cope with the upsetting impact of the reading, such as adopting flexible working time of reading, or debriefing within the researchers' team (Fincham et al., 2008). Similarly, in New Zealand, McKenzie et al. (2017), reported experiences of emotional exhaustion by researchers arising from the cumulative exposure to data — in that case clinical notes related to suicide attempts — as well as

feelings of frustration with the healthcare system. Similarly to Fincham et al. (2008), I profoundly felt the emotional impact of reading multiple times the coroners' reports that included many details, and were not anonymised. Indeed, it was not only a matter of reading about the death of people, but also about suffering, deep emotional distress, suicide of minors trying to escape foster care, or sub-standard healthcare delivery. It also was a reading that spoke of the breach of our collective responsibilities toward homeless people, their families and whānau, and the silencing of injustice in regard to their death. Interestingly, Fincham et al. (2008) have interrogated the possibility for the emotions generated by secondary death-related data to have "epistemological significance" (p.859) for the conduct of research. In regard to their specific study, they concluded that "there is no emotional interaction beyond what we set up ourselves" (p.861) in terms of coping strategies.

In contrast to Fincham et al. (2008), I attached epistemological and ethical significance to the emotional turmoil and thought-provoking questions that arose from the reading and analysing of the coroners' reports. These reports and the stories they entailed contributed to modify my understanding, perspective and approach to the study. Numerous questions have emerged, but some persistently recured: What crucial elements are we persistently overlooking in our understanding of how to prevent the deaths of homeless people? What key factors elude our comprehension and remain unaddressed in our research and within the healthcare system? Where should our focus lie as we strive to break the cycle of premature, avoidable and unjust deaths of homeless people? Furthermore, reflecting on the potential impact of "small acts", I wonder how they might have influenced the trajectory towards suicide, offering hope, instilling feelings of self-worthiness and fostering a sense of belonging? While I have no immediate answers to these interrogations, it remains crucial that we continue asking them because they are relational and ethical questions. These questions relate to our human finitude, and our interdependence and inter-relationality to maintain and sustain life. They also reflect the forgiveness of our foundational vulnerability, and the disruption of our relational responsibility toward all people.

Alongside my companionship with the Peeps, I realized that the pervasive "risk of dying" among homeless people is often overlooked in research and by health professionals. The conventional approach to this problem tends to be divided into two separate realms: prevention of premature mortality and palliative care responses. However, this approach fails to acknowledge the heightened risk of death that homeless people face and the precariousness of their lives. The omnipresence of death in their daily struggles defies linear principles, and compels us to acknowledge the fragile, tenuous, and uncertain interval between life and death intertwined with homelessness. It is imperative that we allocate careful attention to this intricate and nuanced reality. Reflecting on these insights, I started to ponder the significance of genuinely listening to what holds

meaning and significance for people experiencing homelessness, within their unique contexts and own priorities. By acknowledging and honouring their voices and experiences, we can embark on a meaningful pathway towards fostering their wellbeing and enabling their lives to flourish.

The early development of the study was influenced by the careful and respectful reading and analysis of the coroners' reports. This process followed a reverse order compared to more conventional end-of-life research, starting from death and moving towards life. This approach facilitated a shift towards a depolarised, holistic, and uncertain perspective, aligning with a critical CaST approach. It also played an important role in conceptualising the temporal space of life prior to death, highlighting homelessness as complex life-threatening conditions associated with SHS. While emotions are often seen as potential biases to be overcome in post-positivist research traditions, it is important to recognise that "bias does not necessarily mean that it is subjective; bias can be the consequence of interests, more or less conscious, but it can also be the result of ethical choice" (Martin-Baro, 1994, as cited in Hodgetts et al., 2010, p.5). As a researcher, a health professional and a relational human being, I felt a profound responsibility to humbly strive to comprehend at least a fragment of the sobering findings that emerged from the analysis of the coroners' reports. The omnipresent "risk" of dying necessitates greater visibility and calls for compassionate, inclusive, and relational responses.

The first cycle of this study has been a transformative journey of learning, confronting distinct realities and challenging assumptions, all through active engagement with various aspects of the research on the ground. As I conclude this chapter, it is now time to invite the readers into the article that presents the findings from the coroners' reports. The article draws attention to the premature and avoidable mortality of homeless people. This is in line with the aim of this study, which is to raise awareness of the inequalities surrounding the death of homeless people in Aotearoa New Zealand. The article is cited as: Charvin-Fabre, S., Stolte, O., & Lawrenson, R. (2020). Amenable mortality within the homeless population in Aotearoa New Zealand: We can do better! *The New Zealand Medical Journal, 133* (1527), 26-38. The manuscript is reproduced with the permission from the New Zealand Medical Journal.

Upon reading the article, the reader may observe a disparity between the estimation of people experiencing homelessness in Aotearoa New Zealand mentioned in the article and the figures provided in the introduction. This discrepancy arises from a 2021 updated revision of the methodology employed by the author (Kate Amore) of the research in calculating the estimation.

Amenable mortality within the New Zealand homeless population: We can do better!

Introduction

Homelessness is an increasing and complex worldwide issue. New Zealand, like other higher income countries, faces a growing prevalence of homelessness. Estimates indicate that between the 2006-2013 censuses, the absolute number of homeless persons increased from 33,000 to 41,000 (an increase of 24.2%), compared to the population growth during the same period of 5.3% (Amore, 2016; Statistics New Zealand, 2013). Definitions of homelessness vary across countries depending on the social, cultural, and legal context in which they operate (MacKenzie, 2012).The New Zealand Coalition to End Homelessness [NZCEH] (2009) adopted a broad definition of homelessness based on a graduation of housing insecurity, ranging from those living rough or in their cars to those living in unhabitable dwelling, in temporary accommodation or in overcrowded households (NZCEH, 2009). Widening the definition of homelessness means that "hidden homelessness" is accounted for and better illustrate the health inequalities that impact mainly Māori and Pasifika peoples among this population (NZCEH, 2009).

Health inequalities that affect the homeless population worldwide contribute disproportionally to a dramatic premature mortality compared to the housed population. Although, the mortality rate varies between studies, typically homeless people die 15 to 30 years younger than their housed counterparts (Aldridge et al., 2019; Fazel et al., 2014; Medcalf &Russell, 2014). A New Zealand hospital-based study looked at risks factors for mortality of a cohort of homeless patients, which included 126 deaths with a median age of death of 52.6 years (Thornley & Marshall, 2016). Many of the patients had a record of cardiovascular disease and diabetes as well as mental health issues and substance misuse.

Premature mortality results from a complex combination of medical conditions often related to severe and chronic comorbidities, and the consequences of social exclusion shaped by homelessness- that is, marginalisation and stigma, loneliness, violence, and adverse living conditions. Consequently, homeless people experience poor and irregular access to healthcare, unmet care needs, delays in clinical presentations, and high use of emergency departments (Baggett et al., 2010; Corrigan et al., 2015; Lebrun-Harris et al., 2013; Martins, 2008). Yet, access to high quality health care improves many health outcomes and can reduce the number of premature deaths (Barber et al., 2017). The concept of *amenable mortality* as an indicator of performance (e.g., weakness or strength) of the health system has been debated for decades as a way to determine the boundaries

of health interventions (Nolte & McKee, 2004). The New Zealand approach has been to develop a measure of amenable mortality that reflects the performance of the health care system, excluding a wider and intersectoral approach based on the social determinants of health (Ministry of Health, 2010). Amenable mortality is an important indicator of health care access and quality, which serves to identify areas of healthcare concern and support specific healthcare initiatives for diseases where effective intervention exist (Ministry of Health, 2010). The classification of causes of death amenable to clinical interventions is based on expert reviews of medical knowledge and technologies and the causal epidemiology of diseases. To improve health outcomes within the population and reduce health inequalities, the New Zealand amenable mortality list has been updated in 2016 as part of the System Level Measures and the refreshed New Zealand Health Strategy (Ministry of Health, 2018).

The objectives of this present study are to use coroners' reports to describe the context surrounding the deaths of homeless people in New Zealand and to determine the proportion of deaths that could be considered amenable to healthcare intervention.

Method

Data collection

A critical challenge in reporting the deaths of homeless people is the lack of a systematised source of statistics for this population. The Mortality Collection classifies all causes of death registered in New Zealand using the International Classification of Diseases (10th; ICD-10, WHO, 2016). The inclusion of the ICD-10 coding for homelessness (Z.590) has only recently begun to be used for identifying or registering the deaths of homeless people. These data are incomplete, and so the Mortality collection is not a viable source of homeless mortality data. Further, within District Health Boards (DHBs), the use of the Z.590 code has not been generally adopted. How DHBs record " no fixed abode" is unclear and varies between different hospitals.

Instead, the utility of medico-legal databases is recognised worldwide as a valid source of data for public health endeavours, especially for accessing data on populations that are difficult to reach (such as homeless people or prisoners) or to determine the nature, distribution and determinants of amenable deaths such as suicide (Andrews & Kinner, 2012; Bugeja et al., 2016; Sinyor et al., 2017). Under the New Zealand Coroners Act 2006, deaths must be reported to the coroner if the death appears to a) be without known cause, self-inflicted, unnatural, or violent, b) have occurred as a potential result of a medical procedure, c) have occurred while someone was in official custody or care or d) have been in relation to which no death certificate was issued (New Zealand Coroners Act, 2006). The Case Management System is the New Zealand database recording systematically all deaths reported to coroners since 2007. The Information Advisor of the Coronial

Office of Wellington provided data on all coronial deaths with "no fixed abode" criterion at the time of death. One hundred seventy-six full-text (176) coroners' findings reports were identified and released to SCF (first researcher). This included all the deaths of people with no fixed abode that were reviewed by the coronial service from January 2008 to June 2019.

Data analysis

Five cases did not meet the criteria for homelessness. The study sample is thus based on 171 coroners' reports. Demographic information was extracted from each report. Since ethnicity was not reported individually in the coroner's' reports, this information is not available. The circumstances surrounding the deaths were obtained from the elements of information accompanying the coroners' findings: extracts of police and toxicology reports, forensic examination, witnesses' statements, and elements of medical history provided by DHBs, community services or general practitioners. The majority of deaths due to natural causes were not followed up by a coroner's inquiry. Only a few inquiries in patients who died from natural causes (n=10) were considered necessary by the coroners. Detailed medical information for all the deaths included due to natural causes was therefore not available for analysis. Conversely, deaths by suicide were assessed and ascertained after a long and detailed coroner's inquiry, enabling a detailed analysis. Underlying causes of death, based on forensic examination findings, were coded using ICD-10 classification. For the purposes of this study, drug and alcohol related deaths were coded using the proposal from Randall et al. (2009). All deaths directly related to drug or alcohol use were coded as accidental poisoning (X40-X45) or related to mental and behavioural disorders (F10-F16, F19, F55). The causes of amenable mortality were revisited, combining the lists published recently by the New Zealand Ministry of Health (2018), and by the Office of National Statistics in the United Kingdom (Otalunde et al., 2016). This latter list was the main basis used to develop the amenable mortality list common to all the OECD countries (OECD, 2019). It is based on a previous definition of amenable mortality that was developed for use in the Australian and New Zealand context (Walsh & Grey, 2019). Given this common background and that aetiologies of diseases, risk factors and the healthcare standards are likely to be similar, the combination of the two lists was regarded as applicable. Variations across amenable mortality lists relies on different sub-categories within group of diseases, and depend on the local epidemiology of diseases, the evidence of effectiveness of the intervention, as well as the quality of the cause of death coding procedure. For example, pneumonia not related to pneumococcal infection was removed from the New Zealand list because the quality of coding was deemed inadequate by the expert panel (Ministry of Health, 2010). Health inequalities are extreme for the homeless population since they are marginalised in terms of accessibility to

healthcare. Hence, the list that we have used, was enlarged accordingly to capture all relevant amenable conditions. The threshold is set at 75 years of age for amenable deaths other than by accident or suicide, due to the frequent difficulty of assigning a single cause to deaths beyond this age in the general population.

Results

Sociodemographic characteristics

Of the 171 homeless people's deaths reported to the coronial office, the majority were males (n=145, 84.7%), with females accounting for 15.2% (n=26). The mean age of death regardless of cause or gender was 45.7 year; 46.7 years for females and 44.8 years for males. The average age of death by accident and suicide was dramatically young, 36.5 years and 38.2 years respectively (Table 6). At the time of death, a small minority (n= 25) of homeless people were employed (14.6%). The majority of persons (n=91) were unemployed (53.2%) with a small number receiving a benefit (10.5%). Eleven homeless people were retired (6.43%). The information was unavailable for nine individuals (5.2%) and not specified in 17 cases (9.94%).

Underlying causes of death (Table 6)

The main cause of death was from natural causes (42.6%). Among these, deaths from cardiovascular diseases were the most frequent (n=33), followed by infectious diseases (n=9) and from acute alcohol toxicity (n=7). Three cases of death by hypothermia were also reported. Suicide, ascertained by clear evidence of an intention to end one's life, accounted for nearly one third of all deaths (n=49). Thirty-three deaths (19.2%) were classified as accidental mainly attributed to a vehicle crash or a pedestrian struck by a vehicle or a train (n=12), a fall from a height (n=7), a fire (n=4) or a drug overdose (n=4). Deaths from an unascertained nature due to an advanced decomposition of the body or the impossibility to precisely determine the cause of death accounted for 5.2 % of all deaths. Seven deaths were the consequence of criminal homicides.

Table 6: UNDERLYING CAUSES OF DEATH AND AMENABLE MORTALITY BY AGE GROUP (N=171).

Age Group	Suicide N=49 (28.6%)	Accident N=33 (19.2%)	Natural N=73 (42.6%)	Homicide N=7 (4.09%)	Unascertained N=9 (5.2%)	Total cause N=171	Amenable N=118/153 (75.8%)
Mean age (SD)	38.2 (14-61)	36.5(13-57)	54.5 (17-78)	44.2 (27-64)	44.7 (25-57)	45.7 (13-78)	45.4 (13-71)
10-14	1	1	0	0	0	2	2
15-19	1	0	1	0	0	2	2
20-24	7	5	0	0	0	12	12
25-29	4	3	1	1	1	10	5
30-34	4	5	1	1	4	15	5
35-39	9	5	3	0	2	19	13
40-44	7	5	4	3	0	19	12
45-49	6	3	12	0	0	21	15
50-54	6	2	14	0	1	23	18
55-59	3	4	15	0	1	23	16
60-64	1	0	9	2	0	12	7
65-69	0	0	6	0	0	6	6
70-74	0	0	5	0	0	5	5
75+	0	0	2	0	0	2	0

Circumstances of death and amenable mortality (Table 7)

Information on the location of death was available for 168 deaths. The most common place where death occurred, regardless of the cause of death, was public spaces such as streets, doorways, parks and reserves, forests, beaches, harbours or rivers (56.1%), followed by private cars or campervans (14%), private housing but mainly garages (12.8%), hospital (8.7%) and temporary accommodation such as motels, hostels and backpacker accommodation (5.26%).

Information included in the coroners' findings reports was sufficient for assessing amenable mortality in 153 cases of death. According to the amenable mortality list, the categories of death from unascertained and criminal nature were excluded (n=16) as well as death from natural causes that occurred beyond 75 years old (n=2). The contribution of amenable death to the overall mortality of homeless people was extreme with 75.8% of death (n=118) considered as amenable to timely and effective healthcare intervention. The mean age of amenable death was 45.4 years old (Table 6). In the group aged up to 24 years, the prevalence of amenable mortality was 100%, due to suicide and

accidents (Table 6). Among amenable deaths, 45.7 % (n=54) resulted from a natural cause, especially due to cardiovascular disease (n=33), alcohol-related death (n=7) and pneumonia (n=6). A single case was cancer related; however, the post-mortem forensic examination diagnosed four cases of cancers at an advanced stage. Suicide represented 41.5% of the amenable death (n=49), and accidents related to a vehicle crash or pedestrians struck (n=12) or resulting from fire effects (n=3) accounted for 12.7% of all amenable deaths (Table 7).

Nearly half of the amenable deaths from natural causes occurred in public spaces (46.1%), followed by deaths in private dwellings (21.1%), in cars or campervans (17.3%), in hospital (15.38%) and lastly in temporary accommodation (7.6%). Most of the homeless persons who died from an amenable death were alone at the time of death and were found deceased by witnesses sometimes several months after that death occurred.

Table 7: AMENABLE MORTALITY WITHIN THE HOMELESS POPULATION

Group	Conditions	Age	ONS UK*-2016	NZ MOH**-2016	Amenable Mortality (N=118)
Infections	Tuberculosis	0-74	A15-A19, B90	A15-A16	0
	Meningococcal disease	0-74			0
	Pneumococcal disease	0-74	A40.3, G.001, J.13	A40.3, G.001, J.13	
	HCV	0-74	B17.1, B18.2	B17.1, B18.2	0
	HIV/AIDS	all	B20-B24	B20-B24	0
	Other selected bacterial infections	0-74	A.38-A41, A46, A48.1, B50-B54, G00, G03, J02, L03		
Neoplasms	Stomach	0-74	C16	C16	0
	Colon	0-74	C18		1
	Rectal	0-74	C19-C21	C19-C21	0
	Bone and cartilage	0-74		C40-C41	0
	melanoma	0-74	C43	C43	0
	Female breast cancer	0-74	C50	C50	0
	Cervical	0-74	C53	C53	0
	Uterus	0-74	C54-C55	C54-C55	0
	Prostate	0-74		C61	0
	Testis	0-74	C62	C62	0

	Thyroid	0-74	C73	C73	0
	Hodgkin	0-44	C81	C81	0
	Acute lymphoblastic leukaemia	0-74	C91, C92.0	C 91	0
	Liver	0-74	C22		0
	Mesothelioma	0-74	C45		0
	Bladder	0-74	C67		0
	Benign neoplasms	0-74	D10-D36		0
	Lip, oral cavity, pharynx	0-74	C00-C14		0
	Oesophagus	0-74	C15		0
	Trachea, bronchus, lung	0-74	C33-C34		0
Endocrine and metabolic	Diabetes mellitus	0-74	E10-E14	E10-E14	2
	Disease of thyroid	0-74	E00-E07		0
	Addison's disease	0-74	E27.1		0
Drug use disorders	Alcohol related disease	0-74	F10, G31.2, G62.1, I42.6, K29.2, K70, K73, K74 9excl. K74.3-K74.5), K86		7
	Illicit drug disorders	0-74	F11-F16, F18-F19		0
Neurological	Epilepsy	0-74	G40-G47		0
Cardiovascular	Rheumatic and other valvular heart disease	0-74	I01-I09	I01, I05-I09, I33-I37	0
	Hypertensive disease	0-74	I10-I15	I10-I13	1
	Ischaemic heart disease	0-74	I20-I25	I20-I25	19
	DVT with pulmonary embolism	0-74	I26, I80.1-I80.3, I80.9, I82.9	I26	3
	Atrial fibrillation and flutter	0-74		I48	0

	Heart failure	0-74		I50	6
	Cerebrovascular disease	0-74	I60-I69	I60-I69	1
	Aortic aneurysm and dissection	0-74	I71		3
Respiratory	Influenza	0-74	J09-J11		0
	Pneumonia	0-74	J12-J18		6
	COPD	0-74	J40-J44	J40-J44	0
	Asthma	0-74	J45-J46	J45-J46	2
Digestive disorders	Gastric and duodenal ulcer	0-74	K25-K28	K25-K27	3
	Acute abdomen, appendicitis, intestinal obstruction, pancreatitis, hernia	0-74	K35-K38, K40-K46, K83, K85, K86.1-K86.9, K91.5		0
	Cholelithiasis	0-74	K80	K80	0
Genitourinary disorders	Renal failure	0-74	N17-N19	N17-N19	0
	Nephritis and nephrosis	0-74	N00-N07, N25-N27		0
	Obstructive uropathy and prostatic hyperplasia	0-74	N13, N20-N21, N35, N40, N99.1		0
Injuries	Transports accidents	All	V01-V99	V01-V99 (excluded trains)	12
	Accidental falls on same level	All	W00-X59	W00-W008, W18	0
	Suicide	All	X60-X84, Y10-Y34	X60-X84	49
	Fire (burns)	All		X00-X09	3
	Homicide/Assault X85-Y09, U50.9	All	X85-Y09, U50.9		0

ONS UK: Office for National Statistics United Kingdom; NZ MOH**: New Zealand Ministry of Health.*

Modified from sources: Ministry of Health, 2018 and Otalunde et al., 2016.

Suicide (Table 8)

One of the main causes of death was suicide, accounting for 28.6% of all deaths (Table 6). In those under 44 years of age, over two-thirds of deaths were due to suicide (67.3%). Homeless persons who self-harmed were found mainly in public spaces (67.3%) or in their private vehicles (12.2%), while 10.2% died in temporary accommodations and 8.16% in private garages. One person died in hospital from the direct consequences of suicide. Hanging was the most common method used (61.2%). The coroners' inquiries have revealed that 73.4 % of homeless persons who committed suicide were diagnosed with mental health issues, mainly from alcohol or drug misuse and depressive mood disorders. However, the proportion of homeless persons treated for psychiatric disorders was less than a half (46.9%). In addition, there was only evidence of recent contact with health professionals in just under a quarter of cases (24.4%). In the majority of cases (40.8%), the final contact was up to one year or more prior to death, and 22.4% of homeless persons had no contact at all with health professionals. References to lifetime suicide ideation and past suicide attempts were drawn from statements from relatives and health professionals. Nearly 70% of homeless persons had communicated suicide intent in their lifetime (69.3%), and 28.5% had evidence of prior self-harm. In nearly 70% of cases, homeless people have experienced significant and multiple stressful and traumatic life events.

