At the end of the Rainbow:

Rainbow experiences of palliative care through the lens of a situated case study

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Abstract

This thesis explores Rainbow experiences of palliative care in Aotearoa New Zealand through the lens of a situated case study and the local policy context for palliative care. Underscoring this thesis is an understanding that the Rainbow community constitute a subgroup of the population which possess specific needs within the palliative care space. A key concept on which this research rests is good death and how palliative care aspires to achieve a good death. This is a novel, exploratory study conducted to address the lack of literature pertaining to Rainbow experiences of palliative care in Aotearoa New Zealand. The theoretical framework for this thesis is grounded in the socio-ecological model of health and the concept of aroha. A case study research design is utilised to give a fine-grained exploration of a single research participant's experience supporting his partner's palliative care journey. Semi-structured interviews were conducted with the research participant, which provided insights into how palliative care unfolded within the lifeworld of a couple who are members of the Rainbow community. Interview data was analysed with an interpretivist approach. In addition, I conducted analysis of key documents that direct the design and delivery of palliative care in Aotearoa New Zealand. Analysis of the documents was conducted by situating and examining them within the socio-ecological framework. The case study findings include themes of caregiving and the impact of discrimination. Within the theme of caregiving, topics that emerged included transitions in care, dynamic support, and expressions of autonomy. The theme of the impact of discrimination investigated the legacy of the AIDS crisis, the burden of educating people delivering palliative care, and the fear of discrimination. A synthesis of the interview data and document analysis highlights the radical potential of palliative care as a model of care, alongside tensions between aspirations expressed within the palliative care model and lived experience. I also investigate the role of intersectionality in facilitating good death, and the complexities of being openly Rainbow, as key issues within the case study and document analysis. In terms of implications for future research, I argue that fine-grained case study approaches to explore complex, personalised, and deeply contextual experiences such as those included within the study offer novel insights into service delivery. Additionally, this thesis indicates the necessity of further diverse research within the Aotearoa New Zealand context to ensure understandings of Rainbow palliative care experiences are robust.

Acknowledgements

While my name sits on the title page of this thesis, its existence is due to the immense support I have received over the course of writing it. To all who have guided, nurtured, uplifted, and listened to me, thank you.

To Tim, who is not just a research participant but also a dear friend. Without you, this research would not exist. Thank you for your honesty and authenticity and for trusting me with your story. It is a taonga I do not take lightly.

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To the Rainbow scholars that have come before me, thank you for clearing the way for me to be authentic and unapologetic in claiming my identity in my research. The love I hold for my Rainbow whānau is why I embarked on this journey, and it is for them this research exists. It is inspired by the ethic of resistance that is so present in our community

and the tradition of doing things for ourselves when no-one else will. May our lives be ever filled with justice, love, and community, even at the hour of our deaths.

When I began the journey of this thesis, I could not imagine that I would lose a grandmother and an aunt. The irony of writing a thesis on palliative care whilst grieving was not lost on me. It brought into stark relief the importance of this thesis and intimately shaped how I approached and understood my writing. Four incredible women in my family have now received palliative care; this thesis honours them and their memory.

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Glossary

The Māori terms included in this glossary were developed using the online Māori Dictionary (Moorfield, n.d.) (https://maoridictionary.co.nz/). They represent possible translations of each, but care must be taken when interpreting Māori terms as they can have multiple meanings dependent on context, dialect, and usage (Green, 2018).

Cis-heteronormativity - the assumption that heterosexuality and being cisgender are normal and desirable whilst being non-heterosexual and/or non-cisgender is abnormal and undesirable; this assumption underscores marginalisation of the Rainbow community

Karakia - Incantation; ritual chant; prayer

Kaumātua - Elders; a person of status within the whānau

Kaupapa Māori - Māori approach; Māori principles

Koha – Contribution; physical demonstration of appreciation

Mātauranga Māori - Māori knowledges

Mirimiri - Massage

Rongōa māori - Māori medicine; traditional treatment

Tangata whenua - People of the land; indigenous people

Tauiwi – Foreigner; non-Māori; person from afar

Te Tiriti o Waitangi – The Treaty of Waitangi

Tikanga - Culture, custom, method

Waiata – Song; chant

Whānau - Extended family; a family group

Note: Aotearoa New Zealand is used interchangeably with Aotearoa and New Zealand.