Table 8: CIRCUMSTANCES OF DEATH BY SUICIDE

	N=49	%
Socio-demographic		
Age, years, median range	38.2 (14-61)	
Male gender (% male)	41	85.7
Clinical diagnosis		
Psychosis	5	10.2
Bipolar disorder	5	10.2
Depressive illness	23	46.9
Problematic alcohol use	18	36.7
Drug use (casual/regular)	19	38.7
No history of mental health issues	8	16.3
Other	2	4
Unknown	3	6.1
Current or past treatment for mental health issues	23	46.9
Past expression of suicide thoughts and behaviours		

Communicated suicide intent-lifetime	34	69.3
Communicated suicide intent-last year	10	20.4
Suicide attempt-lifetime	14	28.5
Suicide attempt-last year	6	12.2
Suicide notes	2	4
Contact with health professionals		
Contact up to 1 year	6	12.2
Contact last month	12	24.4
Contact last year	14	28.5
No contact at all	11	22.4
Unknown	5	10.2
Suicide method		
Hanging	30	61.2
Self-poisoning	10	20.4
Jump/fall	5	10.2
Other methods	4	8.1
Suicide location		
Public space	33	67.3
Vehicle	6	12.2
Temporary accommodation	5	10.2
Private dwelling	4	8.1
Hospital	1	2
Stressful life events		
Any events	34	69.3
Relationships breakdown	12	24.4
Financial problems	12	24.4
History of legal issues	7	14.2
Conflict with other persons	7	14.2
Bereavement	5	10.2

Discussion

The main findings of this study are the devastating and dehumanising consequences of homelessness that result in premature and preventable deaths. The mean age of death of homeless persons identified in the sample as having “no fixed abode” at the time of death was over 30 years

less than in the New Zealand housed population, with an overall mean age of death of 45 years, reduced further to 38 years in cases of suicide (Statistics New Zealand, 2015b).The vast majority of deaths occurred in public spaces or in private vehicles. Just over three quarters of homeless persons died from conditions amenable to timely and effective healthcare interventions, mainly from natural causes of death and suicide.

Our findings are consistent with previous results showing that premature and amenable mortality associated with homelessness is considerable, although exact comparisons cannot be made due to the variety of data sources and definitions of homelessness (Aldridge et al., 2019; Page et al., 2012; Morrisson, 2009). However, congruent to our results, prior homeless coronial samples indicate an average age of death of 46 years for all causes (Page et al., 2012) and from nearly 36 to 39 years by suicide (Arnautovska et al., 2014; Sinyor et al., 2017). Cross-sectional studies of homeless deaths identified by linking hospital admissions and mortality data in England and New Zealand found a mean age of death of 52 years that remains extremely young (Aldridge et al., 2019; Thornley & Marshall, 2016). These studies included homeless patient samples who had been hospitalised and therefore may have benefited from medical follow-up.

The amenable mortality burden uncovered in our study is significantly higher than in a UK study that assessed this proportion to be approximatively one-third (Aldridge et al., 2019). The UK study focused on the deaths of homeless patients admitted to hospitals that provided links with community healthcare services. Further, our findings were based on an extended list of amenable causes of death in a way that more clearly reflects the medical conditions associated with homeless deaths. The difference between the two amenable mortality lists was relevant in 23 cases and was mainly related to alcohol diseases, acute and treatable pneumonias, and specific cardiovascular diseases (e.g., heart failure and aortic dissection). We reported minimal rates of diabetes and cancers, which contradicts previous international and New Zealand hospital-based studies (Aldridge et al., 2019; Thornley & Marshall, 2016). It is likely that many such cases would not be reported to the coroners, thus illustrating the differences in sampling. The magnitude of social isolation and disconnection from the health system, combined with chronic psychological distress and unstable life conditions, negatively affects the health-seeking behaviours of homeless people (Omerov et al., 2020; White & Newman, 2015). For homeless people, the difficulties in accessing basic human needs compete with the drive to access health and operate as significant additional stressors to receiving care (Omerov et al., 2020). Further, It is likely that the patients with “no fixed abode” cannot be registered with a general practitioner because of a lack of address and that the cost for the co-payment within primary care is a further barrier to accessing regular care. Our findings are sadly

aligned with extant literature and reiterate the pressing need for improving the accessibility to healthcare for homeless people (White & Newman, 2015).

Of particular concern, and in line with other findings, suicide was prevalent amongst homeless youth and young adults (Arnautovska et al., 2014). In addition, the prevalence of lifetime suicide ideation (69.3%) was significantly higher than those of depressive disorders (46.9%). Yet, in the context of homelessness, research identifies that suicide ideation is a more sensitive indicator of acute risk of suicide than depressive symptomatology, in comparison to the general population (Coohey et al., 2015; Fitzpatrick et al., 2007; Prigerson et al., 2003). Abuse and trauma especially is recognised as being major pathways to homelessness and strong predictor of suicide ideation among homeless adults and youth, which is intensified by different sources of emotional distress when living on the streets (Coohey et al., 2015; Moskowitz et al., 2013; Panadero et al., 2018; Prigerson et al., 2003). We found that nearly 70 % of cases had evidence of stressful and traumatic life events that reverberate through the rate of suicide ideation we uncovered. Hence, we would argue assessing suicide ideation should be part of routine screening provided by health providers in contact with homeless patients.

The strengths of this study include detailed data on the deaths of a group of patients who are often hard to identify from routine data sources. Our sample included homeless persons who did not receive regular healthcare, and this reflects the considerable challenges of meeting the healthcare needs among this population. It has been argued that the concept of amenable mortality suffers from a lack of accurate determination of the underlying cause of death (Barber et al., 2017). By using findings from forensic examinations, this pitfall has been avoided. The study has some limitations. The study focused on a specific subset of homeless people identified as having “no fixed abode” at the time of death. People living in transitional housing, motels or private dwellings are provided with an address and have not been identified. Thus, our findings are relevant to those who were the most isolated and deprived in terms of support and access to healthcare, as is suggested by the extremely low rate of deaths in hospital settings for a population without a home. It is also conceivable that some relevant coroners’ reports could have been missed. The proportion of natural causes differs significantly from previous hospital-based studies in England and New Zealand that evidenced cardiovascular diseases, cancers and respiratory diseases as being the main underlying causes of deaths (Aldridge et al., 2019; Thornley & Marshall, 2016). Our sample framing relied on deaths that must be legally reported to coroners due to their violent or undetermined causes, and which represented nearly half of all deaths. This has likely led us to underestimate the contribution of natural causes of deaths to the overall mortality. Ethnicity being not individually reported on the

coroners' findings, means that data regarding Māori and Pasifika people, who are mainly impacted by homelessness within New Zealand, were not available (Amore, 2016).

Implications and need for future research

Our findings carry important implications for the development of health policy to enable earlier identification of homeless patients at high risk of premature mortality. This involves enhancing access to care, as well as providing the continuity and quality of care for homeless people with life-limiting conditions. Considering cardiovascular disease and suicide are leading causes of amenable mortality, regular access to a source of care is an imperative for this population. Within primary care, access to homeless-tailored services that emphasise outreach programs and free care delivery have shown positive outcomes in terms of accessibility and continuity of care, and should therefore be facilitated (Jego et al., 2018). Components of an effective response should also promote a holistic and patient-centred approach (or whānau-centred approach if appropriate) to support self-esteem recovery (Omerov et al., 2020). Treatment plans that actively encourage the participation of the homeless patients are needed to ensure adherence to care and follow-up. A first step in this direction could be to implement homeless-sensitive care training programmes for health providers within primary care and emergency departments, with special attention given to suicide ideation identification. For homeless patients with mental health issues or dual diagnosis, assertive community treatment seems the most encouraging response regarding regularity of health contacts and housing stability (De Vet et al., 2013). That said, many homeless people are not mentally ill or substance users. Future research should assess more specifically heath care utilisation and access barriers in various settings and for different sub-groups of the homeless population. Lastly, this study has also provided the opportunity to highlight the lack of systemic capture of homelessness through different administrative data sets, other than by using a reductive identification of homeless persons by the "no fixed abode" criterion. Equally important, the use of the Z.590 code should be encouraged within DHBs, including during the completion of the Medical Certificate of Cause of Death, if we are to understand how to adequately and effectively improve the healthcare of the homeless population. This would be facilitated if the Law Commission's recommendations for modernising the legislation relating to death, burial, cremation and funerals in New Zealand became the responsibility of the Ministry of Health (New Zealand Law Commission, 2015). This should allow for a better recording of homeless deaths and would also ensure better recording of ethnicity data.

Conclusion

Homeless people experience considerable challenges when accessing the healthcare system, as uncovered by the dramatic rate of amenable mortality. Our findings outline the pressing

necessity to implement specific models of care that are designed to meet the social and healthcare needs of homeless persons and address the significant health inequalities they face. This research highlighted an extreme situation of social isolation and disengagement from the healthcare system that point out the challenges for accessing regular sources of care and for receiving comprehensive and culturally sensitive care. Future work should provide a more comprehensive picture of healthcare utilisation for the diverse groups of homeless patients, to assist policy decisions as part of comprehensive and effective response to homelessness.

Chapter conclusion

In addition to its academic contributions, the article " Amenable mortality within the homeless population in Aotearoa New Zealand: we can do better!" has garnered significant attention from the media. The findings presented in this article resonated with various stakeholders, resulting in significant media coverage (e.g., interviews of myself diffused on national TV News, radio, and newspapers) and sparking discussions within the public sphere, especially with the Ministry of Health (see for example, Broughton, 2020; Miller, 2020; Russell, 2020; Satherley & Carron, 2020). Furthermore, the implications of this article also reached the New Zealand Coronial Office. In line with the New Zealand Coroners Act 2006, that states that "a coroner's role in relation to a death is […] to make recommendations or comments that, in the coroner's' opinion, may if drawn to public attention, reduce the chances of the occurrence of other deaths in circumstances similar to those in which the death occurred" (New Zealand Coroners Act 2006), recommendations were made to the New Zealand Government to take further steps to improve the access to healthcare services for people experiencing homelessness (Office of the Chief Coroner of New Zealand, 2021).

The first cycle of the study involved establishing ongoing companionship with the Peeps, guided by Tikanga Māori values. This companionship created a deep ethical tension when confronted with the alarming magnitude of premature and avoidable mortality uncovered by the coroners' reports. The reports exposed a life expectancy disparity of over 30 years between homeless people and the housed population. Three quarters of homeless persons died from conditions that could have been addressed through timely healthcare interventions, from natural causes and by suicide. This tension prompted a significant shift in the study's approach, focusing on the temporal space of life prior to death, and embracing an ethical and relational responsibility to foster meaningful lives for the Peeps and the broader homeless community, according to their aspirations and within their own reference frames. The next cycle (chapter 6) delves into our companionship with the Peeps on

the streets of Seed Town, leading to collaboratively creating a drama aimed at fostering awareness and critical dialogue between health and allied professionals and homeless communities.

Chapter 6: Within the temporal space of life prior to death (cycle 2)

Narrative prelude

Cycle 2 invites the reader into the temporal space of life prior to death. This chapter narrates the fabric of this temporal space of life as it emerged, organically, from this cycle, shaped with the Peeps and through their experiences, perspectives, priorities and aspirations. This narrative prelude recounts the human face of that temporal space, preceding conceptualisation. The temporal space of life prior to death has been first a relational zone of human encounters, that developed in companionship with the Peeps, woven through whanaungatanga, manaakitanga, aroha, whakaiti, and continuous learning. Cycle 2 has been marked by confrontations with the healthcare system, rejection, suffering, and struggles, but also fulfilled with hope, care, love and resistance.

The constant presence of death, in its various manifestations, generated conditions of study marked with high ethical and emotional tensions. More exactly, cycle 2 developed in conditions of fundamental responsibility in the face of death (chapter 4), inducing a shift in the trajectory of this PhD, described as a *pause*, in chapter 3. Pivotal to this pause/shift was the emergence of profound contradictions surrounding issues of premature mortality, avoidable deaths, the distressing option of suicide, and end-of-life experiences that revealed deep layers of meaning, complexity, and paradox. This understanding led me, in retrospect, to conceptualise the temporal space of life prior to death, as a relational space of potentiality.

The narrative prelude is divided into four sections that delved into inter-connected aspects of cycle 2. In the first section, I discuss the overlapping and multiple roles I embraced as a PhD student, an informal doctor and a companion, all woven with relational ethics commitment and Tikanga Māori values. Section 2 discusses the various manifestations of death and dying in the everyday lives of the Peeps, and highlights the paradox and resistance of the Peeps in terms of their access to mainstream healthcare services. Interwoven with racism, this paradox and resistance stem from the multi-faceted aspects of transgenerational trauma within Pākehā healthcare institutions, in relation to the violation of the tapu of death and persons. As a result, these institutions are often associated with ontological and physical death, rather than supporting hauora and healing. Section 3 highlights and discusses important aspects of the Peeps' resistance and efforts to preserve their wellbeing, distantly from healthcare institutions. In the last section, I discuss the underlying reasons that led me to use a critical performance ethnography approach, which is underpinned by the theoretical foundation presented in chapter 4. Over time and after deep reflection, I proposed to the Peeps the collaborative co-creation of a drama titled "*Before it is too late*". The aims of this drama

are to raise awareness on death inequalities, and to foster dialogue and critical reflection among healthcare and allied professionals. The intended outcomes are to challenge misconceptions and to improve the quality of care provided to homeless people, until death. The Peeps' perspectives are of central importance as a deliberate attempt to build respect, inclusiveness, equity, fairness and a collective commitment forged with homeless communities to support the life and end-of-life experiences of Māori homeless people according to their priorities and aspirations. The chapter concludes with the submitted manuscript titled "Before it is too late: Street performance, life, death and homelessness in Aotearoa New Zealand" which presents the drama and the process of its creation.

Navigating simultaneous roles

I embraced multiple and overlapping roles throughout the study that included being a PhD student, a volunteer assuming a role of informal doctor, and a companion. Volunteering as part of ethnographic research has received limited examination (Goerish, 2017). Typically, studies on this topic have emphasized access to challenging settings, such as prisons (Martos-Garcia et al., 2022), the ambiguities resulting from dual roles (Chadwick, 2022; Garthwaite, 2016; Goerish, 2017; Hagan, 2021; Tinney, 2008), and the difficulties in defining responsibilities and obligations, especially when interacting with marginalised populations (Garthwaite, 2016; Parr, 2000). Some even consider volunteer activities to be incompatible with research practice. For example, within the domain of healthcare-related research influenced by a post-positivist paradigm, Tinney (2008) argued for limited participation in volunteering activities to maintain objective distance in ethnographic research, primarily in a nursing setting.

At the outset of this study, my active involvement as an informal doctor through volunteering with Cuppa Connection was based on a relational commitment to the wellbeing of the Peeps as the outmost priority. Through my volunteering I was in a very manifest way witnessing the Peeps' physical and emotional suffering. This formed the root of my companionship with the Peeps. This visceral experience meant that my analysis of the coroners' reports was arguably a more affecting experience, which intensified and shed new light on the research topic, emphasising the urgency of being attuned to the Peeps' needs and anticipating potential distress. As a result, my responsibilities as a companion and an informal doctor assumed greater significance, surpassing my role as a PhD student, in alignment with the overarching relational ethics principle that has shaped this study. Further, in keeping with notions of trust and reciprocity, I had to be open and accountable myself. Hence, within our companionship, the Peeps became familiar with my own story of homelessness — some had intuited it, while others directly asked — and my whakapapa as

Euskaldun (a person of Basque heritage). This recognition deepened our complicit connections even more.

I engaged in numerous individual discussions with the Peeps, wherein I explained my role as a PhD student, involving in particular the maintenance of a fieldwork diary written at home. Through trusting relationships, June and the Peeps granted me their verbal consent, thus fostering a foundation of relational accountability for me to ensure positive outcomes resulting from the study. Within our companionship, my role as a "researcher" seemed to recede in the background, as the Peeps recognised me as their "friend doc", "my French lady", or simply Sandrine — someone genuinely committed to their care and wellbeing, regardless of research-related circumstances. The Peeps were (and still are) my mentors, guiding me in honouring and upholding their perspectives on what "living well and dying well" could mean in their own contexts.

The fluidity of my roles as a PhD student, informal doctor and companion persisted throughout. The dynamics of my positionality, combined with being a non-Māori and privileged person, added layers of complexity and challenges to the study process, but also depth and richness, as I strived to navigate these different roles with respect, humility, and responsibility. In this process, everyday involvement, compassion, and accepting being deeply touched at an emotional and spiritual level that are non-cognitive ways of understanding were essential, as well as "letting things go with the flow of life". To quote Tillman-Healy (2003), companionship as "method" demands that "we research at the natural pace of friendship" (p. 734). Within the space of resonance mutually constituted between the Peeps and myself, the understanding that emerged from our companionship shaped the temporal space of life prior to death, and the study process as it progressed. I did not seek to address pre-determined "research questions". Instead, I faced the incommensurable magnitude of suffering, injustice and inequalities that came with the coroners' reports and that manifested in various ways into the everyday lives of the Peeps.

Cuppa Connection was rooted in the significance of upholding mana, embracing the notion of whānau with the Peeps, and embodying Tikanga Māori values. Within the specific socio-cultural context of this study, negotiating my multiple roles revolved around embracing the responsibilities and obligations that stem from whanaungatanga and manaakitanga (Vaeau & Trundle, 2020). Amongst these responsibilities, thoughtful and careful considerations of the entanglements of representation and audiences (Cahill, 2007), including the ethical and political implications of "making the invisible visible" (p. 367), and questioning "what is safe to share and what isn't?" (p.367) are critical. I have chosen to highlight, in the following two sections of this chapter, some critical points that shed light on the complex interplay of death and life in the Peeps' contexts, while

respecting the privacy and the stories of the Peeps. The quotes that I present below are extracted from my field notes diary, and are not the exact reproduction of verbatim interactions, but are instead paraphrased statements.

Manifestations of deaths and dying on the streets of Seed Town

The ever-presence of death manifested in the lives of the Peeps in various and complex ways. More exactly, what dying meant was a multi-faceted question, which arises in relation to the body's deterioration within the broader political, socio-economic, and cultural dimensions of homelessness in Aotearoa New Zealand (chapter 2). In the context of homelessness experienced by the Peeps, the state failure to honour Te Tiriti o Waitangi obligations and principles can arguably be understood as a political sentence to an accelerating dying process, even death. Indeed, many of the Peeps found themselves trapped on the streets for extended periods of time, as a result of long-standing effects of neo-liberal housing policies initiated from the 1980s onward. This ongoing neoliberal legacy results not only in dire shortage of emergency housing options, but in a situation where there is nowhere near enough liveable low-cost housing to meet the growing need (New Zealand Human Rights Commission, 2022). Today, access to the minimal quantity of emergency and transitional housing is harshly rationed through complex systems of criteria based on various factors such as gender, age and familial status. Accordingly, whānau with children, single mothers, women and the elderly are given priority in accessing emergency housing over single men who have not much of a hope (Work and Income, 2023). As on a sinking ship, "women and children first" has become the rule for managing the ever-increasing flow of housing applicants.

Moreover, Seed Town is, according to the Peeps, a "wealthy, privileged, entitled, predominantly Pākehā town". In 2018, a city-bylaw was enforced that banned rough sleepers and beggars from the main retail and hospitality areas of the city, forcing homeless people into the distant suburbs, far from emergency services and social life. In 2019, I attended a public debate at the city council regarding a possible revocation of the bylaw. During the meeting, one of the Peeps stood up, painfully, his body visibly damaged by years passed on the streets, to testify. When asked what he needed, he straightforwardly replied "I need to be able to sleep near surveillance cameras and a public light point for my security". However, the reality was that such safety measures were not available where the Peeps sought shelter. An aggravated voice of a representative of the City Council retorted "If it's only that, we can place you in empty containers in the disused carpark" (field-note excerpt, 2020). Yet, the disused carpark was awaiting demolition for reasons of non-compliance with seismic standards, a well-known fact for the Peeps who did not venture into the building.

The temporal space of life prior to death encompassed levels of meaning and complexity that extended beyond healthcare alone. The notable "city-bylaw episode" stands as a striking illustration of the differential treatment and value bestowed upon the lives of the Peeps, which can be further explored with the concept of the "*politics of life*" introduced by Fassin (2009). This concept diverges from the Foucauldian notion of biopolitics, which primarily concerns subtle government techniques to control a population. Instead, Fassin's notion of the politics of life reveals the unequal value placed upon the life and existences of marginalised populations, such as homelessness people, refugees and migrants, highlighting the intricate interplay between life, death, and marginalization. The suffering of those with unequal life value starkly contrasts with the prevailing societal emphasis on preserving life as a supreme good and fundamental right (Fassin, 2009). For instance, technological advancements and significant funding contribute to saving the lives of cancer patients or to decreasing perinatal mortality. Yet, in close proximity, there can be human suffering which is routinely overlooked. Furthermore, the collective practice of valuing life unequally manifests in the daily lives of the Peeps as small doses of death, referred to as "*slow death"* by Berlant (2007). Slow death "refers to the physical wearing out of a population and the deterioration of people in that population that is very nearly a defining condition of their experience and historical existence" (Berlant, 2007, p.754). The city-bylaw "dialogue" is an exemplar of how the "ordinary" imposition of slow deaths, through public humiliations and collective neglect, expose and damage prematurely the bodies of the Peeps. The bylaw was eventually withdrawn in 2020.