List of tables

Chapter 1: Introduction: Purpose of research

This research project explores Rainbow experiences of palliative care in Aotearoa New Zealand through the lens of a situated case study and the policy context for palliative care, by deploying a socio-ecological model approach (Kilanowski, 2017). The socio-ecological model, which will be explained in Chapter 4, provides a means of moving the focus between the individual level experiences encapsulated within a case study analysis, and investigating the broader structure of palliative care as a health model. Underscoring this thesis is an understanding that the Rainbow community constitute a subgroup of the population who possess specific needs within the palliative care space. This current study was conducted to address the dearth of research pertaining to Rainbow experiences of palliative care specifically within the Aotearoa New Zealand context. Whilst there is a growing knowledge base on the topic within the international sphere (e.g., Candrian & Lum, 2015; Cartwright et al., 2012; Cloyes et al., 2018; Maingi et al., 2018), at the time of writing, there were no explorations of the topic available that focus on Rainbow experiences of palliative care in Aotearoa. Hence, a key objective of this thesis is the creation of new knowledge relating to the palliative care space in Aotearoa New Zealand and the stimulation of further research with and attention to the Rainbow community.

The remainder of this current chapter describes the reasoning for choosing to employ the term Rainbow as a collective, community label throughout this thesis. I identify my positioning as a member of the Rainbow community, which has implications for my choice of research topic and is further discussed in relation to methodological considerations in Chapter 4. This introductory chapter outlines the thesis chapters, providing a brief roadmap for how the thesis incorporates analysis of context, as well as the lived experience of Rainbow palliative care.

1.1 A call to community

The research upon which this thesis is based begins and ends with the Rainbow community. It is from the community it emerges and for the community it develops. The choice to utilise the umbrella term, Rainbow, is one made with careful consideration and intentionality. Since the existence of people of diverse genders, sexualities, and sexes entered public conversation, terms for labelling, describing, and referring to the community have gone through periods of change and evolution (Eliason, 2014). In part, intra-community attitudes have prompted the cycling through of labels. This includes the complex history and reclamation journey of 'Queer', the simplified and specifically located 'gay community', and the layered politics of 'LGBT/QIA+' (Eliason, 2014; Ferris, 2006). Moreover, it is important to recognise that these, all terms common in Western and westernised countries, are rooted in westernised notions of gender, sexuality, and sex (Laurence, 2020). These hegemonic understandings of human diversity are being challenged and resisted by indigenous and culturally relevant alternatives, such as takatāpui and MVPFAFF+ amongst Māori and Pacific communities respectively (Brown-Acton, 2020; Hutchings & Aspin, 2007).

This thesis employs 'Rainbow' as a term which seeks to be as widely inclusive as possible without reifying and reproducing exclusionary or limited notions of diverse genders, sexualities, and sexes. For the current study, Rainbow is understood to mean anyone who identifies as having a diverse gender, sexuality, and/or sex, utilising whatever cultural paradigm resonates with them (Sligo et al., 2023). Nonetheless, any and all language utilised by participants is honoured. This is in consideration of the liberating experience of finding language which speaks to your reality in an authentic way and in acknowledging that each participant will understand their own identity experience the best (Rostosky et al., 2010; Smith & Yost, 2023). This is particularly relevant to acknowledge when participants utilise language that may be considered outdated or offensive. Hence, Rainbow is utilised.

1.2 Thesis outline

Chapter 1 is an introductory chapter which establishes the research objectives of this study and explains the decision to use the term Rainbow in this thesis.

Chapter 2 presents an introduction to palliative care as a model of care. It describes the development of the biomedical model as the prevailing model of medicine and the emergence of the palliative care model as a critique of the biomedical model. In addition, Chapter 2 provides a general overview of what palliative care entails. I introduce the idea of ‘good death’ as both a foundational concept to the palliative care model and as a key topic in the context of this thesis.