In the carpark, the adversity of sleeping rough means the Peeps suffer a range of concerning healthcare conditions, compounded by the lack of enrolment with a GP for many of them. I had shared with June the results of my analysis of the coroners' reports. Hence, as part of our proactive responses to the fragility of the temporal space of life prior to death, Cuppa Connection established a partnership with a local pharmacy, building on the insights of Jagpal et al. (2019). The objective was to create a non-judgmental environment where the Peeps could directly access free first aid medications, and/or chronic treatment, without needing to provide justifications. For instance, the medications I frequently encountered in the car park included anti-diarrhoea medications to address intestinal intoxication from eating spoiled products, antihistamine to combat skin rashes caused by insect bites, and dressings for various wounds. However, the Peeps had little recourse to the pharmacy. They explained to me that they encountered difficulties in explaining their symptoms, understanding medication instructions, accessing transportation to reach the pharmacy, and also because of pain, mistrust, and fear of judgment. Instead, the Peeps preferred I bring them medications or rongoa Māori (e.g., kawakawa) to their respective places, allowing me to nourish individual and long-term relationships with each of them.

My frequent encounters with the Peeps became moments of profound sharing, where we exchanged life stories, confidences, struggles and hope, spiritual matters, tears and love, which contributed to weaving our companionship through mutual reciprocity and trust. This took the "fieldwork" dynamic to another level of engagement and responsibility without severing emotions, intuitions, and worries for the lives and existences of the Peeps. I return to this later aspect of the "fieldwork" in the last section. I accompanied the Peeps to various places, advocating for them when needed according to the flow of life events. This included, for example, hospitals, GP's clinics, court, or Work and Income New Zealand (WINZ)[16], but also the public library, churches, beach, *marae* (community and ancestral meeting place), charities, cafes, or private spaces to share moments of friendship. Together, we faced many challenges and also found joy in celebrating birthdays, Christmas, changing bicycle wheels (a transportation asset of inestimable value while dwelling on the streets), or writing together. Throughout our companionship, my phone became an essential tool, serving as a point of reference for institutions such as healthcare services or sometimes the justice system, ensuring the Peeps did not miss any appointments that could have had deleterious consequences for them.

Severe healthcare issues, however, frequently occurred, serving as a stark reminder of the fragility of the temporal space prior to death. The extract from my field diary below illustrates the tenuous interval between life and death for homeless people.

> "I received a distressing call for June. Kauri (pseudonym) has suddenly collapsed while attending a charity's meal. He is now in the Intensive Care Unit, hanging between life and death. The hospital is unsure if Kauri has any whānau that could be contacted. June asked me to call the hospital […]. Kauri is suffering from a massive pulmonary embolism that could have been prevented with appropriate care upstream. There is a chance he could have collapsed in his tent, and died alone, unnoticed at the age of 41, his life ending up in a coroner report" (field-note excerpt, 2020).

My medical knowledge and experience were often called on during health crises, severe and poorly addressed health conditions (e.g., heart chronic conditions), or to advocate for a sick person in the absence of whānau, necessitating engagement with the healthcare sector. Finding a balance between individual agency, the need for mainstream healthcare support, respect, and resistance were essential. Hence, navigating the healthcare system with the Peeps, advocating for their needs, seeking compromises, but most importantly, standing in solidarity with them, became integral aspects of our companionship. However, this also came with various manifestations of what

[16] WINZ is a welfare agency which provides people with limited financial, employment, health disability and housing assistance. For the Peeps, attending to WINZ is a prerequisite to get assistance, however, it remains an unpleasant, bureaucratic and judgmental experience.

Berlant (2007) refers to as “slow death”. These challenges often include judgmental attitudes from desk staff at GP’s receptions, encounters with unsympathetic security guards at the hospital entrance, or unwelcoming and suspicious behaviours from hostile nurses during the triage process. I frequently intervened to defuse escalated confrontations in an effort to avoid having the Peeps being denied admission and sent back to the streets. At the extreme, the example below illustrates the unfairness and inhumane treatment faced by the Peeps in their encounters with the healthcare system. Wiremu (pseudonym) had been experiencing swallowing difficulties for several months. After numerous challenges, a gastroscopy was finally scheduled at the outpatient clinic. We negotiated for light sedation with the nurse, and the procedure was expected to take approximatively one hour. Wiremu was taken to the operating room, yet within fifteen minutes he returned, fuming: “They’re fucking bastards, I’m splitting”. He hastily dressed to leave. At the last moment, the doctor had inserted the tube without providing sedation, claiming that there would be no one present during the night to manage potential side effects. Wiremu tore out the tube. Subsequently, Wiremu categorically refused a hospitalization of 24 hours, despite negotiations with the hospital (extract from field-notes, 2021).

Preserving life on the streets: paradoxes and resistance

The act of subjecting a homeless person to cruel procedures, such as the one described above, provides a “justifiable” reason for the Peeps to avoid healthcare services, despite the potential deleterious consequences for their physical health. However, for many of the Peeps, the primary resistance to seeking healthcare services, particularly in hospitals, originates from other sources rooted in transgenerational trauma, and due to the misunderstanding and marginalisation of the tapu of death, within most healthcare institutions. It is important to understand and acknowledge, as previously highlighted in chapters 1, 2 and 3, that for Māori, death and life are deeply interconnected in holistic views of the world. Death and dying are steeped in tapu, “opening a gateway for the wairua to transition to the spiritual realm” (Moeke-Maxwell, Mason, Toohey, Wharemate, & Gott, 2019, p.297). As highlighted by these scholars, “whatever happens before, during and immediately following death […] can affect the successful transition of wairua” (Moeke-Maxwell, Mason, Toohey, Wharemate, & Gott, 2019, p.297) and influence the grieving process of the living. Cultural rituals accompany death and dying under tapu, facilitating the wairua’s transition and strengthening a spiritual sense of belonging among the living during tangihanga (see for example Moeke-Maxwell, Mason, Toohey, Wharemate, & Gott, 2019; Nikora et al., 2010; Nikora et al., 2012

for a description). In particular, a dying person and a *tūpāpaku* (body of a deceased person) are never left alone.

Many of the Peeps recounted negative experiences when people they know and loved had died in mainstream Pākehā institutions. This included the life stories involving the dying process of members of their whānau in a hospital setting marked by racism, marginalisation of cultural beliefs and practices, and moral judgments from healthcare institutions. During a car ride to a regional hospital for a surgery consultation, Moana (pseudonym) shared her father's story:

> "Dad had emphysema. He kept going back and forth from the hospital to our house. The doctors said he wouldn't live much longer. It was like he was already dead. After that, the nurses stopped checking on him and barely spoke with us. He passed away alone at night, without us, his whānau, by his side. Dad was Māori and my mom was Pākehā. Their marriage was not accepted at that time. We had to live in two different worlds" (field-notes excerpt, September 2020).

The Peeps shared many such stories of instances where the cultural wishes and the social value of the person approaching death were not upheld. Often this resulted from the lack of understanding of the tapu of death by Pākehā institutions, racism, and the suppression of the social, cultural, and spiritual significance of death and dying for Māori. These experiences often had occurred at a young age, leaving lasting traumatic memories and fostering a deep-seated mistrust towards hospitals.

Stories where loved ones passed away, condemned to death before dying, alone, and were without the presence of their whānau, bear the scars of the marginalization of the cultural and spiritual dimensions of death and dying for many Māori, and racism within healthcare institutions. The compounded effect of homelessness and societal marginalization have further solidified the perception of hospitals and Pākehā healthcare institutions as paradoxical spaces that evoke associations with physical and ontological death, rather than sustaining hauora and healing. As a result, many of the Peeps preferred to maintain a distance from these institutions, without support or the presence of their whānau. The concept of resistance could be considered as "any act performed by any individual (or collective) […] that is a response to power, most often in opposition to contentious, harmful or unjust rules, practices, policies or structures" (Essex, 2021, p. 484). Standing in stark contradiction to what is expected from healthcare institutions, resistance meant, for many of the Peeps, protecting their wellbeing at individual, collective and relational levels in keeping at a distance from, or not exposing them to healthcare institutions. This was often deemed "safer" or "healthier" than accessing services, despite potential tragic repercussions for the Peeps' physical health, and their lives, especially given that many were not enrolled with a GP.

In contrast to the so-called "care avoidance" of homeless people which may suggest a personal failure to access to healthcare in a society that is saturated with health promotion discourses, a more fitting description of the situations many of the Peeps find themselves would be "*resistance to social death*". The concept of social death refers to situations where people experience severe compromised wellbeing, resulting from multiple losses, and are treated as if they are already dead within clinical and social settings (Borgstrom, 2017; Kralova, 2015; Sudnow, 1967). Sudnow (1967) described social death as occurring before physiological death, wherein a patient is treated as a dead body, while their body still physiologically functioning. This occurs when healthcare institutions perceive or judge the patient to have less social "viability" than the norm, or to " be as good as dead" (Sudnow, 1967).

Considering the perspectives and experiences of the Peeps, and reflecting on the extent of the Peep's resistance and the insoluble paradox it contains, I began to realise that the dichotomy between prevention and palliation was at odds. In a review of culture and health, Napier et al. (2014) argued that the systematic neglect of the impacts of culture on health is the largest barrier to health advancement worldwide. When combined with transgenerational trauma, and extreme forms of dehumanisation, as described above, the temporal space of life prior to death become palpable.

Over time, as the trust and relationships with the Peeps grew, we had deeper discussions about death and dying. The loss of connection with whānau, albeit to various degrees dependent on situations and persons, was a "presence" that often impacted how the Peeps envisioned their end-of-life experiences. Central to their concerns, was the possible severance from familial, emotional, and spiritual support and care provided by whānau, at the end of life. This would mean a disruption of the spiritual journey of death and dying (Moeke-Maxwell, Mason, Toohey, Wharemate, & Gott, 2019), that extended into the possibility of not being farewelled as Māori, not being recalled as ancestors through whakapapa, and thus not being part of the spiritual continuity between the livings and the dead. As this essential aspect is explored in chapter 7, I do not delve into details in this narrative prelude. However, for many of the Peeps, their own experiences of death within Pākehā healthcare institutions rendered the perspective of spiritual disruption acutely present. When I mentioned the idea of palliative care, through hospice' support, the Peeps rejected it. The ontological wound that led them on the streets — a "soul wounding" (Duran, 2006, as cited in Pihama et al., 2014, p. 251) — cannot be healed by a healthcare system that carries death within it, seemingly closing the door on their existence forever. On many aspects, the very notion of "access to palliative care" as the ultimate response in the face of death was challenged. The proposition to also consider homelessness as complex life-threatening conditions associated with SHS emerged from these pivotal moments of understanding.

Nonetheless, not all institutional spaces are "avoided" by the Peeps. In the midst of the layered complexities of the Peeps' experiences, the public library emerged as an essential centre of care and healing that nourishes their physical, emotional, social and spiritual wellbeing. The library provides a comforting refuge, offering warmth in winter and coolness in summer, where the bodies can find safe rest. The free internet access enables the Peeps to watch movies, reports, news, listen to music, travel into other realities, fostering a sense of connection with the wider world. For some, the library becomes a gateway to reconnecting with their Māori heritage through studying te reo Māori, and/or researching their iwi, hapū and ancestors. These endeavours help fulfil the void left by the disrupted connections with their whānau, their whenua and whakapapa.

Within the delicate balance of seeking care, healing, and a sense of belonging, the Peeps often turn to underground healthcare strategies as alternatives they perceive as more humane and dignified compared to the mainstream healthcare system, which lacks support, welcoming environment, dignity, respect and understanding. These strategies may involve sharing and exchanging medications procured indirectly through proxies (Nikora et al., 2011). Additionally, alcohol and drugs serve as coping mechanisms to compensate for pain, loneliness and the lack of care provided by the system. These practices foster complex social ties with their street companions (Bourgeois, 1998) and embody the notion of home-making (Groot et al., 2015), as whānau-like relationships that play a crucial role in providing meaning, a sense of belonging, and hope in their daily lives. However, amidst these complex dynamics, the emergence of suicidal thoughts unveils a distressing reality that cannot be ignored. Many of the Peeps refer to antidepressant medications as "doctors' pills", highlighting the "misunderstanding gap" between distinct realities and the limited outcomes of Western response in addressing their distressing thoughts. Indeed, it is essential to understand that the experiences of trauma in the Peeps' lives, often multiple and intricate, cannot be reduced to the criteria of Post Traumatic Stress Disorder as referred to in the *Diagnostic and Statistical Manual of Mental Disorders* (5th; DSM-5; American Psychiatric Association, 2013). Traumatic experiences are inseparable from the historical, collective and inter-generational trauma generated by the assimilative colonial practices, its violence, and ongoing effects (Durie, 2017; Reid et al., 2014; Wirihana & Smith, 2014). Understanding and recognizing this broader context is crucial for a comprehensive approach of care and support.

On March 23, 2020, in response to the spread of Covid-19 pandemics across the country, the New Zealand government declared the state of emergency and announced the establishment of a national lockdown, set to take effect in two days. At the carpark, anxiety reached a peak. Community housing providers hurried to secure accommodation in "Covid-19 motels", which housed approximatively 3,826 out of the 102,000 homeless people nationwide (Cooke, 2021) at that time.

However, some of the Peeps would remain on the streets. Meanwhile, June was busy procuring and distributing prepaid phone cards and setting up a community sign in the carpark that allowed the Peeps to leave messages. As Cuppa Connection was deemed an essential service, six volunteers including myself, were granted permission to move around the silent town ensuring daily checks and responses to the messages: «Yeah, got your sleeping bag", or "got your gas bottle for cooking". Maintaining human connections had become a matter of vital importance. The weekly gathering in the carpark was only permitted on the basis of police supervision with strict adherence to sanitary measures. For us, volunteers, these measures included wearing masks and gloves, two metres of social distancing, and a limited gathering time of 30 minutes to distribute bags of food provisions, for three days. However, the sanitary measures of protection were graduated. For the Peeps, only social distancing measure was enforced and masks were not deemed "necessary", creating unequal sanitary measures between the Peeps, on one hand, the volunteers and the police on the other hand.

From a sense of whānau, the carpark had transformed into a space of division, policed by authorities, where bodies and individuals were subjected to unequal levels of protection against a potentially mortal disease, all under the guise of a food distribution deemed essential to the Peeps' survival. The presence of the police deterred the Peeps from openly protesting. Nonetheless, forming a common front, the Peeps tacitly began to perform an art of a shared resistance, a form of silent insubordination or "silent transcript" (Scott, 1990), by revealing their bodies as tangible symbols of a contested legitimacy to exist. They exposed their feet, removing their shoes to reveal the bruises inflicted by walking around the town. Sweaters were raised to reveal backs in need of massages. The wounds become acts of dissent, demanding attention and care. Without directly opposing the "public transcript" (Scott, 1990) permitted by the authorities, the Peeps and I joined in resistance. Except in specific medical situations, throughout my entire medical practice, I seldom wore medical gloves, and never with the Peeps. To me, gloves represent a separation and a violent rejection of the encounter between two bodies, two persons, two embodied mortals, in unequal situations and relationships of power. I removed my gloves, and provided the care the Peeps asked for, in a general silence. A conversation between June and the police ensued, as I continued to provide care, in the space of resistance opened by the Peeps. Over the following weeks, the measures gradually become more flexible. Resistance in the Peeps' contexts was thus a multi-faceted act through which the Peeps performed their rights to recognition, voices, care and life.

Critical performance ethnography in cycle 2

In the unique context of my PhD study, embodiment and performance held particular ethical, political, and epistemological significance that drove my way of practicing the "field" with the Peeps, as well as my proposition of collaboratively co-creating a drama. The notions of performance and embodiment are closely intertwined (Conquergood, 1991). Embodiment refers to the experience and material fact to have a body, encompassing senses, emotions, sensations, and the experience of being in, and connecting with the world (Grinfelde, 2018). As embodied mortals, we share a common humanity in the face of mortality. Lévinas (1986) states that " the approach to the face is the most basic form of responsibility" (Lévinas, 1986, as cited in Butler, 2004, p.131), summoning a radical responsibility to the alive but dying "other" face that is also mine. Embodied ethics (Kramer & Hsieh, 2018) summons a fundamental *kanohi ki te kanohi* (face to face) or reciprocal recognition, too often denied to homeless people, asserting our inherently relational nature as human beings, and the responsibility that comes with it.

Contrasting a semantic approach of the field that predominates in most interview-based methods, performance ethnography engages researchers, people and communities in a "participatory and experiential epistemology" (Conquergood, 1998, p. 27) as a primordial condition of our mutual understanding. On many instances, performance and "performing the field" offered another level of engagement with the Peeps and a more relational and embodied understanding of their struggles, resistance, and hope. Suffering resided in the experiences of the Peeps, which eludes verbal expression. Even "the silence of suffering and the vulnerability and finitude to which it bears witness" (Harrisson, 2007, p.596) exists within a vacuum of communicability. At best, one may recognise the silence for what it exceeds, be impressed by it, but never experience nor comprehend its nature. Encountering wairua demands connecting through feelings, intuition and inner sense, delving into the spiritual essence of being. The indigenous scholar Meyer (2008) states that "*our mind is our body. Our body is our mind*. And both connect to the spiritual act of knowledge acquisition" (p.223). The dynamic and performative nature of the encounters with the Peeps aligned more with the notion of "co-experiencing" the field (Conquergood, 1998), at the level of "rough ground of the human condition", in the "ordinary" life of slow deaths, political neglect, threat of social death, and violation of the tapu of death and persons. "Performing the field" meant the ethical embodiment of kanohi ki te kanohi, whanaungatanga, aroha, manaakitanga, being present and worried for the lives and existences of the Peeps, and trying to respond.

As a non-Māori doctoral student, I had no immediate response. I reflected that issues of power imbalance, representation, benefit and control were in high tension, to the point I could not

write anything. Yet, I was obliged to "do something". The resistance the Peeps performed on the streets, as described above during the Covid-19 lockdown, was not an isolated moment. Without entering into the extensive details that are presented in the article, it is enough to mention that the carpark itself was a space of resistance, where we ironically gathered beneath the windows of the city council, while the bylaw was effective. Reflecting on their resistance, although no one should be compelled to resort to such extreme measures to survive and protect hauora, I realised that resistance and performance share the promise of mutual recognition and solidarity, urging us towards collective action, dialogue, and transformation, in the face of the pervasive presence of death in the lives of the Peeps. The Peeps and myself nourished deep and trusting relationships built over time. After long reflection, I thought that I could propose to the Peeps to collaboratively co-create a drama where their voices would be honoured, and that could perhaps render the temporal space of life less tenuous and fragile. The Peeps welcomed my proposition.

Narrative epilogue

Throughout this chapter, I have emphasised the significance of companionship informed by Tikanga Māori values as a relational response and an ethical way of performing the "fieldwork", especially with marginalised populations. This chapter outlines my journey, which began with conventional research methods and over time moved towards an atypical research output. I was drawn into an unconventional PhD journey by the need to maintain accountability to the Peeps, recognising that the process of knowledge production is equally as important as knowledge itself (Mead, 2016). As a non-Māori doctoral student, the complexities inherent from my position and the need to navigate power dynamics in the study process also include the way of writing this thesis.

The project of "Before it is too late", and its making are presented below in the article cited as: Charvin-Fabre, S., Moeke-Maxwell, T., Stolte, O., & Lawrenson, R. (2023). "Before it is too late": Life, death, street performance and homelessness in Aotearoa New Zealand. *Ethnographic Edge, 6*(2), 5-26. The article contributes to the aim of this PhD study by creating awareness around the issues of death inequalities faced by homeless people in Aotearoa New Zealand and building an understanding of what "living well and dying well" may mean for Māori homeless people. The article is reproduced with the permission of the journal titled *Ethnographic Edge*. While there may be some unavoidable repetitions between this chapter and the closing article, they serve the purpose of providing comprehensive understanding to the readers. The article offers contextual explanations, while the chapter delves into greater details, providing transparency and a more thorough understanding of the study process.

Before it is too late: Street performance, life, death, and homelessness in Aotearoa New Zealand

Nāu te rourou nāku te rourou ka ora ai te iwi

With your food basket and my food basket, the people will live

Abstract

This article examines the creation of "*Before it is too late*", a collaborative performance project created with the Peeps — short for Peoples — living on the streets of Aotearoa New Zealand who identify as Māori (Indigenous New Zealanders). The Peeps face profound, persistent, unjust inequalities, inequitable mortality rates, and devaluation of their lives by the wider community. The performance project is centred on the Peeps' perspectives, and is informed by whanonga pono (Māori values) and tikanga (customs), the principles of community-based research, relational ethics, and critical performance ethnography. The project aims to initiate a conversation with health professionals to improve the quality of care provided, and to ensure greater respect and dignity in relation to the death of Māori homeless people. We present the drama "Before it is too late" that has resulted from this collaboration with the Peeps, to open a transformative space for their voices, experience, priorities and rights to be heard and acknowledged.

Introduction

Death inequality looms large in the lives of homeless people, exposing the disparity in the value placed upon their existence. In Aotearoa New Zealand, this reality is exemplified by an abysmal "gap" of 30 years in life expectancy that separates homeless people from the general population. Within this "gap", the majority of deaths (76%) are avoidable, including suicide, unmet chronic conditions and the frequent occurrence of lonely deaths in public spaces (Charvin-Fabre et al., 2020).