Chapter 3 describes the palliative care model in the context of Aotearoa New Zealand, including an exploration of the development of palliative care and the nature of present-day delivery of palliative care. Additionally, this chapter explores Māori experiences of palliative care as a demonstration of culturally specific care provision within the palliative care model. Finally, there is a brief review of extant literature pertaining to Rainbow experiences of palliative care, with reference to the lack of comparable literature within the Aotearoa New Zealand context.

Chapter 4 describes the research approach and methodology for this study. This begins with the theoretical and ethical frameworks on which this research is based alongside discussion of my positionality as a researcher. Theoretically, this research is underpinned by the socio-ecological model of health and the concept of aroha whilst ethically it is guided by the emic/etic paradigm. The chapter then details the case study design this research employed. I outline the recruitment process, including the challenges I experienced, and provide a brief profile of my participant. The interview procedure is described, and I specify the documents which I analysed in conjunction with my interview data. Finally, the analysis procedure is explored, highlighting the interpretive methods deployed within a socio-ecological model (SEM) framework.

Chapter 5 and *6* introduce the major qualitative findings of this study. *Chapter 5* investigates the overarching theme of caregiving, with specific focus on navigating transitions, support, and autonomy. *Chapter 6* highlights how the impact of discrimination can shape the Rainbow experience of palliative care, with specific reference to the historical legacy of the HIV/AIDS crisis, the burden of education and advocacy, and anticipated discrimination.

Chapter 7 provides a discussion chapter for this thesis, synthesising the interview data and analysis of the documents in relation to pre-existing literature and within the context of the study's theoretical framework. This includes discussion of the radical potential of the palliative care model contrasted with the possible systemic disconnection between the model's aspirations and the lived experience of patients and their whānau. The impacts of intersectionality and its relevance to facilitating good death, and the complexities of being openly Rainbow within the palliative care space, both emerge as core points within this thesis discussion. Further, this chapter argues that palliative care in Aotearoa New Zealand is founded upon values that can be compromised when the full diversity of human experience is not fully integrated into the wider health system.

Chapter 9 offers the final words of this thesis. This chapter provides a summary of the thesis including key findings and conclusions. Further, it describes implications of the study and advocates for further research exploring diverse Rainbow experiences within the palliative care space in New Zealand.

Chapter 2: An introduction to palliative care

This chapter traces the emergence of palliative care as both a branch of medicine and a model of care. Through discussion of the scientisation and medicalisation of health, specifically the development of the biomedical model, this chapter demonstrates the transformative potential of palliative care, specifically the way in which it, and the patients who receive it, traverse the categories of biomedical expertise and care. Furthermore, this discussion of historical context and the way in which the palliative care movement developed helps to situate a core concept of this research, that of 'good death'. Specifically, this chapter explains how the promotion of good death underscores the palliative care space and shapes palliative care decisions.

2.1 Emergence of the biomedical model

Within traditional Western societies, death was both inevitable and visible; the frequency with which it occurred engendered a level of familiarity for the general populace, compounded by its presence within homes and communities (Ariès, 1981; 1985). The authority on death was religion with religious officials providing guidance and shaping death attitudes and practices (Ariès, 1974). However, the transition of Western societies from rural and agrarian to urban and industrial precipitated fundamental changes in the way death is understood and responded to and thus how the dying are cared for (Winnington et al., 2018). The scientisation of medicine has led to both the medicalisation of death and the institutionalisation of dying (McManus, 2013). Within this transition, the location of death shifts from within the community towards the medical institution and the authority on death changes from religious officials to medical doctors and practitioners (Winnington et al., 2018). Significantly, this paradigmatic shift represented revolutionary developments in understanding malaise, leading to greater consistency and efficacy in disease treatment (Rocca & Anjum, 2020). This transformation was articulated as the biomedical model of health.

Biomedicalism is predicated on three core assumptions, namely: that illness has an inherent and singular underlying cause, that this cause is disease, and that the removal or reduction of this disease will precipitate a return to good health (Wade & Halligan, 2004). Therefore, within the model, biological factors are prioritised (Ireland & Yeung, 2020). This yields a definition of health whereby good health is the absence of definable illness or physiological dysfunction and is an individual experience devoid of broader environmental significance (Willis & Elmer, 2007). Furthermore, this produces a treatment imperative wherein medicine 'fixes' ill-health with the focus on this treatment rather than on prevention (Willis & Elmer, 2007). The medical profession is therefore privileged under the model as medical professionals possess the knowledge and expertise at diagnosing, researching, and treating underlying physical pathologies (Ireland & Yeung, 2020).

The biomedical model is not without critics. Critiques have focussed on the biomedical model's reductionism, which leads to ignoring the psychological, environmental, and social influences on both good and poor health and even an erroneous assumption that health systems are socio-politically neutral as opposed to being embedded in social structures (Annandale, 2014; Wade & Halligan, 2004; Willis & Elmer, 2007). Nonetheless, the biomedical model remains an enduring model of health in many Western health systems (Ireland & Yeung, 2020).

Within the biomedical model, death occupies a unique space. As discussed, a core assumption underlying application of the model is that ill-health can be traced to specific physiological dysfunctions, which are able to be found, diagnosed, and treated, resulting in ill-health being constructed as controllable and good health as inherently achievable (Rocca & Anjum, 2020). The prevention of death, as the ultimate physiological dysfunction, is a fundamental, baseline objective within many Westernised health spaces (Braunias et al., 2018). Death is characterised consequently as a failure of medicine at treating dysfunction (Frey et al., 2013; Winnington et al., 2018). However, it is a simple reality that death remains a part of the natural human life cycle irrespective of the quantity or quality of intervention provided. Therefore, there is an inherent tension between the acknowledgement of the inevitability and immutability of death and the treatment imperative of the biomedical model. Furthermore, when healthcare systems privilege biological factors within the biomedical model it can create a reductionist view of health and well-being which allows little space or capacity for the non-biological factors associated with health such as the psychological, spiritual, and sociocultural (Annandale, 2014). Consequently, the purpose of healthcare within the biomedical model becomes one focused on curative care over holistic care (Radosta, 2021). This compounds the tension surrounding death under the biomedical model as, when the purpose of intervention is to cure, the inability to cure cannot be tolerated nor can the non-curative needs of the patient be met (Frey et al., 2013b; Radosta, 2021). It is within this historic tension and the inability of the biomedical model to respond to the specific needs of dying patients that palliative care emerges, beginning with the hospice movement.

2.2 Emergence of palliative care as a model of care

Whilst the practice of caring for the dying has its roots early in human history, the formal field of palliative care is a relatively recent phenomenon (Stolberg, 2017). Indeed, it is from the modern hospice movement that palliative care emerged (Stolberg, 2017). It is widely accepted that modern hospice care was first articulated in the work of Dame Cicely Saunders, particularly in her founding of St. Christophers Hospice in London in 1967 (Mino & Lert, 2005). Saunders, having been influenced by her experience volunteering with terminally ill poor patients, developed a philosophy of patient-centred care, introducing the concept of 'total pain' which encompassed psychological and spiritual as well as physical dimensions, and included considerations for patients' families (Mino & Lert, 2005; Radosta, 2021). Total pain represents a paradigmatic shift away from pain and suffering as symptoms of biological dysfunction towards an understanding of pain as a constitutive element of a patient's subjective experience which must be understood and responded to holistically (Radosta, 2021). This conceptualisation stood as a direct challenge to what was seen as the de-humanisation of the biomedical model due to its construction of suffering as an analytical problem to be responded to scientifically (Mino & Lert, 2005). Hence, the hospice movement positioned its holistic focus as a re-humanisation of dying (Radosta, 2021).

In contrast to earlier precursors which were regarded as places solely of death and dying, contemporary hospices centre quality of life and support for the patient in context, challenging the pervasive view of death as something to be denied, hidden, and feared (Bertman, 2014). Saunders work, and that of her early contemporaries who disseminated her philosophy, was firmly rooted in the notion of compassionate care (Bertman, 2014; Radosta, 2021). As such, where the biomedical model represents a model of health, the hospice philosophy represents a model of care. This conceptualisation of care at the end of life encompassing a holistic focus provided a direct precursor to the modern palliative care field (Mino & Lert, 2005).