The intersection of marginalisation, devaluation of lives and unjust deaths raise profound questions regarding prevention, premature mortality and end-of-life care. These injustices shed light on society's failure to care for all of its members, and emphasise the persistent and considerable obstacles faced by homeless people in accessing mainstream healthcare systems that are not designed or tailored to their needs; healthcare providers lack understanding of their realities and

experiences. Māori are disproportionally affected by entrenched disparities, resulting from colonisation and its lingering impacts and transgenerational trauma (Amore et al., 2021; Lawson-Te Aho et al., 2019). For many Māori, homelessness also encompasses cultural and spiritual dimensions of loss in relation to the notion of home, rooted in dispossession from land and associated disconnection processes from whānau (family, extended family), tribes, knowledge, language, rituals and traditions, and spiritual resources across generations (King et al., 2016).

Performance has gained critical attention in health-based research due to its capacity to capture complexity and nuances related to sensitive health issues, such as homelessness (Clarke et al., 2005), disability situations (Shah & Greer, 2018) or the institutionalisation of the elderly with dementia (Kontos & Naglie, 2006). Through emotional, cognitive, and physical engagement with audiences, performance-based research has the potential to challenge taken-for-granted assumptions, to disrupt stereotypes and processes of marginalisation, and to reveal issues and challenges faced by people that might otherwise go unnoticed (Gray et al., 2003; Kontos & Naglie, 2007; Mitchell et al., 2006). Furthermore, motivated by the often-neglected responsibility of researchers to their participants, arguments have been made for disseminating findings to audiences, beyond academic institutions (Boydell et al., 2012). Performance health-based researchers are committed to communicating their results in an accessible and relevant manner, directly to "health audiences" (e.g., health and allied professionals), to better inform positive change in healthcare practice and policy development.

This article delves into the making of "*Before it is too late*", a collaborative performance project created with the Peeps[17], a community of men and women who live on the streets of Aotearoa New Zealand who identify as Māori. The unique perspectives of Indigenous homeless people on death inequalities that impact them have received little attention in New Zealand research and health and palliative care discourses. With this performance project, our aim was to create a space with and for Māori people who experience homelessness and to confront dominant narratives. The resulting drama serves as an invitation and catalyst for initiating a critical conversation with healthcare professionals. It aims to promote critical reflection, raise awareness, foster dialogue, and establish trusting connections with Māori homeless communities to improve the quality of care provided. The outcome hoped for is that their end-of-life experiences are respected and honoured according to their priorities and aspirations.

[17] The "Peeps" -short for "People"- is the term chosen by this community to identify themselves, rejecting stigmatising labels such as 'the streeties" or "the homeless". Throughout this article, we will use the term "Peeps" as the designated reference for this community.

"Before it is too late" is part of a PhD study that seeks to explore the complex dynamics of life and death in the everyday experiences of Māori homeless people, recognising the omnipresence of death in their lives. The project emerged from the long-term embodiment of building trusting *whanaungatanga* (relationships and connections) between the first author (SCF), a non-Māori PhD student and medical doctor, and the Peeps. Recognising the profound impact of colonisation, power dynamics, injustice, cultural disruption and systemic marginalisation on the lives of Māori homeless people, the project actively engages with these complex dynamics, and places the perspectives, priorities and aspirations of the Peeps at the forefront of the development and aims of "Before it is too late". By actively engaging with the Peeps' priorities and aspirations, and centring our project within Māori world views and *hauora* (holistic wellbeing), encompassing inter-related physical, spiritual, emotional, familial dimensions of health (Durie, 1985), we aim to create a space for their voices to be heard and for their experiences to shape the study process. Aligned with the principles of relational ethics (Hodgetts et al., 2021), critical performance ethnography (Conquergood, 1991; Madison, 2020), and community-based research (Cornish et al., 2023), the project prioritises the value of experiential knowledge, and mutual engagement. Moreover, it embraces culturally informed practices and values, embodying whanaungatanga, *manaakitanga* (kindness, care and respect), *aroha* (love and compassion), *kōtahitanga* (collective action, togetherness), *whakaiti* (acting towards all people with humility), and ongoing processes of learning and reflection. Together, these foundational principles, values and practices form the basis of a "collaborative and relational ethics" (Hodgetts et al., 2021; Lassiter, 2001) to foster positive and meaningful actions to social change based on the Peeps' aspirations and priorities.

The authors of this article bring together diverse perspectives and experiences. Sandrine Charvin-Fabre (SCF), of Basque ethnicity, has long practiced as a palliative care doctor with homeless people in her home country. She also worked alongside poor populations in multi-cultural settings of the South Indian Ocean area, where she practised as a General Practitioner for many years. Tess Moeke-Maxwell (TMM) is an Indigenous Kaupapa Māori end of life researcher; she is co-director of the te Ārai Palliative Care and End of Life Research Group (University of Auckland) and she is a founding member of the ACP Mana Enhancing Design Partnership Team for Māori. TMM and SCF entertain a research friendship that has grown from the informal medical support that SCF provided to TMM when her new born mokopuna (baby grand daughter) died during the Covid-19 national lockdown. Ottilie Stolte is a Tauiwi/Pākehā Senio Lecturer in Psychology with 15 years of experience researching poverty and inequalities alongside Māori colleagues, and Ross Lawrenson, a Professor of Population Health researching inequities in cancer, both supervise SCF's doctoral work. Tess Moeke-Maxwell provides cultural advice on SCF's research project. Together, this team seeks to shed light on

the experiences of Māori homeless people, initiate critical dialogue within the healthcare community, and drive positive change towards a more equitable, compassionate, respectful and inclusive approach to the end-of-life care.

Before delving into the making of the drama, we first provide a further description of the relational context in which the project developed, offering a more comprehensive understanding of its progression.

Relational context of "Before it is too late"

In early 2019, I (SCF) crossed paths with June (pseudonym) and the Peeps. June, a Māori woman, had created Cuppa Connection (fictional name), a not-for-profit organisation that provided material and human support to the Peeps. Centred on *Tikanga Māori* (ways of doing, being, knowing) values (Mead, 2016), June fostered whānau-like relationships with the Peeps, to uplift *mana* — their authority and prestige — and provide healing and hope. I shared with June my home country, my *whakapapa* (genealogic ties), my PhD project which resonates with my own story, and my desire to contribute as an ally in Aotearoa (Li et al., 2021). June invited me to volunteer at Cuppa Connection, where I am still involved as an informal doctor, providing essential care to the Peeps, such as treating foot or dermatological conditions, and dressing wounds, as well as support and advocacy within the mainstream healthcare sector.

Cuppa Connection operated in an open-air carpark, strategically located at a crossing space in the town centre. By 2019, approximatively 40-60 Peeps and volunteers congregated there weekly, defying a city-bylaw banning the Peeps from the downtown area. Situated amidst the bustling hub of the bus station, restaurants, the city council and the public library, the carpark provided critical visibility to our gathering, transforming the streets into a performative site of resistance, mutual recognition, and human connections demanding action and dialogue (Madison, 2005). This visual presence and blatant occupation of space echoes the spirit of Māori resistance and occupations of Bastion Point (1977-78) and Ihumātao (2016-2020). Anchored into the values of whanaungatanga, manaakitanga, aroha, and inclusiveness, the street performance evocated a "spontaneous communitas that offers the alchemy of human connection" (Madison, 2005, p.545).

In the midst of the busy noise of the town, the performance unfolds, creating its own melody, rhythm and movement. Tables are set up, hot coffees poured, a barber officiates, an outdoor library assembles, tents and sleeping bags are provided. *Waiata* (Māori singing) fills the air, a transistor plays in the background guiding dance steps. In this liminal space, the street performance

intertwines and encounters voices and acts of daring, camaraderie, resistance and hope, weaving stories, emotions, relationships and connections.

This collective gathering provided a momentary respite from the burden of exhaustion and shame, exclusion and solitude, danger and violence associated with street life, restoring the human bonds dislocated by homelessness. Disrupting the common flow and order of city life, domiciled inhabitants, as "spect-actors"[18] (Boal, 1974/1985), displayed disdain or indifference, astonishment or marks of sympathy, reflecting broader tensions that permeate New Zealand contemporary society.

In that context, I assumed a dual role of informal doctor and doctoral student. Many of the Peeps had been disengaged from the healthcare system for years, facing limited and irregular access to primary care and often resorting to emergency departments, if they sought care at all. These challenges reflect the considerable obstacles homeless people encounter when trying to access mainstream healthcare services, which arise from a complex interplay of structural, individual and inter-individual factors (Siersbaek et al., 2021). Among the commonly reported factors are fragmented healthcare and social services, mistrust towards health professionals due to repeated experiences of racism, stigma and marginalisation, prioritisation of survival necessities such as food or shelter, and bureaucratic and financial constraints. As a result, unmet healthcare needs, fragmented care, lack of follow-up, delayed diagnosis, and ultimately preventable deaths contribute to the persisting "gap" in life expectancy among homeless populations over decades (Aldridge et al., 2019; Fazel et al., 2014; Siersbaek et al., 2021). Moreover, the isolation from the mainstream healthcare system exacerbates unpredictable death trajectories, leading to sudden death and/or preventable deaths from palliative care conditions. Often, if end-of-life care is provided at all, it is inadequate (Hudson et al., 2016; Stajduhar et al., 2019).

The relational context of Cuppa Connection marked the starting point of a profound and enduring engagement with the Peeps, rooted in the values of whanaungatanga, manaakitanga, and the aligned cultural obligations and responsibilities. What initially started as providing basic care in the public carpark transformed into something deeper — a journey of solidarity, reciprocity, trust, and companionship that developed at its own pace over time. Throughout this shared journey, the Peeps came to know my own historic story about homelessness which created a sense of mutual understanding and complicity. Nonetheless, I am aware of my privileges and of the inherent power dynamics that exist in our relationships. Over time, the Peeps gradually shared their many hurts,

[18] The notion of "spect-actor" refers to audience members being not seen as passive receptacle but as co-creators of meaning and knowledge. The notion originates from Augusto Boal's work "*Theater of the Oppressed"*, first published in 1974, aligned with movements of liberation in Latin America (Freire, 1970/2005).

struggles, suicidal thoughts, resistance to accessing healthcare services, and their hopes. Together, we confronted the complexities of socio-cultural marginalisation, racism, misunderstanding, assumptions, and exclusion criteria within healthcare institutions and the everyday life. We faced various challenges, including the lack of material resources (e.g., phone, physical address, means of transportation) and human resources (e.g., support person). It has been, and continues to be, a reciprocal journey where the Peeps, with their generosity, have allowed me to learn and grow, gaining a deeper understanding of their unique contexts, challenges, perspectives, priorities and aspirations. Reciprocally, I provide a listening ear, medical advocacy and support.

The making of "Before it is too late"

As a non-Māori migrant doctoral student whose legitimacy to undertake research with Māori on issues affecting Māori communities is contested (Smith, 2012), SCF acknowledges the power imbalances and challenges inherent to doing research with the Peeps. Grounded in relational ethics principle and moved by a deep sense of responsibility that emerges from whanaungatanga and companionship, SCF was committed to explore alternatives that genuinely benefit Māori homeless communities (Hodgetts et al., 2021; Smith, 2012; Wilson, 2008) and address the cycle of death inequalities. This commitment led SCF to propose to the Peeps the idea of collaboratively creating a drama.

In this research context, the idea of a drama emerged from the embodied research practice as co-performance and co-engagement (Conquergood, 2002), forged in proximity, solidarity and humility with the Peeps. The collaborative creation of "Before it is too late" was born out of the street performance of Cuppa Connection, and its transformative power as an act of resistance, embodiment, mutual recognition, dialogue, and human connections (Madison, 2005). A driving force was the desire to move away from authoritative, monological, and colonial practices of representation (Conquergood, 2002; Smith, 2012). We aimed to shift away from the paternalistic act of "giving voices to", which can be seen as an act of charity from the dominant to the dominated (Ahmed, 2000). As argued by Madison (2005), a street performance is "a performance of possibility, […], a possibility of another strategy, for collective hope and dreams coming to fruition" (p.539). Art-based strategies (e.g., drama theatre, art exhibits) have been increasingly recognised as alternatives to bridge the knowledge-application gap by generating critical awareness regarding the relationships between social, cultural, human contexts and care practices (Boydell et al., 2012; Conquergood, 1988; Gray et al., 2003; Rossiter, 2012).

Our focus, however, goes beyond traditional performance and ethnographic approaches shaped by Western conceptions of theatre and anthropology. Instead, we aimed to create a transformative space informed by Indigenous perspectives, emphasising the relational, embodied and spiritual dimensions of life and knowledge (Meyer, 2008; Smith, 2012). Performance ethnography may take on a new dimension, with the potential to become a "ceremony" (Wilson, 2008), a place of well-being and healing, a participative dance that makes people feel better, happier and want to live longer (Magnat, 2012; Wilson, 2008). Accordingly, performance, may become a medium of exchange, a site of dialogue where encounters and relationships are essential to understand "into" and respond to the world differently. Health audiences are thus invited to important forms of "response-ability" (Rossiter, 2012) which means the ability to respond to the dramaturgy of unequal lives and early death impacting homeless communities.

The entire performative project, its purpose, the why, the how have been extensively discussed and collaboratively developed with the Peeps to ensure that the project is the fruit of shared, mutual, relational, and respectful understanding. Throughout these discussions, the project, including the script, was shaped with and by the Peeps' strengths, aspirations, priorities and lived experiences. All of the decisions regarding the project were made collectively, fostering a sense of ownership and agency amongst the Peeps.

During these discussions, the Peeps addressed several key issues and areas of improvement within the healthcare system. These encompassed improving access to primary care, fostering more supportive welcoming, respectful and humanistic environments, reducing judgmental attitudes, and simplifying enrolment and follow-up procedures, particularly for people with chronic health conditions. Mental health issues, suicide ideation and addiction were identified as a critical area, given the prevailing stigma and stereotypes of all homeless people as "drugs addicts". Further, the Peeps highlighted the conflicting responses between biomedical responses to mental health, primarily centred on "distributing pills" (e.g., anti-depressants), and their own perspectives on health and wellbeing. In face-to-face moments of sharing with SCF, these conversations delved into experiences of trauma that were not being addressed collectively. Over time, some of the Peeps courageously shared some aspects of their traumatic stories that, for many, began at early age and are deeply intertwined with the broader context of transgenerational trauma (Wirihana & Smith, 2014) and its impact on homelessness.

Familial abuse, for example, is not an isolated issue, but is interwoven in complex ways with the collective and transgenerational trauma resulting from the impacts of colonisation, which undermine the social and cultural resources to protect children and whānau (Johnson, 2009;

Wirihana & Smith, 2014). Those who find themselves forced onto the streets to escape violence, or placed in state care where they often experience further abuse, often carry the burden of trauma and intricate connections, whether symbolic or tangible, with their whānau (Groot et al., 2015). In such circumstances, the perspective of death and dying can intensify or rekindle these experiences (Te Ohu Rata o Aotearoa, 2019). Indeed, for many Māori, in continuity with life, death and dying is a relational, spiritual, and transitional journey, primarily cared for by whānau within whakapapa and honoured through *tangihanga* (death rituals and customs) (Moeke-Maxwell et al., 2014; Moeke-Maxwell, Mason, Toohey, Wharemate, & Gott, 2019; Moeke-Maxwell & Nikora, 2019). Tangihanga is one of the last Māori institutions that has survived colonisation (Ngata, 2005), and is considered the "pinnacle" of Māori cultural expression, of deep spiritual significance (Moeke-Maxwell, Mason, Toohey, Wharemate, & Gott, 2019; Nikora, et al., 2010). Paratene Ngata (2005) states that through tangihanga, "the spiritual dimensions of humanity strengthen the delicate relationships between the living, ancestral and spiritual worlds" (p.31). Being farewelled as Māori, to be part of a spiritual continuity within their whakapapa, to be recalled as an ancestor, and buried on tribal lands were uncertainties that significantly penetrate the lives of many of the Peeps and often depend on the possibilities – or not – of familial reconnections and relational healing processes. Challenging the dominant assumption that quality of end-of-life care for homeless people should focus on pain and physical symptom management in shelters and healthcare settings (Podymov et al., 2006), as it is often the case with the Western notion of palliative care, the Peeps opened up the possibility of a different conversation, regarding their priorities and aspirations prior to death. This conversation cannot be separated from collective practices of love and care, and their spiritual and relational experiences of the world through whakapapa, that provide and nourish a sense of belonging and spiritual continuity (Moeke-Maxwell, Mason, Toohey, & Dudley, 2019; Moeke-Maxwell, , Mason, Toohey, Wharemate, & Gott, 2019).

The cultural and social support provided by a "whānau-like" fabric on the streets, embodying ancestral knowledge, beliefs and home-making practices (e.g., learning/reconnecting with te ao Māori, and the Māori language, at the public library), which play a vital role in sustaining wellbeing, hope and self-esteem. This perspective counters a view of homeless people as passive victims and highlights their resistance, agency, and the significance of community relationships and connections. These discussions underscored the importance of active listening and suspending judgment when confronted with the everyday lives of the Peeps, as health professionals remain poorly aware of the challenges they face, and their socio-cultural contexts and life conditions on the streets.

An important ethical stance throughout the project was to avoid creating more suffering, or clichés and stigma in relation to homelessness. The script was carefully crafted, prioritising cultural humility (Danso, 2018), sensitivity and respect for the Peeps' experiences. It moved away from a commitment to verisimilitude and realism, which raises important ethical, epistemological and political concerns. Questions of ownership, authorship, breaches of confidentiality, potential harm that could result from the use of direct "data", and the notion of a singular and naturalistic "truth" are pivotal in this context (Smith, 2012).

Aligned with the critical stance of the performance ethnography endeavour, the project embraces the creative power of performance as an interpretative and critical tool by accounting for various narratives and perspectives. SCF has drawn on her abundant field-notes, and memories of shared and embodied emotions throughout the journey with the Peeps, to write a loose and preliminary script that included key messages towards more equity, compassion, respect and understanding as agreed with them. Composite characters, a dialogical plot with confronting interactions and relevant fictional situations were woven into the script to capture the nuances and complexities of the Peeps' experiences. Moreover, to ensure engagement and connection of future audiences in the conversation, careful consideration was given in the script crafting, to avoid a defensive stance that could obscure the messages being conveyed (Gray & Kontos, 2015; Mitchell et al., 2006). SCF then sought collaboration with a drama teacher and students who brought their scenographic and artistic skills to enhance the emotional range and imaginative possibilities (Saldana, 2003). The script was reviewed and corrected by Moana (pseudonym) and Mark (pseudonym), two of the Peeps, before being presented with shared emotions in the community garden where we met weekly. This collective effort aimed not only to create an engaging performance, but also a heartfelt conversation with health audiences, fostering a sense of collective responsibility and care.

Before it is too late

Narrator: Ladies and gentlemen, we now invite you on a journey with two Māori friends, Tāmati and David (composite characters), who have decided to introduce you to the intimacy of their daily lives on the streets, to uncover the hidden part of their struggles and suffering, to share with you their hopes. Their purpose is for you to confront the unexamined assumptions about homelessness in Aotearoa New Zealand, to deeply feel with your open mind and heart their call for presence, recognition and attention (Charon, 2016), so that together you can initiate a healing conversation about life and death, about the unequal value and worthiness of their existences, from their perspectives. We hope after Charon (2016), that you will "affiliate" with Tāmati and David to form a

culturally safe community of care and connection. David is struggling with complex mental health issues and suffers a high burden of disconnection from his whānau. Tāmati experiences significant challenges while suffering an underdiagnosed cardiovascular condition. Their bodies, their souls, their selves tell a story — their story — that David and Tāmati invite you to read aloud to enter in resonance with them. A glossary of Māori terms and scenographic conventions has been included at the end of the play to ease your encounter with the everyday life of the Peeps and the cultural context. The words that are marked with an asterisk refer to glossary terms. We invite you to familiarise with the glossary before reading. Given the disturbances due to the Covid-19 pandemic, the performance project to be diffused to large audiences, including a video of "Before it is too late", has been delayed. Hence, it is a reading version, in three acts, that is presented here. We now leave you, members of the audience, in the company of David and Tāmati.

Act I

Actors, all turning their back to the audience: *David, a homeless man in his 50s, a General Practitioner (GP) with a stethoscope around his neck, a woman in her 40s, a man in his 60s, a man in his 30s wearing a label on his shirt "Mental Health", a woman nurse in her 50s wearing the same label, a narrator.*

Scene 1

Two chairs, a desk, a computer on. The GP sits on a chair, turns to his computer, clicks on, and looks to David who is sitting on the other chair, looking straight forward.

GP: Medical consultation. Time is 11.30 am. A jumbled monologue. David is rambling and I can't get a word in. Time is running short.

DAVID *(agitated)*: All this shit, it's hurting me all the time.

Playing on my mind. Family hurts. I walked away from them.

Now, they've come back into my life. The hurt's back with them.

I've been to the police about that just recently.

'You're a disgrace to your whānau'. I can't be a disgrace to my whānau. We're all fucking offenders and bloody liars.

Going to the cops, it's the only bit of safety I have.

Now they've heard from the law. Get it through the courts. I'll pay the punishment. Better than the shit I'm having.

They're going to bury me. Bury me somewhere.

The police, I've got a better deal out of them. I seem to be catching all the fucking trouble for this shit.

The pills? Not taken for months, they don't fucking work on me! But if I don't take them at all, shit gets real fucked up.

Alcohol? Two years sober.

Drugs? Weed, smoking tinny, no worries.

GP: The monologue continues with the ghosts in his head, with the darkness. There has been no counselling, no aid. Time is over now. 11.45 am.

David takes the script while standing up. He returns striding to align with the row of actors, turning back to the audience. The doctor stays on his chair, holding his head in his hands.

Scene 2

All actors turning their back to the audience, except David who is lying on a bed.

NARRATOR: A small and dark dingy room in a boarding housing. Flickering light, a single bed. No other furniture. 4 pm the same day.

David lies perfectly still on his bed, grounded with a blanket over his head. Only his shoes exposed.

The woman turns to the audience, walks slowly and knocks on a door. No noise. She knocks again, louder. She waits. An eternity of one minute. Carefully, the woman opens the door and enters into the room. Dead silence. She reaches the bed, stops. Waits again. Looks back on the door, hesitates. She wipes her hands on her pants, several time. She leans over and delicately lifts the blanket to the level of the head.

David opens the eyes and pops up on the edge of the bed like a Jack-in-a-box, ready to move on.

THE WOMAN: Jesus! You scared me!

A slightly curved man, in his 60s, wearing old pants, a khaki tee-shirt, bare feet, passes along the stage.

THE MAN *(continuously repeating)*: What's my name? What's my name? What's my name?

DAVID (*exasperated*): Shut up ! You 're going to give me a headache. I can't hear myself think. Get out of here!

The man disappears, *leaving the stage.*

DAVID (*angrily*): They're putting a lot of crazy guys here. It's not right for me when they throw them in here. You don't wanna talk to people who are talking crap all the time.

David puts his head in his hands.

DAVID *(distressed)*: My head is in a really bad place. I don't know which way to move, which way to turn. All this shit, it's hitting me like a sack of bricks. It's all coming down on me and I can't do anything about it. I feel really down and about to give up. Here is where the unwanted people go. I need help, I went for help and I'm still here, nothing has changed.

David and the woman slowly return to align with the other actors, turning their backs to the audience.

Scene 3

Three chairs are arranged in a circle. David sits on a chair. The nurse and the young man sit in front of David, widely distanced from him. The man types continuously on a laptop, laying on his knees. A table with a medical tray, an injection, a phone.

NARRATOR: 7.30 pm the same day in an acute mental health service.

DAVID *(begging*): You're going to put me in the ward. I'm really sick. I don't know what I wanna do with myself. I'm three seconds away from throwing myself off a bridge.

The man is still typing. The phone rings, the woman nurse answers.

NURSE *(turning to David)*: *S*orry David, it's very complicated but we can't admit you tonight on the ward. But we can discuss other options.

David stays silent, crossed arms, bends forward and looking at his feet.

The nurse stands up, preparing an injection, then takes an injection to David.

NURSE (*pulling down David's sleeve*): Here we are. You should feel better tonight. Tomorrow, mental health will contact you for the follow-up, right?

DAVID (*resigned*): How? With what?

The nurse looks at David emphatically but has no answer for him. Staff members return into the row of actors, then David. All turn their back to the audience.

Act II

Actors: Tāmati is a homeless man in his 50s, a nurse, a doctor in his 50s (stethoscope around his neck), a triage nurse, an Emergency Department (ED) health practitioner in his 60s wearing a hospital scrub, a lady well dressed, wearing flashy red lipstick and a showy pearl necklace, a narrator; Voices in the head (3 people, A, B, C). Same dispositions as Act I, all actors turn their back to the audience when they are not acting.

Scene 1

Tāmati and the nurse are sitting on chairs. A table with a computer on. A phone.

NARRATOR: A medical consultation in a community primary care organisation. Time is 8.30 am.

NURSE: Kia ora*

TĀMATI: Kia ora

NURSE (*cheerfully*): Seems I've seen you before or your cousin, maybe? Are your whānau* coming from Nūhaka?

TĀMATI: Yeah.

Tāmati rubs his scalp with his hand.

NURSE: Did you fall ?

TĀMATI: Um…Yeah.

NURSE: When was that?

VOICES IN THE HEAD (*3 people, insistently, turning around Tamati*):When? When? When?

TĀMATI: Um…Three…or may be four months ago.

VOICES IN THE HEAD* (*3 people*, *insistently, turning around Tamati*): Why? Why come today? Not another day?

TĀMATI (*rubbing his scalp again)*: Um… I feel like there's something wrong in my head. It' s moving, you know, like water running down my face.

NURSE: How did this happen?

VOICES IN THE HEAD* (*anxiously, turning again around Tamati*): How? How? How?

TĀMATI: Um…. I fell down …. Um… Three times that day like getting sucked into a black hole. (*Rubbing now his right leg)* And my legs feel like jelly.

NURSE (*looking at Tāmati, smiling with complicity)*:You look very TIRED

TĀMATI (*smiling*): No, I'm fine

NURSE (*insistently*): No, you're NOT. You're tired. Do you understand what I mean ? There's no GP here, so I'm sending you to a GP clinic. It will be free the first time, you understand?

The nurse and Tāmati hug.

NARRATOR: Consultation is over, the time is 10 am.

The nurse returns with the actors, all turning their backs to the audience. Tāmati stays on stage, sitting on his chair and slowly falling asleep.

Scene 2

A table. Tāmati sleeps on a chair, slightly snoring.

NARRATOR: A GP clinic, same day. The time is 10.30 am.

*Dramatic pause**

NARRATOR: Still in the GP clinic. The time is 12 pm.

The doctor turns to the audience, walks toward Tāmati and clears his throat loudly.

Tāmati sits up on his chair, surprised.

DOCTOR: Why are you coming today for something that's happened four months ago?

TĀMATI *(to himself)*: Fuck, it's always been the same question …. (*louder)* um… you know, it's like something wrong with inside my head, like moving inside. And also, I feel …. Um …. (*determined*) TIRED and also, it's SORE.

Medical examination takes place.

DOCTOR: Well, I will call the ED and see if you can get a CT scan for today and email ED the form.

TĀMATI: Hospital? Is there anywhere else I can go?

VOICES IN THE HEAD* (3 people): A:That's where dad died B: They left him C: He died alone.

NARRATOR: Consultation is over; the time is 12.30 pm.

The doctor moves back to the backstage, back to the audience. Tāmati walks on stage.

Scene 3

A chair.

NARRATOR: Emergency Department, 10 km away. People are sitting on a row of old grey plastic chairs, waiting. A TV screen displays the same programme over and over. One hears routine hospital noises including the sound of sliding doors and ambulance sirens. The time is 1.30 pm.

The triage nurse turns to the audience and walks toward the front stage.

TRIAGE NURSE: Why are you here today for a fall that's happened four months ago?

TĀMATI (*hesitating*): Um…. I've been to the GP. He told me to come here.

TRIAGE NURSE (*exasperated*): Wait here.

She disappears on the backstage for a while. Tāmati is anxious. The triage nurse comes back holding a piece of paper in her hand.

TRIAGE NURSE: Go to the reception. Then, wait until we call you but it could take a few hours. It will depend on the flow of patients needing REAL URGENT care.

Tāmati sits on the chair. The triage nurse goes back to the line, turning her back to the audience.

NARRATOR: The time is 4 pm. *(Dramatic pause).* The time is 5 pm. The CT scan has been performed. (*Dramatic pause).* The time is 7 pm.

Sound effects including noise of beeping machines and curtains on the metallic rods.

The young doctor turns to the audience, walks to Tāmati and stands in front of him. He holds a folder in his hands.

ED DOCTOR *(reading aloud and quickly)*: Your CT scan has shown that there was neither involution of the parenchyma overlying the alveolar interstitial space nor any infarction of vital structures or dysfunction of intra capillary pressures (*looking at Tāmati and cheerfully*) Which is GREAT! But we still

don't know the reason you fell down so many times. We need to do more tests. So, go visit your GP first, then he'll refer you to the specialist.

TĀMATI (*looking all around, hesitating, with a stifling voice*): I' m not with a GP.

ED DOCTOR: I see, but ED cannot do the referral. It's the process. You need to be referred by a GP so we can organise the follow-up if you need a treatment and so forth. Does it make sense?

The ED doctor goes back to the lines of actors, turning his back to the audience.

NARRATOR: The time is 8 pm. It is a dark and freezing winter night on the streets.

TĀMATI (*standing up and rolling a cigarette*): Fucking seven hours worrying with just a glass of water. I'm fucking hungry now. Holly shit, I missed dinner at St Marys' church. (*lamenting*) It's the best feed of the week. There's always this old lady with her cake. It gets me wired for the night. She knows how to pile on the sugar. At least, I can stay awake for as long as I can and feel a bit safe with all these guys just hanging around waiting to steal my stuff and trying to give me a hiding.

Scene 4

TĀMATI and the NURSE sit on chairs. A table, a computer, a phone.

NARRATOR: Back to the community primary care organisation, one week later. The time is 9 am.

TĀMATI: Kia ora*

NURSE: Kia ora, Tāmati. Lovely to see you again. How are you going today? You're looking much better.

TĀMATI: Yeah. I feel relieved. I was really worried. I didn't understand all their medical stuff but it seemed all good. I need more help from a specialist though. At hospital, they asked me to enrol with a GP. I don't know how to do that. I haven't been to a GP for so long now. Last time was maybe 5 or 6 years ago in Wellington.

NURSE: Oh, that's quite a long time ago. First, you need official documents: An ID photo, a birth certificate, and evidence of your address; for example, an electric bill or a tenant agreement showing you have an address. Or a sworn statement from a friend or a member of your whānau that certifies you live with them but anyway you'll have to provide an invoice or an official document with their names and address on it.

TĀMATI (*taking out of his pocket an ID and showing it to the nurse)*: Does the photo on here work?

NURSE: Yeah, sure. It's great you have that because it would have cost you at least $55 more to get another ID. For the birth certificate, you can order it online. It costs $33. I'm not sure if you can get it through email though. You'll probably need an address to get it. Or you can go to WINZ* if you are on the benefit. They may provide you with a copy, but not all GPs accept a copy. Otherwise, WINZ will retain the cost on your benefit. Do you have any documents to show evidence of an address?

TĀMATI (*laughing, sarcastically)*: Lucky I'm on the waiting list for housing. It's only been FOURTEEN months. I'm stuck in this town for now. *Pause.* Yeah, I'll get a piece of paper with an address on it.

NURSE: Perfect. Where is this address?

TĀMATI (*hesitating*): Um …. 24 Lake Road.

NURSE: I know that place, it's not that far from Central Care Clinic. Should we try this one?

TĀMATI: Um… I' d prefer the medical centre near the church on Greenwood Road.

NURSE: I know what you mean, but with the address on Lake Road, unfortunately you can't go there. You'd need to find a GP near Lake Road. It's zoned (*looking on the computer).* Not that much, around there. I can give a call to Central Care Clinic and see if they accept new clients.

The nurse gives a call, another one, another one. Soundscape of recorded voices saying "We don't take any new clients. We don't take any new clients. We don't take any new clients".

NURSE: Finally! So, you have an appointment booked for next Friday, the 23rd at 9.15 am at Compass Health on Bolton Street. That's near the Warehouse*. Don't forget, bring all the documents with you. Good luck.

Hugs. Tāmati returns to the lines of actors, back to the audience. The nurse stays on her chair, holding her head in her hands.

NARRATOR: The time is 10.30 am.

Scene 5

A lady stands behind a table with food and a pile of plates. A chair.

NARRATOR: Friday the 23rd, time is 9 am. A foyer of a church.

LADY: Good morning, let me guess…. Tama?

TĀMATI: Good morning. My name is Tāmati.

LADY: I was so close (*laughing*) it's quite hard to remember all the Māori names. (*declaiming loudly*) Today, we have: Hot hand made pancakes with fresh fruit salad and topped with cream. Can I serve you a plate?

Tāmati sits and eats his pancakes in silence. Then disappears backstage. Soundscape of recorded shower noise. Tāmati back on the front stage, smoking a cigarette.

TĀMATI: It feels like I can forget about that GP appointment and go find somewhere to relax. For sure, that lady doesn't even remember my name. But at least, she didn't start her sentence by "Hi, homeless guy! ". Where can I go ?

VOICES IN THE HEAD*: A (*severely*): WINZ*?; B (*more neutral*): Church?; C (*nicely*): Public Library?

TĀMATI: There will be some mates at the library. What's the day today? Friday. Bloody Hell! There's that security guard, he hates us, always yelling: Why should I let you come in? Why should I have to help you, eh? Bloody bastard! I'm fed up with all their questions.

Tāmati turns alternatively to the voices in the head.

VOICES IN THE HEAD* (*insistently*): A: Do you have an address? B: Do you have a paper with an address? C: Do you take any drugs or alcohol? A: Are you on the benefit? B: Which category? C: When did you fall? A: Why are you coming today?

TĀMATI: I feel like shit all the time.

VOICES IN THE HEAD*: A: Housing first*? B: Salvation Army? C: Hot pools*?

TĀMATI: I would have had great time at our hot pools and free my shoulders from pain. But that's always the same shit. Too many rich people living around the area and the council closed it. Like it's in our DNA to be under dogs. Fuck you.

VOICES IN THE HEAD: A: Citizen' Advice Bureau*? B: Pak'n Save*? C: Gardening?

TĀMATI: That's a great spot, the garden, the one of connection. Relax, smoke cigarettes, have a chat with the bros. Yeah, feels like I'm the king of the street, (*smiling*), a luxury streety in my Mercedes, eating the potatoes of our whenua*. Better than the fucking sandwiches they serve at the soup kitchen! I' m the boss. I'll protect the bros from all these crazy fucking gangs. Bloody dealers ! They won't get us.

Act III

Actors: David and Tāmati sit on the floor. Recorded soundscape of street noise. A chorus (5 people) in line turn to the audience. One holds money in his hands, another one a pizza box.*

NARRATOR: Time is endless.

CHORUS (*pushing aside one another*): A: Give them money; B: No, food; C: Make them invisible D: Visible; E: Give them nothing.

DAVID *(coughing a lot)*: Fucking shit, I feel like I'm dying.

TĀMATI: Hey, Bro. Not yet, not the right time. Not the right place.

DAVID: That's the one. I can't afford going back to my whānau*. It'll kill me. Even away from them, I'm going to get hurt. Look at me, Bro, when I got off the streets, I was nearly dead. Now my sanity has returned away from them. And right now, I'm feeling good about my achievement. I mean, I used to wake up on the streets and say to myself, I 'm going to get more cans. If I have three cans, I'm certainly going to end up in a coffin, so I'd go and buy just two so I wouldn't kill myself on the spot knowing I was that close to fucking death. I'd still go and get two cans and not three. If I was still alive after those two cans, I'd go over and get that third can.

*Dramatic pause**

TĀMATI: Seven years I didn't see my kids and my moko*. It's just like I know them, but I don't know them. I mean, I can't even go back to see my whānau*.

DAVID: Do you remember Jack, the bro who died from cancer, last Christmas? He moved back to Wellington to care for his mum. She had cancer. He did all he could for her, trying to make her life on earth as comfortable as possible. He gave up his job and all sorts. And holy shit, she's back in heaven now and him too. He was floating around, staying at friends' places here and there, trying to sort out a rental without a job.

TĀMATI: Yeah, I remember Jack. He was a good dude. It was too late when they found his cancer. One day, I was putting up with that fucking pain in my shoulder. "Eh Bro, I have a talent with spiritual healing. I ain' t been doing it for long time now cos… um… I burnt someone one time with too much heat". He was doing by heat and he just wanted to give me a bit of that gift. He put all his energy on my shoulder, heated up and heated up and suppressed it. Far out, that was great stuff. And always putting aroha* in all he did.

DAVID: And now he's dead too. He never saw his moko before dying. And he never got his campervan or to travel around the country.

TĀMATI: You're right, Bro. Just don't feel it. I'll give my body to medical training so it will cost nothing to my whānau*.

DAVID: I'm planning that day too. I don't want my family at my funeral. I don't care about their protocol or whatever.

TĀMATI: Bro, we're a kind of family, right? Don't give up on life. Not time for your wairua*.

DAVID: That's true.

*Dramatic pause**

DAVID: I'm used to talking bad about my whānau* and that is because I miss them, and I love them so much. That's why I'm talking like that. They're all having difficult times. You remember that guy, last week at the community meal. The bros were fighting. "You're all one. You don't need to fight. Choose aroha". That's not true, bro. I can't choose aroha cos I don't know what's going on with that.

TĀMATI: Stop mixing up your mind, Bro! Let's go for a meal, see if there's some new faces coming.

DAVID: No, Bro. I want to go forward with Hoani Waititi's book. It's really intellect, man, this guy's books. I'm getting it straight away. Te Reo*, that's in my DNA and something I love, made up of structure. I even caught out a kaumātua*one day. He was wrong with connecting the noun with the verb. Without a connector, your sentence is dead straight away.

TĀMATI (*standing up*): Sweet as. I'm not that clever, man.

He leaves the stage.

DAVID *(to himself)*: Connecting ….or …. Dying straight away.

A tui sings. David smiles at the sky then leaves the stage.*

Conclusion

In the pursuit of anti-oppressive research practice, critical performance ethnographic inquiry has usefully provided a meaningful methodology, allowing the voices of the Peeps to be heard by healthcare and allied professionals. The perspectives and concerns of the Peeps are of central importance as a deliberate attempt to build respect, inclusiveness, equity, fairness and a collective commitment forged with Māori homeless communities. This commitment aims to enhance the quality of care provided and support their wellbeing and end-of-life experiences in accordance with the priorities, aspirations and rights of the communities. To bring the project of "Before it is too

late" to fruition the next step involves producing a video-recording of the drama, and disseminating it among healthcare and allied professionals. This dissemination will provide a platform for audiences to offer comments and feedbacks. Notably, several professionals on the ground have already expressed interest in the project and its potential to shed light on the challenges faced by the Peeps within mainstream healthcare services that perpetuate unequal and ineffective care.

Glossary

Alienation effect: Device of distancing audiences from emotional identification with dramatic action for the purpose of making political or social comment through drama, (e.g., position of actors turning their backs to the audience).

Aroha: Love and compassion.

Citizen's Advice Bureau: Charitable organisation that provides free and independent legal information and advice.

Chorus: Convention in which a group of people provides spoken explanation or commentary on the current action.

Dramatic pause: A beat or two of silence to heighten the anticipation of reveal or that can also be used after the reveal.

Hot Pools: For generations, Māori have used thermal waters for medical purpose such as skin and rheumatic conditions.

Housing First: Agency that provides housing assistance with a focus on recovery, community inclusiveness, and self-determination.

Kaumātua: Elders. Kaumātua have an important role within their whānau and tribes, including preserving traditions and knowledge, providing leadership and nourishing the younger generations.

Kia ora: Informal way to say hello.

Moko: Māori abbreviation for mokopuna which means grandchildren.

Pak'n Save : Large discount grocery store.

Te Reo Māori: Māori language. Until recently, Te Reo Māori was threatened with disappearance due to the assimilation policies over the course of the 20th Century that discouraged Māori to speak their

own language. It is considered now as an essential element of cultural reconnection and central for health and well-being. Te Reo Māori was recognised as an official New Zealand language in 1987.

Tui: Endemic bird that has two voice boxes in one body, enabling it to sing in two realms at the same time. Tui are a metaphor for diversity, polyvocality and possibility.

Voices in the head: Refer to actors voicing the inner thoughts of a character.

Wairua: Spirit. Foundational aspect of Māori metaphysics and Māori health, the spirit of a person exists before birth, transits during the physical life to return to the spiritual realm at the time of death. Dying is thus experienced as a spiritual and transitional journey.

Warehouse: Large discount retail store.

Whānau: Extended family network. First link of Māori societal organisation committed to provide collective health and wellbeing, secure identity, intergenerational transfers of knowledge and experience, and cultural heritage. Seriously dislocated by the colonization process, the notion of whānau is nowadays the focus of health policies to support healing, development, and empowerment processes of Māori communities.

Whenua: Land. Must be understood as a place of physical, social, cultural and spiritual nourishment, connections, and belonging.

WINZ: Acronym for Work and Income New Zealand. Welfare agency which provides people with limited financial, employment, health disability and housing assistance. For Māori street people, attending to WINZ is a prerequisite to get assistance, however, it remains an unpleasant, bureaucratic and judgmental experience.

Acknowledgment

We are deeply grateful to the Peeps for their immense generosity, courage, and commitment to the project, for us to learn, grow, and altogether work towards a more compassionate, respectful, and inclusive healthcare system. You are the driven force behind this endeavour, and it is an honour to be a companion. We acknowledge the drama teacher and students for their unvaluable support and involvement in this project.

Chapter summary

Companionship, relationality, collaboration, accountability, embodiment, and (street) performance have marked cycle 2 of this thesis, centred on, guided by and responsible to the Peeps. Within the temporal space of life prior to death, emphasis has been put on the impact of socio-cultural marginalisation, racism, assumptions, misunderstanding of the tapu of death, transgenerational trauma, and unfairness within the healthcare system. The fragility of life on the streets is a reality that cannot be ignored, demanding a comprehensive approach of care (see chapter 3). Importantly, strengths, resistance, and the importance of dis and re-connection cultural and familial processes have been highlighted, challenging Western assumptions about the end-of-life perspectives in regard to the Peeps' contexts. The next chapter presents *a* proposition of a reconnection process with whānau in the perspective of death, that extends upon the collaborative work of "Before it is too late" and draws on the value and practice of whanaungatanga and companionship.

Chapter 7: Within the temporal space of life prior to death (cycle 3)

Narrative prelude

This chapter invites the reader to contemplate the relational disruptions on the Peeps' wellbeing, and conversely, the centrality of the relational dimension across all domains of hauora to sustain *mauri* (the life force) within the temporal space of life prior to death. This cycle was a period of deep reflection and maturation, leading to the emergence of the proposition presented in chapter 3. For the Peeps, the interval between life and death is fragile and tenuous. However, the Peeps guided me towards another level of meaning and understanding of this interval, of a sacred and spiritual nature. Life and death are an inter-related and connected spiritual essence, indivisible, in contrast to mainstream Western understanding of death as an endpoint, that the current divide between life and end-of-life or cure and palliative care may also suggest.