Palliative care itself represents a bridging between the compassionate, holistic care philosophy of the hospice movement and the professionalised expertise of healthcare systems. The eventual incorporation of palliative care as a branch of medicine into the health system distinguished it from the largely philanthropic tradition from which it emerged, and which continues to underscore hospices today (Radosta, 2021). It also allowed for a secularisation and mainstreaming of the care provided, evolving away from the Christian traditions from which the hospice movement and its values emerged (Ashby, 2014). Furthermore, it solidified palliative care as a professionalised service marked by technical competencies that nonetheless occurs within a care paradigm wherein patients are centred rather than the analytical pursuit of a cure (Frey et al., 2013b; Radosta, 2021). Consequently, although palliative care remains allied to health systems which can privilege the biomedical model, it maintains a commitment to holistic care, incorporating medicalised interventions only where they intersect with the overarching pursuit of quality of life (Mino & Lert, 2005).

The scope and specifics of palliative care can vary globally. Nonetheless, there are common threads that exemplify palliative care and juxtapose it to other branches of healthcare. Firstly, palliative care centres quality of life, which is understood as an idiosyncratic, multi-dimensional experience defined by the patient, and promotes their holistic well-being (Ashby, 2014). Second, palliative care is not curative care although it may occur alongside curative or life-prolonging treatments (Ashby, 2014; Frey et al., 2013b). Third, although palliative care was initially limited to those experiencing terminal illness, it now encompasses those with life-limiting or chronic illnesses who may not be likely to die in the immediate future (Ministry of Health, 2017). Similarly, whilst patients with incurable cancer remain a core demographic and were historically the focus, palliative care is not limited to oncology (Stolberg, 2017). Palliative care exists in numerous care settings and incorporates professionals across the healthcare system including specialist palliative medicine professionals, general practitioners and primary care providers, nurses, medical social workers, and psychologists (Mino & Lert, 2005). Further, palliative care draws in non-professionals including family and community members to provide an all-encompassing network of care for the patient (Ministry of Health, 2017). Finally, there is a conceptualisation of dying, specifically of dying well, that underpins these common threads and forms an ideological basis for the palliative care model to rest upon. This is the concept of 'good death'.

2.3 Good death: The notion of dying well

Good death is a ubiquitous, persistent, and influential concept that permeates society. It is important to note that, whilst 'good death' was for a time used euphemistically for euthanasia or physician assisted suicide, good death here refers to the existential idea that it is possible to die well (Kehl, 2014). Indeed, there is considerable lay literature which refers to and ruminates upon the idea of what it means to have a good death (Meier et al., 2016). For those who have considered their own mortality, many hold opinions on their 'ideal' death and, perhaps more readily, opinions on death considered particularly horrific, such as those characterised by pain, violence, or chaos (Braunias et al., 2018; Young & Cullen, 1996). Whilst at the individual level conceptualisations of good and bad deaths are idiosyncratic, formed at the intersection of personal and social context, overarching themes are apparent which reflect societal expectations, social values, and cultural norms (Cottrell & Duggleby, 2016; Kehl, 2014). Within many Western societies, a good death is associated with reflection, preparedness, the chance to say goodbye, continuing social connection, peacefulness, memorialisation, autonomy, respectful relationships with healthcare providers, spiritual fulfilment, dignity, and a lack of pain or unnecessary suffering (Braunias et al., 2018; Cottrell & Duggleby, 2016; Kehl, 2014; Krikorian et al., 2020; Meier, et al., 2013).

Nonetheless, there exists no consistent, external criteria on what constitutes a good death as that determination is inherently idiosyncratic and reflects dying as not just a physiological experience but also an existential journey (Meier et al., 2016; Krikorian et al., 2020; Scarre, 2012).

Good death, and prevention of bad death, is foundational to palliative care. As discussed previously, the conceptualisation of and response to death within the biomedical model was seen by the hospice care movement as de-humanising and ill-equipped for responding to the complex array of non-biological factors which are inherent to the dying process (Mino & Lert, 2005). Therefore, the core framework of the hospice care movement is predicated on the notion that the biomedical model promotes bad death and, by 're-humanising' death through holistic care, hospice philosophies promote good death. Although the palliative care movement has secularised and allied itself to more mainstream healthcare modalities, these core values of preventing bad death and promoting good death are nonetheless relevant and apparent. As McNamara (2004) describes, palliative care as a concept is essentially a critique on how death and dying is responded to and understood within highly medicalised contexts. Consequently, the very existence of palliative care as a paradigm must logically be predicated upon an understanding of death as a non-neutral process. Further, it is also important to consider how death exists as a social phenomenon.