For Māori, the spiritual journey of dying does not end with the physiological death of the *tinana* (body). As mentioned in chapters 1 and 3, tangihanga holds deep spiritual and social significance for Māori, strengthening kinship togetherness, fostering a sense of belonging and spiritual continuity between the living and the dead (Moeke-Maxwell, Mason, Toohey, Wharemate, & Gott, 2019). Tangihanga and death rituals (see for example Moeke-Maxwell, Mason, Toohey, Wharemate, & Gott, 2019; Nikora et al., 2012, for description) can be enacted over several days, within the marae of origin (Nikora et al., 2012). They encompass various aspects such as the disposal of the body, the care given to wairua, the celebration of the life of the deceased, the recalling of the ancestors, and the processes of memorialization and mourning, supported by a wider grieving community (Nikora et al., 2012). The decisions relating to tangihanga, however, rest solely with whānau, without exterior interventions (Nikora et al., 2012). For the Peeps, the spiritual journey of dying and the spiritual perpetuity of life in death through whakapapa often hinges on the possibilities, or lack thereof, of familial reconnections and relational healing processes.

The article presented in this chapter focuses on a reconnection and healing process between Daniel (pseudonym) and his whānau, in which Advance Care Planning (ACP), envisioned as a relational space, expressive of Māori holistic care and wellbeing has been conducive to healing past traumatic experiences and restoring familial relationships and connections. However, this article also delves into dark zones of the temporal space of life prior to death — a space of relational abandonment — where the distressing consideration of suicide is ever-present just beneath the surface. The narrative contained in this article was not motivated by a research agenda. Rather it

embodies whakawhanaungatanga as a sacred wellspring of life, a principle that is also mirrored in the co-authorship of this article with Daniel.

Recognising "the welfare of relationships" (Gergen, as cited in Magnat, 2012, p.33) among individuals, society, ideologies, and worldviews is vital, particularly in a time period saturated by power dynamics and individualism that intensify inequalities. The centrality of the relational approach in our engagement with each other and the world needs to be both practised and defended. Through trusting relationships with the Peeps, cultivated from within their everyday life and perspectives, new conversations have emerged about their priorities and aspirations in regard to death and dying. These conversations encompass essential processes of reconnection at an emotional, familial, and cultural level towards healing transgenerational trauma and the ongoing legacy of colonisation, preserving and sustaining mauri.

The aspirations discussed in this chapter transcend the political and cultural modalities through which "healthcare needs" are typically determined by dominant top-down approaches. These approaches often suffered from restricted views on health and wellbeing that narrowly focus on the physical domain, and linear processes. For example, as discussed in chapter 3, recognising the omnipresent "risk" of dying in the lives of the homeless people is vital. Consequently, considering homelessness as complex life-threatening conditions associated with SHS necessitates that professionals maintain vigilance and attentiveness. This involves anticipating "palliative care situations" throughout the course of homelessness, before it becomes too late, in order to address the dying experiences of Māori homeless people with dignity and respect. Similarly, issues surrounding suicide and suicidal thoughts should be understood in a broader context of transgenerational trauma and the intricate dynamics of societal marginalization. This demands a departure from the biomedical view of mental health and an expanded understanding of the socio-cultural and historical factors influencing mental wellbeing (Durie, 2001; McNeill, 2009; Rangihuna et al., 2018; Rimke, 2016; Woodard & O'Connor, 2019).

Therefore, it is vital to demarginalize the space in which the "healthcare needs" of the Peeps are currently confined by exclusionary processes and entrenched assumptions. Establishing and strengthening a relational zone of accountability wherein the voices of the Peeps are respected and listened to is both critical and pressing. As the reader will notice, the article underscores the critical importance of Māori spaces, led by respected *kaumatua* (elders), community members and Māori professionals. This stands as a critical recommendation to address the complexities and uncertainty inherent to the temporal space of life prior to death, to support healing processes, and to improve the wellbeing of the Peeps in a culturally safe manner.

Upon reflection, the article can be viewed as an exemplification of a comprehensive approach of care, as discussed in chapter 3, which recognises homelessness as complex life-threatening conditions associated with SHS. As such, the use of ACP, as detailed in the article, aligns with a comprehensive approach of care intended to alleviate severe health suffering throughout the whole course of homelessness. It is worth noting, however, that this article has not been initially written with this conceptual framework in mind. The conceptualisation emerged over time, retrospectively, aligning with a CaST approach. Ultimately, the narrative presented in this article conveys a message of hope and care, while also recognising the profound ontological distress that may threaten the existence of the Peeps, as relational beings and embodied spirits.

The article aligns with the aim of this PhD, which seeks to understand how the existence of the Peeps can be sustained and flourish in life and in death. The article is cited as: Charvin-Fabre, S., Moeke-Maxwell, T., Stolte, O., & Lawrenson, R. (2022). Can Advance Care Planning (ACP) be a relational healing space for Indigenous homeless people in Aotearoa New Zealand? *Mortality*, 1-14. The article is reproduced with the permission of the journal titled *Mortality*.

Can Advance Care Planning (ACP) be a relational healing space for Indigenous homeless people in Aotearoa New Zealand?

Introduction

Advance care planning (ACP) is defined as a voluntary process of discussing and sharing with loved ones and/or health professionals personal values, life goals, and preferences regarding future medical care. Although traditionally located within a holistic palliative care framework, ACP may take place at any stage of health. ACP aims to help ensure individuals receive preference-concordant care over the course of a serious illness, should decision-making participation be impeded (Ministry of Health, 2011). Ideally, individuals will discuss their preferences with spouses and families before completing an ACP form to share with their medical doctor thereby transforming their preferences into a legally binding agreement.

Tonight, sitting at my desk[19], in my home office, I cannot avoid thinking how advance care planning as a process, while relevant, does not suit the life and death concerns of my friend Daniel

[19] This reflection below is those of the first author.

(pseudonym), a Māori (indigenous people of Aotearoa New Zealand) man who is homeless. According to the New Zealand official definition, "homeless" means to lack housing (Statistics New Zealand, 2015a). For Daniel, being homeless means to stand without a place to belong to, to relate and connect with. Severed from the loving ties and support of his *whānau* (family, including extended family and friends) and *hapū* (sub-tribes), Daniel lives with the uncertainty that his embodied *wairua* (spirit) will return to his ancestral land at the time of his death, allowing him to be inscribed into genealogical relationships (*whakapapa*) of a spiritual order. I contemplate the magnificence of the kuaka bird (bar-tailed godwit), wings flapping, drawn on the book cover of "Whenua ki te Whenua", an introduction to the advance care planning guide, intended for Māori whānau. The kuaka is said to accompany the wairua of the departed back to the spiritual homeland of Hawaiki. I have just finalised the advance care plan for Daniel, according to his wishes. Tomorrow I will give it to him. His words float on air, moving inside my office. I wander with them, wondering if his wishes and most sacred aspirations for his remaining life and end of life will reach a shore, find their proper home, and like the Indigenous kuaka, settle on their own land?

We provide an autoethnographic reflection of an ACP conversation that the first author, (Sandrine Charvin-Fabre, SCF) had with Daniel. Envisioned as a relational space, expressive of holistic care and wellbeing, ACP has been conducive of returning Daniel to his home land, his whānau and hapū to receive healing. In the Māori world, genealogical connectedness is the foundation of relatedness and belonging to the collective, the land, the ancestors and the sacred that gives a sense of self. The dislocation of familial relationships and subsequent associated losses, as experienced through homelessness (King et al., 2016) is source of intense suffering, too often silenced by homeless policy as well as health professionals. The perspective of death may become a cataclysmic event, troubling a sense of belonging and spiritual continuity, and the assurance of afterlife togetherness, bonded and related through *whakapapa* (genealogical connections). The perspective of death may inscribe into one's life in a way that the future dramatically collapses into the present.

Retrospectively, SCF believed that sharing the narrative of that ACP conversation fell within her ethical researcher responsibility given that ACP potentially could open a relational space of healing for many Māori people who experience the fracture of homelessness and subsequent suffering. However, Daniel is the guardian of his story, a story of relations with others that engages broader communities, connections and responsibilities. SCF asked Daniel if he would like to share his narrative with others. "Remember, I have always wanted to be an ambassador for my people who are on the streets. No one should have to live on the streets, especially women and children" he replied. Daniel has, with his habitual generosity, participated in the elaboration of this ethnographic narrative, and decided which parts of his story needed to be retold and how. For the most part, this

article has been written, according to the ethics of "collaborative and relational autoethnography", where the storyteller and the story listener are intimately connected, joined in mutual friendship and dialogic exchange (Ellis & Rawicki, 2013). Daniel has preferred not to be included as co-author of this article. However, Daniel and SCF, a non-Māori migrant researcher of Basque ethnicity, have fully shared the construction of that story and its meaning, becoming narrators together. By giving priority to *whakawhanaungatanga* (building relationships and connections), relational autoethnography diverges from the more conventional approach of autoethnography that draws upon "the personal experience of the author/researcher for the purposes of extending sociocultural understandings" (Sparkes, 200, p.21). From within the dying space, loss of meaning and disruptions of cultural and spiritual relationships as the distinct expression of homelessness for many Māori people, relational autoethnography is apt to collaboratively and meaningfully create sense-making and a shared narrative (Bishop, 1996). It also calls for people, as relational beings, to resonate with the story, to care about it and do something to act (Ellis & Bochner, 2006; Niemeijer & Visse, 2016). Tess Moeke-Maxwell (TMM) is a Kaupapa Māori and end of life researcher and founding member of the ACP Mana Enhancing Design Partnership Team for Māori. TMM and SCF entertain a research friendship that has grown from the informal medical support that SCF provided to TMM when her new born mokopuna (baby grand daughter) died during the Covid-19 national lockdown. SCF worked in her home country as a doctor in palliative care alongside marginalised populations and contributed to develop palliative care in paediatrics, before moving to the South Indian Ocean area where she practised as a General Practitioner in multi-cultural settings. She has ceased her medical activity since she has been in Aotearoa. Ottilie Stolte is a health researcher who has researched poverty and inequalities alongside Māori colleagues for 15 years. Ross Lawrenson is a specialist public health physician, a former General Practitioner and Professor of population health who has been researching inequities in cancer for many years. He has long standing interest in palliative care and chairs the Waikato DHB Palliative Care Steering Group and is a former board member of Hospice Waikato. Ross Lawrenson and Ottilie Stolte both supervise SCF's doctoral work. Tess Moeke-Maxwell provides cultural advice on SCF's research project. Collaborative work extended beyond SCF and Daniel, and all co-authors have worked collaboratively on the manuscript. This work has received the approval of the Human and Research Ethics Committee of the University of Waikato.

Being friends

Daniel and I first encountered each other in August 2019. I was in my first year of doctoral research aiming to understand the healthcare needs of homeless people prior to death in Aotearoa

New Zealand. I volunteered in a local not-for-profit organisation, supporting the homeless community of a city where I have been living for three years. Volunteers and 60 to 150 homeless people (most of whom are Māori) gather in the downtown public carpark once a week. Assuming a double role of informal doctor and researcher, I provide basic care to men, women, elderly and children. Most of the persons present in the carpark have been disengaged from the mainstream healthcare system for years, with few possibilities to access regular sources of care, due to the important structural and personal barriers they experience (Siersbaek et al., 2021). Anecdotally, we share some respite, love, compassion, care and a sense of human connections within our relationships.

In the carpark, this evening, the night is particularly freezing and dark. Street lighting does not work. "The city council has forgotten to pay the bill" claims a man, with a mocking voice. "Hey, Doc, do you want more light?" It is the voice of Tony (pseudonym) at my back. "Thanks, all good. We will manage with the light of my phone. We have nearly finished" I reply. Jason (pseudonym) directs the beam of light above the palm of his hand. Still some fragments of glass to remove. "Not too thick- the dressing Doc, you know that. I need my hand for working tomorrow" said Jason with a complicit smile.

I remove myself from my moment of privacy with Jason. Daniel stands against the wall, his head tilted to his right shoulder. He stands a bit apart from the group, as always. The lights of cell phones, like a ballet of fireflies, wag around the pots of hot coffee and meals. Daniel is relieved to finally have his surgery planned for next week. The operation has been deferred several times due to the surgery backlog induced by the national Covid-19 lockdown from March to May 2020 in response to the spread of the virus across the country. Being in his 60s, Daniel's vertebral column plays tricks and he expects much from the operation in the hope to regain better mobility. "You will visit me at hospital?" Daniel asked me. "Of course, I will" I replied, cheerfully, trying to hide my concerns about how things will go for him at hospital and afterwards.

At that time, Daniel was living in a boarding house. The interior of the building perspires with decrepitude, abandonment and denigration for the men who "have no choice but to live there" as the New Zealand official definition of homelessness would describe the situation (Statistics New Zealand, 2015a). Additionally, for Daniel, the boarding house is nothing more than a place to sleep and to prepare coffees, with milk and a lot of sugar. The sugar is a habit that Daniel has kept after four years on the streets to help him to stay alert and safe during the nights. He prefers to read his bible in places of his own, guarded like treasures in the interstices of the city.

The surgery went well and Daniel has been discharged Into a rest home for three weeks. After that time period, he will go back to the boarding house, no matter what his concerns, needs or wishes are. The morning of his discharge arrives and Daniel's immaculate room at the rest home has the appearance of a battle field. Daniel is sitting on the remote-control chair, his frail body, curled unto himself, prostrate. Amongst his things scattered on the floor, I recognise his bible, laying open, the block of pages dislocated from its cover. It is not the first time I have seen this. It is always the sign that the suffering resulting from Daniel's life story is over-flooding what he can contain. I pick up the bible. "It's a liar. The bible is a liar". His voice is sharp. "The dead punish me; I hear their voices".

I have entered the Māori world by its "ultimate reality" (Marsden & Royal, 2003), the spiritual world, a world of beauty, creation, mystery in which life and death stand in an absolute relationship, unified by *wairua* (spirit). It therefore comes as no surprise that the dead converse with the living, and may continue to exercise a guiding presence as a living part of a narrative network of genealogical relationships and spiritual connections (Mark & Lyons, 2010; Nelson-Becker & Moeke-Maxwell, 2020). With no cultural comparison, I reflect on my own conversations with my father who has been dead for 30 years, our souls maintained, bonded and connected across the vast universe and over death. Although I was not surprised, I had the immediate "certitude" that the nature of the spiritual conversation Daniel had with his dead during the night was a terrible affair, in the order of a cataclysm. I did not associate Daniel hearing voices of the dead with mental health issues or psychotic manifestations. For many years, I practised in the South Indian Ocean area, where porous borders of different cultural and spiritual representations of disease and mental illness co-exist, where the vast universe of sickness is plural. My practice has been a "nomadic" one that has offered me insights to navigate from certainty to uncertainty about the dominant representation of disease. At that precise moment, in the immaculate room, I did not challenge my intuition with cognitive problems of representations. I "knew" that the line between death and life had become extremely tenuous.

"They [my family] are going to bury me somewhere and forget me". Daniel's words strike me deeply. As for many Māori people who experience homelessness, Daniel's life is a complex story of abuse during his childhood, exposure to early death and ensued addiction, all of which has pushed Daniel to escape his whānau and resulted in dislocated relationships with his community. For many Māori people who are on the streets, trauma events do not stand in isolation as solely a personal affliction, but are a reflection of the trauma of colonisation that has passed down across generations, at a collective level (Wirihana & Smith, 2014). Attempts to reconnect Daniel with his whānau have most often failed, making him feel more isolated, distressed and hurt. He was also missing the support of participating in the everyday life in his *marae* (tribal gathering place, land, building),

preparing meals for his community in the large kitchen, and sharing collective practices and values that had, in the past, provided meaning to his existence, and a sense of relatedness and belonging (King et al., 2016).

I was standing in this room, in a "zone of abandonment" (Biehl, 2013), where the magnitude of multiple losses produces someone's "dying to life". At this point, the loss of meaningful connections, of social, cultural and spiritual resources from Daniel's community, the loss of roles and participation with his whānau and community's life, the loss of personal-worth, the shame, and the anticipation of a loss of future genealogical connections was collapsing into an extreme form of ontological devastation.

"What would you like?", I responded simply after a long silence, holding his hand with mine. There was only space for care without compromise, as those that exist within sincere friendship.

A relational space for Advance Care Planning

Over the following weeks, Daniel shared with me the best and the darkest parts of his story, his regrets and hopes, his love for his whānau, and his aspirations for his life, end of life and after death care; they combine towards the same reality. He often told me how our conversation was "healthy". However, I felt that, in the face of death, I would be unable to honour Daniel properly. Within the healthcare system, I reflected that if Daniel became incapacitated and unable to speak for himself, without his whānau by his side, I could possibly be in a position as a friend and as a doctor to advocate for him. I would be able to care for some of his emotional and physical concerns, and be present for him. However, I knew I would be of no help to provide him with the appropriate cultural and spiritual support to prepare his spirit to transition to the other side of the *ārai* (veil) (Moeke-Maxwell, Mason, Toohey, & Dudley, 2019). I recognised I would be unable to recite *karakia* (prayers, chants, incantations) that form part of Daniel's existence and are needed to accompany him throughout his days. My friend also shared with me the intense turmoil that his wishes for his final arrangements, his *tangihanga* (funeral rituals) and his burial at his *urupā* (ancestral cemetery) would likely to remain unknown from his whānau. Yet, I understood that it would be impossible for me to do anything, especially as the tangihanga is informed by whānau decision-making processes without any external intrusion (Nikora et al., 2012).

On the basis of paternalistic assumptions, the relevance of engaging with homeless people in an ACP conversation has been rarely considered, since it has been presupposed that concerns

about death and dying are not among survival priorities, such as seeking shelter or food (Hubbell, 2017; Song et al., 2005). However, whether I practised on the streets of Paris (France) with homeless people, in palliative care, or in the South Indian Ocean area, too often, the zones of abandonment created by many forms of exclusion processes, has rendered the experience of dying and death itself trivialised, even negligible. I often surmised that ACP could act as a safeguard against the stigma and discrimination experienced by homeless people within the mainstream healthcare system, and perhaps would open a space of listening, consideration; a space for respect for people who are likely to be isolated, or unsupported at the end of life, denigrated of their agency and rights, and blamed for their own misfortune. Although still marginal, research that has invited homeless people to engage into ACP conversations has been welcomed with high rates of ACP completion and surrogate decision-maker designation (Leung et al., 2015; Song et al., 2008; Song et al., 2010). Homeless people have expressed feeling less worried about their end-of-life care and after-life, compared to being left alone on the streets or in hospital, uncertain if their preferences, beliefs, and wishes would be heard and honoured (Bartels et al., 2008; Ko & Nelson-Becker, 2014; Leung et al., 2015; Song et al., 2005; Song, Ratner et al., 2007; Tarzian et al., 2005). Research also reports that when the ACP process has been engaged through shelter-based interventions (Leung et al., 2017) and in primary care settings (Kaplan-Weisman et al., 2020), homeless people have been more likely to have their care preferences respected during subsequent hospitalisations. The ACP process has been facilitated by receiving professional guidance (Leung et al., 2015; Song et al., 2008; Song et al., 2010) and using adapted forms (Song et al., 2010; Stone et al., 2019). However, qualitative studies that have genuine involvement with Indigenous First Nations people facing homelessness are rare. In the few that exist (Bartels et al., 2008; Song, Ratner et al., 2007), how ACP has been used by researchers and/or First Nations people in regard to distinct worldviews, values, beliefs and perspectives on homelessness (Peters & Christensen, 2016), health and well-being, death and dying (Duggleby et al., 2015) has not been examined.

Offering Daniel the opportunity to engage in an “advance care planning” process, has matured slowly because the fact remains that the primary goal of ACP is defining the future healthcare experience from a biomedical perspective and according to the Western notion of autonomy. I assumed that for Daniel the latter would mean little. I could feel how a part of him was dying in life because he was bereft of relationships with his whānau. Thinking of his death, he imagined dying within a network of spiritual and familial relationships, connected to the land of the ancestors where he could rest with sacristy. I could feel how deeply he was hurt and how he thought that his desire would likely to be out of reach. I thought that if this ACP conversation happened, it would be in a relational space from which Daniel may make sense of his future and situation. At the

beginning of my research, TMM suggested that I turn my attention to ACP and homelessness in relation to the unique significance of death and dying to Māori as intertwined with the Māori holistic approach of life, health and well-being. *Te whare tapa whā* (Durie, 1998) is one model amongst others that uses the metaphor of a *whare* (house) to conceptualise Māori views on health and wellbeing. Rooted in the land, the four pillars of the house stand in dynamic inter-relation and connection, harmony and balance, each pillar representing a dimension of health: the physical (*tinana*), the emotional and psychological (*hinengaro*), the social and familial (*whānau*) and the spiritual (*wairua*). Introduced by TMM, I had the opportunity to meet up with Veda (pseudonym), a Māori woman, who manages the Advance Care Planning project regionally. Veda, generously, shared with me her experience, expertise and view on ACP. Importantly, Veda pointed my attention to a storytelling approach of the ACP conversation that interweaves past, present and future. Storytelling creates a shared story, but also a shared present where the deceased exist as integral part, and where the future may promise a genealogical linage (Jonsson, 2015). Within the four pillars of the whare, protected and guided by the wairua of his tupuna (ancestors), a relational space of care, wellbeing and peace may exist for Daniel to sow the seeds of his story into his land for them to grow, flourish and join the infinite through whakapapa, as a home promise.

The ACP journey towards reconnecting

Daniel and I sit on the terrace of the coffee shop where we often meet to share a breakfast, as we converse and pursue our writing sessions. This is our weekly routine. The manager of the café does not look at us with suspicion and Daniel feels safe and comfortable here. A few weeks ago, I proposed to Daniel that he thinks about the opportunity to engage with an "ACP story-telling conversation". He has taken time to examine "Whenua ki te Whenua" and ACP guidelines, he has asked me questions on legal issues, and then said, with a large smile illuminating his face "I want to do that and I want to complete the [ACP] book". For Daniel, first and foremost, ACP is about telling his story, with his own words, free of any forms of constraints, including those of research, and expressing his wishes for his after-death care. For him, it is a kind of spiritual testimony. It took approximatively eight weeks to go through the ACP journey. Daniel reads the guiding questions, according to the order of his priorities and concerns. When the wording was too complicated, abstract or conjectural in terms of his future medical care, I reformulate and adapt the questions to enable him to fully understand their meanings. Discussion about future healthcare treatment and choices are of less importance for Daniel. He is very clear on what he would or would not want in specific medical circumstances. As a friend and doctor, I have accepted Daniel's request to be

included in discussions with health providers as a proxy in the event he is unable to make decisions for himself and is not supported by his loved ones. He is reassured. It is not at the level of physical care or, at least, not only at this level, that Daniel locates his priorities and aspirations for his life and end of life, nor the ACP conversation.

At his own pace, Daniel finds his way, in its own intimacy or while sharing with me parts of his story, feelings and emotions. I take notes for him in a large note book. It does not belong to me and he knows it. It is just easier for him to proceed like that. Then, at home, I put his words into sentences. Daniel reads again, rewords, corrects, erases or adds something of importance he had thought about in the interval of time between two breakfasts. Some days are more peaceful than others. He goes back in his past, stops at the intersections, the crossroads of his life, reflects on the tracks he walked on, and on the tracks he imagines for his future, weaving his own *kete* (basket) of meaning across the ocean of time.

Reconnecting with whānau

Daniel is not at our usual meeting spot. I drive to the coffee shop, hoping he would be there. I do not have very good sight from that distance but I recognise his silhouette. "Sorry, I couldn't wait. Do you have the paper?" he asks me, excited and anxious at the same time. Our coffees and sausages will wait. Daniel reads the final version of his advance care plan, his story that I printed last night, in silence, and focused. Still silent he signs at the bottom of the document and turns his face to me. "Now I can go see my whānau and share it with them". His voice is peaceful and to my eye a profound joy illuminates him. My heart leaps. One day, I had asked Daniel what wairua meant for him, apart from the simple Māori-English translation of spirit. "Wairua is a miracle, a world of infinite possibilities", he replied.

Daniel is enrolled with a GP with whom a minimal relationship has been established. Despite that, and at Daniel's request, I provided his GP with a copy of his advance care plan, to be recorded in the health information system. Hospital staff and primary care professionals could access the document if needed through Daniel's National Health Identity number. For Daniel, it was a kind of insurance that his choices and wishes will be respected at best. Beyond that, the security bestowed by the legality of the document has merged with and has recognised Daniel's legitimacy to exist as a relational being, not reduced to his body, and hence to secure his fragmented identity in life and after his death. At the time Daniel completed his advance care plan, he moved from the solitude of the boarding house to transitional housing offering a more supportive environment in the presence of a Māori social worker with whom he has built a trusting relationship. The three of us had

several *hui* (gathering). The social worker was very clear about what Daniel wanted as a result of the ACP transformative process. With his support, step by step, Daniel has engaged into a process of restoring connections with his whānau, even though it is a fragile, and time demanding process. According to his wishes, he has shared with his family his advance care plan that contains his most sacred aspirations, not only for his end of life and afterlife but also for his remaining time of life. He has created a place where he could tell of his hopes to find his place back amongst his whānau; a place for him to be included into a narrative that maintains and extends the ties with the living to both sides of the grave through genealogical connections, to be recalled and honoured as an ancestor and be buried with sacredness in his urupā, his wairua participating in the broad cosmological story. A few weeks later, as part of the reconnection process, Daniel asked for my help to write a *korero* (speech) intended to be shared amongst persons belonging to his *iwi* (tribe) that he identified to be important for him. I felt that I was not the best person to endorse that responsibility, not being Māori. However, I accepted as I felt that to be true to our mutual friendship, respect and trust was the enactment of the Māori values of *manaakitanga* and *whanaungatanga*. This reflects building and nurturing relationships, and caring with compassion about people with a sense of obligation and mutual respect (Mead, 2016).

Challenges for ACP within the context of Māori homelessness. Practical implications.

How many Māori people like Daniel live on the streets, in their cars, in garages, in the anticipation of death experienced as an all-encompassing devastation because people already believe or live (which is, at this point, the same thing) as if they were already "ex-communicated" from the relational world? How many people like Daniel feel themselves *whakamā* which means feeling withdrawn, self-alienated at a physical, psychological and spiritual level from the capacity to connect with significant others and oneself to the point that *mauri* (energetic life force) dissipates and disperses away from them (Love, 2004; Smith, 2019; Woodard & O'Connor, 2019)? How do people who experience homelessness, cope or not cope with the perspective of dying, alienated from their whānau, set apart from a cultural framework of care that fortifies, nourishes, provides meaning, a sense of belonging and of spiritual fulfilment and continuity at the end of life (Moeke-Maxwell & Nikora, 2019)? To what extent, do such disruptive contexts of multi-dimensional loss of meaning, upsetting anticipation of death, and feelings of whakamā lead to suicide which is the second leading cause of death within the homeless population of New Zealand (Charvin-Fabre, et al., 2020)? Even though suicide does not stand in isolation, given the strong link evidenced between cultural identity-cultural alienation (Durie, 2017), it is reasonable to ask the question. We cannot

answer these interrogations because we simply do not know. But we must ask these questions because, importantly, they are relational and ethical questions. They tell us about our finitude, our primary corporeal vulnerability of being born naked, without defences other than our inter-relationality and inter-dependence to preserve and sustain life. These questions relate to the forgiveness of our foundational vulnerability, and to the disruption of our relational responsibility towards all people.

ACP is envisioned as a relational place, expressive of holistic care and wellbeing, and following a storytelling approach. In that way, ACP may be restorative of meaning and conducive to healing for Māori homeless people who experience the disruptive process of relationships and connections in multi-related domains inclusive of the emotional, familial, and spiritual. The narrative that Daniel has shared accounts for a transformative process that might occur if the ACP conversation is located in a place of hospitality and flexibility and extends beyond that for which it has been originally conceived. It is not to say that aligning future medical care with personal preferences and beliefs is not important, especially for people who experience more often than not discrimination within the mainstream healthcare system. Rather it means to extend the ACP conversation beyond the sole bodily-centred aspect of healthcare that prevails within the bio-medical culture.

For ACP to be conducive of healing, the process would be better situated within a network of professionals who would be able to respond adequately to the subsequent demands that might arise from that process. Collaboration is needed. In the context of homelessness, we recommend that ACP be a Māori place, in the first instance, led by respected Māori *kaumatua* (elders), community members or health professionals, and operating within the context of a Māori cultural framework. Māori healers, *rongoā practitioners* (traditional practitioners) and *kaimahi Māori* (Māori community workers) could have an important role to play in bridging the ACP gap for Māori who experience homelessness as they are likely to forge meaningful relationships with those they care for. From Daniel's narrative, four key action domains could emerge from ACP, depending on each person's situation: 1) Establishing restorative connections with whānau and providing appropriate and consistent support over time; 2) Establishing connections with whānau in the perspective of the end of life and after death care; 3) Appointing a nominated person or an enduring power of attorney to be included in discussions about future personal care and welfare. People could designate members of their whānau, hapū or iwi who they identify as important to them but with whose ties have been loosened over time; 4) Addressing the needs and distress that may arise from expressing trauma events and offering a space to weave those experiences within a collective and transgenerational experience of trauma (Wirihana & Smith, 2014).

Consequently, offering Māori homeless people the opportunity to engage with an ACP process requires the identification of physical and relational places where people may feel welcomed, and culturally and emotionally safe. Specific social services dedicated to homeless people, some primary healthcare organisations and/or marae could be identified as such places. These are places where trusting relationships have already been established or could be established over time, based on non-judgmental attitudes, compassion and care, within a culturally safe environment. Lastly, most people who live on the streets for long periods of time are disconnected from the mainstream healthcare system, and are rarely enrolled with a General Practitioner. They access healthcare on an irregular basis, mainly through Emergency Departments, and it is unlikely that health professionals will provide adapted guidance and explanations regarding future medical care preferences. It is therefore important to provide the assistance of trained ACP professionals who can also ensure the recording of the ACP document in the health information system.

Final comments

Relational ethnographic inquiry has usefully provided a meaningful methodology to explore one person's experience of engaging with ACP, in the context of cultural, emotional and spiritual disruptions of relationships, connections and supports as the distinct expression of homelessness to many Māori people. From having nowhere to stand, relate and belong to, ACP offered to Daniel and his whānau a pathway to heal the "wound made to the soul" (Duran as cited in Pihama et al., 2014) through trauma and to restore with peace and dignity nurturing and meaningful familial bonds and relationships that provide Māori people with a collective sense of self, home and belonging. Further, through healing and re-establishing the vital relational link, the possibility of fulfilling the sacredness of Māori end of life and death customs has been restored. Importantly, these relationships will sustain Daniel until the time comes for his wairua to transit to the other side of the ārai (veil) as he passes from this realm to the next (Moeke-Maxwell, Mason, Toohey, Wharemate, & Gott, 2019).

A story-telling approach of the ACP conversation is essential to create a Māori space within which disrupted narratives might get a sense of spiritual and relational connection in a way that is both responsive to a broader disruptive context, and is also meaningful to the person. According to Daniel's own words, homelessness is a "near to death experience". Therefore, ACP is arguably conducive of healing, restorative of mauri (energetic life force), and can also be adapted in form, content and delivery making it acceptable and useful to the people who experience the fracture of homelessness. For example, people may not feel as threatened by medical jargon that too often reflects processes of marginalisation and subjugation experienced by Māori homeless people within

the mainstream healthcare system. Adapting the current ACP form in a version that would acknowledge and reaffirm the values and beliefs reflecting Māori views on health and well-being, on death and dying, could offer a space for Māori homeless people to be affirmed in their worthiness and uniqueness as embodied spirit and relational beings, on their own terms. Thus, a culturally informed ACP conversation provides a space for them to reconnect to the sacred home, the places and spaces that resonate deep within their wairua (spirit).

Daniel has journeyed far to reconnect with his whānau and receive healing. His words resonate for all:

> 'Sometimes, I recite my *pepeha* (cultural process Māori use to introduce themselves in relation to genealogical relationships and connections to people and place). I relate to land features; mountains, my iwi, my hapū, my *wharenui* (ancestral meeting house) and all these things give me incredible strength and they are who I draw life from. They are my friends, Te ao Māori (the Māori world), hence I am never alone. Our mountain, Mauao, was not there before. It was up in the Hautere forest but because it was in love with Puwhenua, whose heart already belonged to Otanewainuku, it summoned the *patupaiarehe* (bush fairies) to take him out and submerge him in the depth of the ocean, all because of his broken heart. They dragged him by night. The dawn set upon them and they had to leave. Before they went, they said "This is goodbye forever but before we go, we will name you." Mauao was caught by the day.
>
> I know this *pūrākau* (story) is real. Why would Māori come out with these things to believe in them if they were not real? They wouldn't. That is us. Inside the Tauranga Moana harbour there are three mountains. I was told they were whales but I did not believe it. "You're mad" I thought. Years later, I was on the beach facing one of them and I saw with my eyes, not my imagination, its tail. The tail was as huge as the mountain and it seemed I was caught forever. There are three whales, a mother, a father and a baby. They are called Maungamana (te mama/the mother), ko Kopukairoa (te tane/ the father) and ko Hikurangi (te pēpi/the baby). They were taught to guide *te Mātaatua* (one of the ancestral canoes) from Hawaiki. The story goes on. The mother got stranded and tried to get to the soul of the ocean. She drank out of a magic well, died and turned into a mountain, caught by *taniwha* (sea creatures). I know this is real, that taniwha exist. When a friend of mine told me that he saw a lepricorn, I believed him.
>
> This is a *whakataukī* (proverb):

He kōtuku rerenga tahi

It is a bird of single flight seldom seen — speak once and never been forgotten.

Our people, those who are on the streets, must believe in themselves and cherish te reo Māori. It is a treasure language, te wairua tapu. It's gonna bring them home".

Acknowledgment

We are deeply grateful to Daniel for courageously sharing his story about his experiences so that other people can learn and grow. We acknowledge Māori leaders who provided their feedback on the manuscript.

Chapter summary

To effectively reduce the health impacts of homelessness, it is crucial to address the broader relational context of disruptions across all inter-related domains of hauora. This chapter has delved into a relational and holistic approach of Advance Care Planning (ACP) as a potential means to foster healing processes for Māori homeless people and their whānau, both in life and in death. The significance of the story Daniel has shared will be promoted by the New Zealand Health Quality & Safety Commission through its national ACP campaign, known as *Kia Whakarite.* In the next chapter, I conclude the thesis by reflecting on my research journey with and for the Peeps as a non-Māori PhD student, bound to them by the responsibility of our shared mortality, albeit unequally. Additionally, I highlight elements that could contribute to a comprehensive approach of care.

Chapter 8: Moving back and forward

Life, death and homelessness in Aotearoa New Zealand lay at the core of this study. The Peeps have been its beating heart and soul. Exploring the unknown, and proceeding from death to life, this study began by uncovering extreme, unjust, avoidable and invisible death inequality (chapter 5). On average, a 30-year disparity in life expectancy stands as a sobering demarcation between people with "no fixed abode" and the domiciled population, further compounded by 76 % of avoidable mortality, and frequent lonely death in the public space. This abyssal gulf parallels historical life expectancy discrepancy, reminiscent in proportion of those that existed between Māori and the new settlers by 1887 (Pool & Kukutai, 2018). In the hierarchy of societal and moral valuation of existences, the value of homeless people' lives is situated at a position where their legitimacy to exist is denied, their existence on the streets often hinging on their resistances (chapter 6). Further, the denial of existences, or "legal inexistence", is accompanied by the invisibility of this denial. The identification of homelessness in health and mortality databases is arduous, rendering an appreciation of the "healthcare needs" and situations almost infeasible (chapter 5). Against Te Tiriti o Waitangi principles, for homeless people, the politics of life have a politics of death for a horizon, but this horizon remains obscured (Fassin, 2009). The deaths of homeless people are thus not only unequal, unjust, untimely and avoidable but also remain invisible and occluded (chapter 5).

This study, however, has not been only about death inequality and avoidable mortality, but, first and foremost, about life, until and in death. Guided by relational ethics, and using a critical CaST approach, aligned with Tikanga Māori and Māori ways of knowing, this study has explored the "temporal space of life prior to death", with and for the Peeps, and Māori homeless communities. This space has been conceptualised as a relational zone of uncertainty and potentiality wherein complex "life-death" dynamics operate (chapters 1 and 3).

The impetus behind the conceptualisation of the "temporal space of life prior to death" has been the ethical obligation to balance the binary and dichotomous approaches between prevention of premature mortality and palliative care provision at the "end of life period" on one hand, with the equally vital obligation of preserving the right to life, and honouring it until and in death on the other (chapters 1 and 3). This essential aspect has penetrated every facet of the study, resulting in a two-fold proposition: Considering homelessness as complex life-threatening conditions associated with SHS, necessitating a prevention AND a palliation approach encapsulated in a more comprehensive approach of care (chapter 3). Aligned with the recommendations of IAHPC (Radbruch et al., 2020) and the *Lancet Commission* (Knaul et al., 2018), this proposition recognises and reflects the intricacy

of life and end-of-life experiences associated with homelessness, where boundaries become blurred in the face of the omnipresent "risk" of dying, often insufficiently acknowledged by health and allied professionals (chapters 3 and 5).

Moreover and critically, the political and cultural tensions resulting from my own presence as a non-Māori person, engaged with the Peeps under various hats, the sensitivity of the topic, and the uncertainty inherent to explore the unknown have resulted in a unique, distinct, and complex study process, that could be considered as an "insight" in itself. I would describe this process as one of creativity, collaboration, and companionship. The study has been profoundly influenced by the guidance of the Peeps, their unique experiences, strengths and active roles in shaping the process of "knowing", the outcomes, and my accountability to them. In addition, the dynamic, non-linear, and retrospective sense-making approach of this study, influenced by my critical CaST approach, has compounded further complexity. Lastly, aligned with CaST, this PhD has worked in inter-disciplinarity, and dialogue between disciplines, with relational ethics as its overarching principle. Combined, these factors and influences have resulted in an unconventional PhD, that has extended into the structure and writing of this thesis. The form and narrative of this thesis has unrolled the thread of the study as well as its modelling, recognising that generating knowledge is equally as important as knowledge itself (Mead, 2016).

As a result, in this unconventional format, several important points of discussion have already been explored throughout the thesis, including the proposition to consider homelessness as complex life-threatening conditions, of particular relevance for people living on the streets, as shown throughout this thesis (chapters 3, 5, 6, 7). While I will not revisit that discussion in this chapter, given this proposition is embedded and central in this study, I present some avenues of reflection and actions towards a more comprehensive approach of care in the second section of this chapter. Further, given the format of this study, the notions of contributions, limitations and conclusion might also be better understood as invitations to new propositions, revisions, and openness to new possibilities. Accordingly, the first section of this chapter will critically revise my research journey with a focus on significant aspects of my learning, as a non-Māori PhD student and companion of the Peeps.

Revisiting the research journey

Epistemic violence, prejudice, deficit-oriented discourses, marginalisation of Māori knowledge systems, have long-term shaped research on, rather than *with*, Māori people, especially

in the field of health research (Smith, 2012). At the outset of this study, three fundamental questions guided my approach: "How can I work as an ally in Aotearoa"? , "which starting points should be privileged that may be responsive to homeless peoples' concerns to contribute a positive difference to their lives according to their priorities, aspirations, and their own rights"? and "how to proceed with cultural sensitivity and humility in the face of an unexplored and highly sensitive topic"? These questions cannot be disjoined, encompassing political, cultural, ethical, epistemological tensions.

In navigating the complexity of power dynamics, uncertainty, and high sensitivity at multiple levels, this set of questions remained inextricably interwoven and present throughout my PhD, acting as a kind of reflexive frame. These questions also reflected the inherent limitations of my understanding regarding the complexities faced by Māori people, as well as the depth and beauty of te ao Māori. Cilliers (2005) echoed this complexity, stating that viewing the world as constructively complex implies recognising the limits of our understanding. In other words, claiming a modest understanding of complex situations is not only an epistemological position but an ethical one of responsibility (Cilliers, 2005).

Therefore, this study has not sought to offer definitive conclusions, universal truth, neither relative nor absolute answers. Instead, it has been a transformative journey, akin to clearing and opening *a* path into the unknown with respect, humility and integrity to contribute to positive outcomes in the lives of homeless people. This differs from the conventional pursuit of closing knowledge gaps outlined in a literature review and pre-determined research objectives. Exploring the unknown necessitates engaging with uncertainty and a temporary suspending of a purely rational approach (Rajagopalan, 2020). It requires accepting the possibility of making errors, recognising impasses along the way, retracing steps that are never identical upon reflection, and choosing alternative directions. This transformative process requires time, careful progression, cultural humility, critical reflection, ongoing commitment to learning, as well as a genuine openness to engage into the process of encountering and to be transformed by the encounters experienced along the paths taken.

It is through encountering the Peeps that I have deeply felt and understood that their wellbeing and the flourishment of their existences on the streets are critically rooted in uplifting mana, and honouring the tapu of each person in life and death. While this may appear an easy "statement" on what "living well and dying well" could mean for many Māori people living on the streets, it is far from simple. Daniel has generously shared a narrative, for us to learn and grow, that sheds light on the erosion of mauri in conditions of multiple relational losses and trans-generational trauma, as a distinct aspect of homelessness for many Māori (chapters 2 and 7). Daniel also revealed

how mauri can be restored through uplifting mana, healing, and reconnecting with his whānau, that gives him a sense of belonging, and celebrate the spiritual and relational uniqueness of his being in life and death through whakapapa.

I envision "encountering" as a relational process of co-creating the conditions for knowing, but also for being and doing through shared values, and mutual and long term-engagement. In other terms, encountering encompassed weaving and nurturing a genuine whānau with the Peeps, rooted in, and nourished by aroha, respect to my companions, and the responsibilities and obligations aligned with whanaungatanga and manaakitanga. As highlighted by Stewart (2021), while manaakitanga is usually translated by hospitality, it combines the two words "mana" and "aki" (exert or encourage), so refers to all practices and actions that enhance mana. The addition of the suffix "tanga" emphasises the "general quality of attention to mana in relationships" (Stewart, 2021, p.92). The Peeps are often deemed a "vulnerable population". However, it has been by drawing on their strengths, mana, and bringing mana into our relationships that this study has flourished with and for them. Throughout this journey, I have learnt that the most important research "starting point", was not the questions I could pose, but whakawhanaungatanga, enabling meaningful encounters with the Peeps. Encountering and being affected by these encounters is a relational, constitutive and indivisible process. Emotions, intuitions, inner-sense, embodiment remained unrestrained as they are integral to trusting relationships building, and learning and understanding processes. For example, the coroners' reports were encounters, as they form a kind of avoidable and hidden "cemetery" that I had to honour. Reflecting on this journey, I am humbled by the privilege to be alive. Within this process of encountering, I embraced "not knowing" as a relational, political, and ethical act for learning, which is of utmost significance in Māori contexts to not perpetuate colonial practices of research and to respect the tapu of knowledge (Bishop & Glynn, 1999), as well as to maintain cultural humility and modesty in conditions of complexity and uncertainty (Braithwaite, 2010).