Death is not merely an individual, existential experience but also a social process experienced in relation to those who surround us (McNamara, 2004). At the broader, societal level, cultural expectations and practices around death shape and are shaped by social norms, values, and customs (McNamara, 2004; Woodthorpe & Brennan, 2014). However, death is also social when considering the microcosm that surrounds each dying person. There is a communalisation of death wherein the patient exists within a network composed of their family/whānau[1], loved ones, and healthcare providers (Ashby, 2014). Situating death as a social process is important when considering good death, since what constitutes a good death may differ between the dying person, their family and whānau, and their healthcare providers (Kehl, 2014). This can create tension within the palliative care space, particularly where the wishes of the patient may differ from those of their family and loved ones (Kehl, 2014; Krikorian et al., 2020). Furthermore, there can be tension between patient autonomy and professional expertise which necessitates careful navigation by involved professionals (De Jong & Clarke, 2009).

2.4 Chapter summary

In summary, this chapter has introduced palliative care as both a branch of medicine and a model of care. To begin, the chapter discussed how the scientisation and medicalisation of health lead to the emergence of the biomedical model, a model of health which prioritises biological determinants of diseases and centres curative, medicalised interventions. Critiques of the biomedical model include the perspective that it de-humanises healthcare and neglects to consider the complex interplay of non-biological factors which contribute to ill-health. Further, the inherent tension of responding to death within the treatment imperative inherent to the biomedical model was described. Subsequently, the hospice movement, as a precursor of the palliative care model, was described, specifically its reinterpretation of care for the dying as a holistic, person-centred endeavour which occurs within context. This current chapter highlights how palliative care developed as a bridge between the compassionate, holistic care philosophy of the hospice movement and the professionalised expertise of healthcare systems. A brief overview of the

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[1] Extended family; a family group.

scope and specific of the palliative care model was presented. The chapter concludes with recognition of how conceptualisations of good death and the prevention of bad death underscore the palliative care model.

Chapter 3: Palliative care in Aotearoa New Zealand

Building on the context of the preceding chapter, this chapter shifts focus to the context of Aotearoa New Zealand, where this research was undertaken. I discuss how palliative care emerged locally, tracing its development to the present day. In doing so, it demonstrates how the core tenets of the palliative care movement have been shaped to reflect the specific social and healthcare context in Aotearoa. This includes discussion of how palliative care is constructed, administrated, and delivered in Aotearoa New Zealand, with reference to specific, foundational documents and significant organisations in the palliative care space. Additionally, this chapter includes an exploration of how the palliative care model has been applied to respond to the specific needs of Māori and how this represents a framework for exploring how to do so for the Rainbow community. Finally, this chapter concludes with a brief review of relevant international literature on the topic of Rainbow experiences of palliative care to situate this study as well as to demonstrate the gap in knowledge as relating to domestic, localised literature.

3.1 Development of palliative care in Aotearoa New Zealand

The emergence of palliative care in Aotearoa New Zealand has been much in line with its development around the world. The first dedicated services for the terminally ill and dying were provided by religious orders such as the St Joseph’s Home for Incurables in Wellington, opened in 1899 by the Sisters of Compassion (Swarbrick, 2018). Over time, similar hospices were established nationwide which existed outside an explicit religious structure (Swarbrick, 2018). Further, whilst early iterations of hospices centred in-patient care, later generations moved towards home-based care (Phillips et al., 2015). This evolution is significant as it echoed a move towards a truly patient-centred model of care wherein the family is empowered to be involved in care (Swarbrick, 2018).