Ultimately, it is for the Peeps to assert if our companionship has contributed to uplifting mana, and enhancing hauora. However, two intertwined points of learning are worth highlighting, which concern the notion of " whānau of interest" (Bishop & Glynn, 1999, p.172), and the strength of collaboration and creativity in this study. A whānau of interest refers to a research group, typically led by kaumatua, who share a research initiative oriented toward Māori concerns, interests and benefits as defined by and for themselves, and developed within preferred Māori cultural practices (Bishop and Glynn, 1999). Control and accountability are important functions assumed by the research whānau of interest within which the researcher does not necessarily assume the leadership (Bishop & Glynn, 1999). An important learning for me, has been navigating with the absence of a whānau of

interest. The presence of death, and the conditions of indeterminacy and uncertainty in which this study developed hindered the gathering of a whānau of interest around this study, reinforcing the dilemmas encountered throughout the whole study process, in terms of legitimacy, power dynamics and privileges on one hand, and ethical responsibility and relational obligation in the face of death, on the other hand (chapter 4). On many instances, the Peeps have been my unconventional whānau of interest, to which I am accountable.

Within this unique whānau, my responsibility and obligation, as a non-Māori PhD student has not been to "lead" research, but to search for, and to propose alternatives ways for the voices of the Peeps to be heard and honoured, recognising the tensions and potential prejudices related to issues of power, representation, benefit and control, especially critical with marginalised populations such as the Peeps (Smith, 2012). Without dismissing the power inbalance at stake in this study, I have found that creativity holds particular significance in the engagement of anti-oppressive research practice, as creativity is relational, infused with the potential to liberate hidden forms of knowledge, transformational narratives and actions (Nopera, 2016). The collaborative co-creation of "Before it is too late", as discussed in chapter 6, presents such an alternative. The many informal hui around the drama and its content was a creative event in itself, infused with the collective breath of the Peeps directed towards changing the healthcare system to be a better place for them. Further, in a creative way, audiences are also invited, "by" the Peeps to listen to their voices and engage in respectful dialogue and relationships with them. To bring the project of "Before it is too late" to fruition, the next step involves producing a video-recording of the drama and disseminating it among healthcare and allied professionals. This is essential to truly maintain my accountability to the Peeps and their collective breath of life, beyond this PhD.

Clearing *a* path is a complex and disordered process, especially considering the gravity of the "topic", and its potential consequences for Māori homelessness people and their whānau. CaST frameworks applied to complex health issues have encountered challenges in delivering on the promises of their approach to effective interventions (Brainard & Hunter, 2016; Carey et al., 2015; Thompson et al., 2016). Yet, as astutely pointed out by Morin (1990/2008), "complexity is a problem construct, not a solution provider" (p.10), and therefore should not be seen as a "new orthodoxia" to solve complex issues.

Nevertheless, when CaST is not used with the purpose of designing health interventions in complex situations, but rather is embraced for its intrinsic relational modes of thinking *and* being, becoming, and doing, it carries political, ethical and epistemological dimensions, crucial in this study. CaST is deeply anchored in connected and inter-related perspectives of the world, and non-linear

processes, aligning with relational Māori ontology and epistemology. While recognising my privilege and power inbalance inherent to my presence throughout the study process, I believe that my CaST approach offered a platform for respectfully honouring te ao Māori and Māori people, because CaST also embraces a fundamental uncertainty as knowledge. I believe that uncertainty prevents imposition. Further, CaST not only granted the flexibility necessary to approach the unknown, but also granted me a relational sense of time. With this temporal perspective, comes the possibility of learning, whakawhanaungatanga, companionship and friendship, encounters, the co-creation of a space of resonance (chapter 4), and a deliberate and gradual progression in my understanding. Finally, relational time allowed for a moment of pause, as discussed in chapter 3, from which the temporal space of life prior to death emerged. Proceeding from death to life, not making a *pause* in this temporal space of life prior to death would have meant an abandonment of my fundamental relational responsibility in the face of death (chapters 4 and 6), and of my obligation to care.

The "temporal space of life prior to death" revises the divide between prevention and palliation. However, this revision does not diminish the significance of addressing end of life matters and questioning. Throughout my companionship with the Peeps, I have learnt that approaching these matters and questions must not only be culturally safe to avoid imposing assumptions, but should also be undertaken with extreme cautious and care. It is essential not to overlook the multi-levelled impacts of transgenerational trauma, that have also been generated by and within Pākehā healthcare institutions in relation to death and dying. The impacts of early loss, violation of the tapu of death and persons, racism, and the marginalisation of wairuatanga within Pākehā healthcare institutions, have been highlighted in chapter 6. These "events" have forged an ontological resistance that, combined with the multiple systemic, cultural and inter-personal barriers (chapter 3), shape the Peeps' struggles to access, or not to access, mainstream healthcare services, including hospices. When addressing end-of-life matters, it is essential for health professionals and researchers to recognise the Peeps' resistances within the context of their end-of-life experiences. This recognition would help not perpetuating an ontological threat to the spiritual and relational existences of the Peeps, as discussed in chapter 6. It is also essential to acknowledge that, for many of them, their aspirations to reconnection with whānau in the perspective of the end of life, is a priority that goes beyond a biomedical approach of palliative care (chapters 6 and 7).

This study did not aim to prescribe a singular understanding of what "palliative care" could mean for the Peeps and Māori homeless communities. More participative and collaborative research is needed to appreciate the diversity of the needs and demands, along with the modalities of responses, that may be found inside and outside the current palliative care organisational scheme (Buchanan et al., 2023). For example, chapter 7 discussed an alternative proposition, through the use

of ACP, envisioned as a relational and holistic space, led by Māori, toward healing and honouring the end-of-life experiences of Māori homeless people, as Māori in their diversity. This PhD journey, shaped with, and for the Peeps, has profoundly illuminated the significance of reconnecting with whānau and initiating healing processes resulting from trans-generational trauma (chapters 6 and 7). These aspirations are vital, capable of transforming life and death into a meaningful "ceremony" (Wilson, 2018) for many of the Peeps may live better and want to live longer, provided with a sense of belonging, spiritual continuity through whakapapa, and connections to the cosmological movement of life and death. Throughout my study, I encountered issues of suicide, as a main cause of death in the coroners reports, with 70 % of people having communicated suicide intent during their life-span at some point, and nearly one-third having evidence of prior self-harm. Some of the Peeps also shared with me their own struggles and suicidal thoughts related to many and deep hurts and trauma. I am acutely aware of the sensitivity and complexity to issues related to suicide. These issues demand urgent and culturally safe research, led by Māori scholars. I reiterate the crucial importance of health and allied professionals being attuned to suicidal ideation as a strong marker of acute risk of suicide, as discussed in chapter 5. I strongly reaffirm the pressing need for the integration of suicide ideation screening into routine assessment conducted by health professionals across all settings, as articulated in chapter 5.

Complexity comes with emergence and uncertainty that stands at the beginning and the end of this study. Propositions are possibilities, that reflect and recognise zones of potentialities, transformation, and growth. These zones are invaluable when confronting processes of marginalisation and spaces of invisibility wherein death inequality affecting homeless communities are confined. Elaborating on the proposition to also consider homelessness as complex life-threatening conditions associated with SHS, I propose in the next section some avenues of reflection and actions that may initiate a more comprehensive, supportive, proactive and relational approach of care, taking into account the simultaneous aspect of prevention AND palliation.

Avenues of reflection and actions toward a comprehensive approach of care

Central for a shift towards a comprehensive approach of care is the critical notion that the healthcare sector should pro-actively (re)-engage with homeless people, rather than placing the burden on homeless people to engage with healthcare institutions. This is especially true and urgent for the Peeps and homeless people on the streets. It requires homelessness be prioritised by Te Aka Whai Ora-Māori-Health Authority and the Ministry of Health. In accordance with the Pae Ora (Healthy Future) Act 2022, national mortality review committees have been established to avoid

premature and unjust mortality. Yet, homelessness has not be considered as a subject matter, unlike perioperative mortality, for example (HSQC, 2023). By shifting the focus on (re)-building meaningful and respectful connections and relationships with homeless people, and by assuming a leading response-ability in this process, the health sector may work towards demarginalizing the healthcare needs of homeless people, and alleviate suffering throughout the course of homelessness. This shift holds the potential to create opportunities towards comprehensive support, that align with an understanding that homelessness may also be considered as complex life-threatening conditions associated with SHS.

The practical elements proposed below have emerged from my companionship with the Peeps within the healthcare system, coupled with the insights of health professionals at ACM who have long experience (chapter 5). These proposals are also enriched by international initiatives. While these propositions may hold positive change, it is important to recognise that they require more research and validation by homeless people. A dual approach is necessary. The first aspect involves promoting education and awareness among health and allied professionals. Without this foundation, a shift toward comprehensive care would remain elusive. The second aspect centers on creating meaningful points of contact between health professionals and homeless people, as well as reducing the fragmented communication between services. Collaboration is urgently needed.

The following practical elements are proposed:

- Educate and inform health and social care professionals through programmes and webinars (e.g., continuing personal development; courses in health and social curriculum), including in tailored services (e.g., in shelters, housing services) where healthcare needs are often reduced to addiction issues.
- Prioritise whakawhanaungatanga and manaakitanga as foundational principles for engagement.
- Consider the contribution of community health workers (Wallace et al., 2018) such as kaimahi Māori, or people who have experienced homelessness in the past, to bridge connections between homeless people and health/social services, drawing from successful strategies for marginalised populations (Wallace et al., 2018) and in indigenous contexts (Gampa et al 2017).
- Consider the contribution of care coordinators/navigators within tailored services, building partnerships with district hospitals for effective follow-up, support and advocacy, particularly during hospital visits and admissions (experience of ACM). This avenue has

shown to add positive value to community-based palliative care teams caring for homeless people (Robinson et al., 2023).

- Examine the involvement of street-based mobile outreach care services for sustained engagement with homeless people. Informed by my personal experience on the streets of Paris and Nanterre, and with the Peeps, outreach mobile care holds substantial potential in addressing the needs of the people who cannot or do not seek care within mainstream services. This model has been launched in France in 1993 (Samu social international, 2023), diffused internationally, with positive health and social outcomes for the most isolated people on the streets (Suris et al., 2017; Sarradon et al., 2014), including in palliative situations (Buchanan et al., 2023).
- Consider a multidisciplinary "pathways teams" model (Hewett et al., 2016; Khan et al., 2019), operating within the secondary health sector with a primary care-led approach during hospitalisation of homeless people, to strengthen collaboration between sectors and levels of care, with proven success to improve discharge practice, health outcomes (e.g., enrolment with GPs), and reducing street homelessness. Pathways teams also provide education among hospital staff.
- Streamline access to primary care by addressing bureaucratic constraints (e.g., evidence of address), and consider expending the Care Plus scheme (chapter 3) to improve the continuity of care in reducing the cost barriers.

It is essential that these practical avenues for actions prioritise cultural safety, centering on hauora, and involve Māori leadership, and Māori professionals within multidisciplinary teams, on the ground. This will ensure an inclusive and culturally aligned approach of care that respect the values, perspectives and aspirations of Māori homeless communities, promoting holistic wellbeing and meaningful connections.

Final words

The high rate of homelessness in Aotearoa New Zealand is under the spotlight, but its impact on health and wellbeing is not. This PhD has cleared a path to understand the magnitude of the issue and the stakes for Māori people who live and die on the streets. The current healthcare system is not tailored to homeless people who do not receive equitable and effective care. Homelessness is not only a complex issue, it is a human tragedy, that may end up in death, and for the most isolated people in a coroner's report. Understanding homelessness as complex life-threatening conditions associated with SHS is a proposition towards reversing this possibility, as well as supporting the end-of-life experiences of Māori homelessness people to be honoured, dignified

and respected. Although no one should suffer the “nearly death experience” of homelessness, the health community to which I belong has the obligation to respond to suffering and alleviate it as much as possible. However, how we respond will depend on our capability to think differently about the value of homeless people’s lives. Paraphrasing St Exupery, I would say that our task is not to foresee the future, but to enable it. My hope is that this PhD may have contributed to creating awareness and drawing attention to the avoidable intrusion of death into the lives of people who are trapped on the streets, so that the future will be enabled, knowing their ancestors are waiting and their mana is intact. As Mauao, the Peeps would be caught by the light of the day.

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Appendix A: Te reo Māori glossary

My use of Te reo Māori in this thesis signifies the acknowledgment of Te reo Māori as the first language of Aotearoa. It is a way of honouring tangata whenua, the people born of this land where their ancestors have lived and are buried. Throughout this thesis, I have drawn upon various Māori aroro (concepts) as explained and articulated by Māori scholars. These concepts, treasured within Te ao Māori, hold profound significance. This glossary is based on the translation from Te Aka Dictionary – Māori/English dictionary (Moorfield, 2011), and is intended to facilitate the reading of this thesis. It does not fully encompass, however, the depth and spiritual meaning of Te reo Māori.

Ārai: veil

Aroha: love, care, compassion

Hapū: subtribe

Hui: gathering, meeting.

Hauora: holistic health and wellbeing

Iwi: tribe

Kaimahi Māori: Māori community workers

Karakia: prayer, incantation, ritual chant

Kaumatua: Respected elderly

Kaupapa Māori: Māori approach, ideology, agenda

Kawakawa: pepper tree

Kōtahitanga: unity, togertheness, solidarity, collective action.

Mana: prestige, authority, control, status, spiritual power.

Manaakitanga: kindness, generosity, support, hospitality; the process of showing respect, generosity and care for others.

Marae: the open area in front of the wharenui (meeting house), where formal greetings and discussions take place. Often also used to include the complex of buildings around the marae.

Mātauranga Māori: Māori knowledge, wisdom

Mauri: Life force, vital essence

Rongoā: Māori natural medicine

Tapu: sacred, prohibited, restricted

Tangihanga: funeral, rites for the dead

Te ao Māori: Māori world

Te reo Māori: Māori language

Tikanga: correct procedure, protocol, customary system of values and practices

Tino Rangatiratanga: self-determination, sovereignty, autonomy.

Tūpāpaku: deceased person

Tūrangawaewae: place where one has the right to stand, to belong to through kinship and whakapapa.

Waiata: song

Wairua: spirit, soul

Wairuatanga: spirituality

Whakaiti: humility

Whakamā: shame, embarrassment

Whakapapa: genealogy, lineage, descent

Whakawhanaungatanga: process of establishing relationships, relating well to others.

Whānau: family, extended family; sometimes used to include friends who may not have any kinship ties to other members

Whanaungatanga: relationship, kinship, sense of family connection

Whenua: land, placenta

Appendix B: Ethics application approval

The University of Waikato
Private Bag 3105
Gate 1, Knighton Road
Hamilton, New Zealand

Human Research Ethics Committee
Mark Apperley
Telephone: +64 7 838 4528
Email:humanethics@waikato.ac.nz

THE UNIVERSITY OF WAIKATO
Te Whare Wānanga o Waikato

2 March 2020

Sandrine Charvin-Fabre
By email: sandrinefabrenz@yahoo.com

Dear Sandrine

HREC(Health)2019#80: End of life and Homelessness: What access to care prior to death exits for this group of population in New Zealand society?

Thank you for providing the information requested in our letter dated 13 December 2019. On the basis of this extra information we are now pleased to provide formal approval for your project.

Please contact the committee by email (humanethics@waikato.ac.nz) if you wish to make changes to your project as it unfolds, quoting your application number with your future correspondence. Any minor changes or additions to the approved research activities can be handled outside the monthly application cycle.

We wish you all the best with your research.

Regards,

Professor Mark Apperley
(Acting) Chairperson
University of Waikato Human Research Ethics Committee

Appendix C: Co-authorship form (article 1)

This form is to accompany the submission of any PhD that contains research reported in published or unpublished co-authored work. **Please include one copy of this form for each co-authored work**. Completed forms should be included in your appendices for all the copies of your thesis submitted for examination and library deposit (including digital deposit).

Please indicate the chapter/section/pages of this thesis that are extracted from a co-authored work and give the title and publication details or details of submission of the co-authored work. In chapter 5, the following article has been reproduced integrally with the permission of the journal: Charvin-Fabre, S., Stolte, O., & Lawrenson, R. (2020). Amenable mortality within the New Zealand homeless population : We can do better! *New Zealand Medical Journal, 133*(1527), 26-38.

Nature of contribution by PhD candidate	I collected 176 coroners' reports and read them multiple times. I conducted an initial statistical analysis for a descriptive purpose. Subsequently, I expanded the analysis to include the concept of amenable mortality. This involved conducting a literature review on amenable mortality and methods of analysis, and avoidable mortality linked to homelessness. I developed a conceptual framework for the analysis, specifically focused on the rate of amenable mortality categorized by causes of death, according to ICD-10. I conducted the second round of statistical analysis. Additionally, I conducted a literature review on the relationship between suicide and homelessness. I wrote all the drafts, cover letter, and responses to reviewers' comments. I managed the submission process.
Extent of contribution by PhD candidate (%)	90

CO-AUTHORS

Name	Nature of Contribution
Ottilie Stolte	Read & commented on 5 drafts. Assisted with two rounds of reviewers' comments, author responses & cover letter
Ross Lawrenson	Advised on data analysis, writing of paper and approving final version for submission

Certification by Co-Authors

The undersigned hereby certify that:

- the above statement correctly reflects the nature and extent of the PhD candidate's contribution to this work, and the nature of the contribution of each of the co-authors; and

Name	Signature	Date
Ottilie Stolte		14/08/23
Ross Lawrenson		28/08/2023

Appendix D: Co-authorship form (article 2)

This form is to accompany the submission of any PhD that contains research reported in published or unpublished co-authored work. **Please include one copy of this form for each co-authored work**. Completed forms should be included in your appendices for all the copies of your thesis submitted for examination and library deposit (including digital deposit).

Please indicate the chapter/section/pages of this thesis that are extracted from a co-authored work and give the title and publication details or details of submission of the co-authored work. In chapter 6, the following article, currently under revision by Ethnographic Edge has been reproduced integrally: Charvin-Fabre, S., Moeke-Maxwell, T., Stolte, O. & Lawrenson, R. (date?). "Before it is too late": Street performance, life, death, and homelessness in Aotearoa New Zealand.

Nature of contribution by PhD candidate	This article results from 3 years of collaboration and companionship with the Peeps. I conducted a literature review on critical performance ethnography in health-based research, and in indigenous contexts. I wrote the drama in collaboration with the Peeps, and on drawing on my fieldnotes. I sought professional advice from drama teachers and students, with whom the drama script was reviewed. I wrote all the drafts of the article, cover-letters, and responses to reviewers' comments.
Extent of contribution by PhD candidate (%)	80

CO-AUTHORS

Name	Nature of Contribution
Tess Moeke-Maxwell	Provided cultural advice on the manuscript content. Read and commented on the drafts. Provided advice to the PhD candidate on changes and author responses.
Ottilie Stolte	Read & commented on 5 drafts. Assisted with reviewers' comments, author responses & cover letters for 2 different journals
Ross Lawrenson	Involved in study design, reading manuscripts and advising on final version of paper

Certification by Co-Authors

The undersigned hereby certify that:

- the above statement correctly reflects the nature and extent of the PhD candidate's contribution to this work, and the nature of the contribution of each of the co-authors; and

Name	Signature	Date
Tess Moeke-Maxwell		30/08/23
Ottilie Stolte		14/08//23
Ross Lawrenson		28/08/2023

Appendix E: Co-authorship form (article 3)

This form is to accompany the submission of any PhD that contains research reported in published or unpublished co-authored work. **Please include one copy of this form for each co-authored work**. Completed forms should be included in your appendices for all the copies of your thesis submitted for examination and library deposit (including digital deposit).

Please indicate the chapter/section/pages of this thesis that are extracted from a co-authored work and give the title and publication details or details of submission of the co-authored work. In chapter 7, the following article has been reproduced integrally with the permission of the journal. Charvin-Fabre, S., Moeke-Maxwell, T., Stolte, O., & Lawrenson, R. (2022). Can advance care planning (ACP) be a relational healing place for indigenous homeless people in Aotearoa New Zealand? *Mortality*, 1-14.

Nature of contribution by PhD candidate	This article results from whanaungatanga with Daniel (pseudonym), one of the Peeps, and has been written according to relational principle. I conducted a literature review on homelessness and ACP. The form and content of this article has been suggested by Dr Moeke-Maxwell, especially envisioning ACP as a relational space, expressive of holistic wellbeing, as well as the use of autoethnography. Dr Moeke-Maxwell also sought feedback from Māori leaders. I wrote all the drafts, cover letters, and responses to reviewers' comments.
Extent of contribution by PhD candidate (%)	70

CO-AUTHORS

Name	Nature of Contribution
Tess Moeke-Maxwell	Provided cultural advice on the manuscript content. Read and commented on the drafts. Provided advice to the PhD candidate on changes and author responses.
Ottilie Stolte	Read & commented on 4 drafts. Assisted with review process: reviewers' comments, author responses & cover letter
Ross Lawrenson	Advised on concept, study design and writing of manuscript

Certification by Co-Authors

The undersigned hereby certify that:

- the above statement correctly reflects the nature and extent of the PhD candidate's contribution to this work, and the nature of the contribution of each of the co-authors; and

Name	Signature	Date
Tess Moeke-Maxwell		30/08/23
Ottilie Stolte		14/08/23
Ross Lawrenson		28/08/2023