Today, palliative care in Aotearoa New Zealand encompasses the treatment and care provided to patients and their families and whānau for whom curative care is futile, of diminishing return, or inappropriate (Ministry of Health, 2017a). Importantly, palliative care in Aotearoa is not a static space but rather a dynamic process which evolves as the needs of patients, families, and communities and the complexities of care evolve (Heath et al., 2021). This is particularly noted given the increasing life expectancy[2] of the New Zealand population, and the associated health concerns such as dementia, which prompts a re-calibration of how care is provided and what that care entails (Ministry of Health, 2017a).

The New Zealand Palliative Care Glossary (Ministry of Health, 2015) defines palliative care as:

> care for people of all ages with a life-limiting or life-threatening condition, which aims to:
>
> > optimise an individual's quality of life until death by addressing the person's physical, psychosocial, spiritual and cultural needs
> >
> > support the individual's family, whānau and other caregivers where needed, through the illness and after death (p.12)

3.2 Delivery of palliative care in Aotearoa New Zealand

Palliative care in Aotearoa is provided within the context of a system that extends beyond care providers to include the factors which facilitate their provision of palliative care

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[2] This thesis recognises that, although life expectancy has increased over time in Aotearoa New Zealand, there still remains a consistent disparity between Pākehā and Māori life expectancy which must be recognised and addressed.

including communication and coordination between services (Ministry of Health, 2015). Currently, the design, provision, and funding of palliative care in Aotearoa is guided by the New Zealand Palliative Care Strategy, specifically by the implementation of the following vision: “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, 2001, p. vii). Within the context of this study, the specific reference to cultural appropriateness is particularly important. Furthermore, the Palliative Care Strategy also recognises that specific population groups, such as Māori and people with disabilities, may possess specific needs which will require flexibility in care delivery (Ministry of Health, 2001). The significance of these within the current study will be discussed in further sections.

The delivery of palliative care in New Zealand occurs within a broader, publicly funded healthcare system which ensures free to access palliative care services provided by hospital-based specialist teams or other providers within the public health system (Van Dalen, 2021). Palliative care is also provided free of cost by hospices which are partially funded by the government, alongside philanthropic and community support (Groeneveld et al., 2017).

Palliative care in Aotearoa falls into two distinct categories which nonetheless have overlap and, ideally, integration between them: specialist palliative care and primary palliative care. It is understood that quality of care is maximised when strong links exist between specialist and primary palliative care as well as with auxiliary support care providers and communities (Ministry of Health, 2015).

Specialist palliative care refers to care that is provided by medical professionals who have undergone additional, specific training and/or accreditation in palliative care within the context of an interdisciplinary team of other expert palliative care health professionals (Van Dalen, 2021). It can be provided by hospice or hospital-based palliative care services (Palliative Care Subcommittee NZ Cancer Treatment Working Party, 2007). There are two key ways in which specialist palliative care is provided: directly and indirectly. Direct specialist palliative care refers to the direct management and support of the patient and their family/whānau which can be continuous or episodic (Ministry of Health, 2015). Direct care is provided when the palliative care needs of the patient are understood to be of a complexity beyond the resources of primary palliative care providers (Ministry of Health, 2015). Indirect specialist palliative care refers to the support specialist palliative care professionals can provide for the primary provision of palliative care through advice, training, and education (Ministry of Health, 2015).

Primary palliative care refers to the broad care provided to palliative care patients by professionals, organisations, and clinicians who do not work within the context of a specialist palliative care team (Van Dalen, 2021). The provision of primary palliative care can occur within the community, provided by general practitioners, Māori health providers, residential care staff, or within hospital contexts, including general ward staff and disease-specific wards such as oncology or renal units (Ministry of Health, 2015). Primary palliative care providers undertake a central role in the integration of specialist and primary palliative care by assessing and referring patients to specialist providers when appropriate (Ministry of Health, 2015). It is important to recognise that, while primary care providers are integral to the care of those with palliative care needs, the nature of primary palliative care as a community-based and, generally, home-based paradigm means that caregivers within family/whānau networks are doing the majority of the work of meeting and managing the day-to-day needs of palliative care patients (Gott et al., 2015; Gott et al., 2018; Moeke-

Maxwell et al., 2014). The fundamental importance of family and whānau caregivers will be discussed further in following sections and chapters.

Palliative care represents a transition in care when a patient is diagnosed with a life-limiting illness, or a pre-existing illness becomes life-limiting (Ministry of Health, 2017a). This transition is guided by the patient's needs and will be supported by the advice, knowledge, and expertise of health professionals (Ministry of Health, 2001). Primary palliative care may commence whenever practicable or appropriate, as guided by a patient's care team. However, the transition into specialist palliative care can reflect a more formal process wherein a patient's principal primary care provider will refer them to a specialist provider (Ministry of Health, 2017a; Ministry of Health, 2001). The Palliative Care Council of New Zealand[3] (2014) articulated five criteria which guide referral to specialist palliative care services, specifically:

- the presence of active, progressive, and advanced illness;
- patient need exceeds the resources of primary palliative care providers;
- patient consent (or consent of appropriate health advocate);
- New Zealand citizenship, residency, or reciprocal rights;
- registration with a primary healthcare provider.

It is important for referrals to specialist palliative care services to be done when appropriate and in a timely fashion to ensure the best outcomes for patients and their family and whānau (Ministry of Health, 2017a). This referral process is facilitated by knowledge amongst primary care providers, communication across the primary-specialist divide, and a

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[3] The Palliative Care Council of New Zealand was disestablished in 2015 by the Minister of Health. Its referral process document remains available on the Health New Zealand (Te Whatu Ora) website hence its inclusion here.

focus on the continuity and coordination of care (Trainor & Naylor, 2012). Notably, whilst this formal process remains a core pathway into specialist palliative care, self-referral into such services is also possible (Hospice Waikato, n.d.).

There are numerous organisations involved in the delivery of specialist palliative care services in New Zealand. These include hospital-based palliative care services, present in many hospitals nationwide, and hospices, encompassing both inpatient and outpatient care (Ministry of Health, 2017b). Hospice New Zealand is a national organisation which represents affiliated hospices throughout Aotearoa. Each hospice within the Hospice New Zealand network is independently governed and locally managed with Hospice New Zealand working in partnership with them to represent their interests at the national level. Hospice New Zealand works in close consultation with Health New Zealand, as well as the district health boards (DHBs) which preceded it, as evidenced by their involvement and inclusion in several core documents such as the New Zealand Palliative Care Strategy (2021), the New Zealand Palliative Care Glossary (2015), and the Review of Adult Palliative Care Services in New Zealand (2017).

In its capacity as a foremost palliative care organisation, Hospice New Zealand has written and released several resources, publications, and educational courses aimed at promoting cohesion and consistency of service provision and ensuring a high quality of care for patients. A significant such publication is the Hospice New Zealand Standards for Palliative Care (the Standards) which provides nine standards for the delivery of consistent and best quality palliative care alongside guidance for the interpretation and application of these standards (Hospice New Zealand, 2019). As such, the Standards create a framework for member hospices to develop their services with a focus on continual quality improvement. Further, it has been stated that the Standards may, in the future, inform and enhance the service planning and delivery of non-hospice palliative care providers (Hospice New Zealand, 2019).

3.3 Māori experiences of palliative care

It is vital to acknowledge and locate the position of this research within the context of Aotearoa New Zealand and the relationship between tangata whenua[4] and tauiwi[5]. This thesis reaffirms Te Tiriti o Waitangi[6] and the specific duties and responsibilities the Treaty affords Māori and non-Māori (Furness et al., 2015). Furthermore, a commitment to biculturalism and the recognition of inequities Māori experience are present in several core documents and publications including the New Zealand Palliative Care Strategy and the Hospice New Zealand Standards for Palliative Care (Hospice New Zealand, 2019; Ministry of Health, 2001). Thus, it would be remiss to fail to discuss how Māori experience and access palliative care in Aotearoa. Additionally, by discussing the intricacies of experience for Māori as a specific community, this section demonstrates the real-world applications of the provisions for specific communities in the Strategy and other documents.

Traditionally, Māori practices of care as pertaining to illness, death, and dying are guided by tikanga[7] and mātauranga Māori[8] (Mead, 2003). Colonisation, and the subsequent forceful introduction of Western values and suppression of Māori ways of being, had a profoundly disruptive impact on the transfer of knowledge surrounding these practices although they have endured and survived to the present day (Durie, 1998; Mason & Moeke-Maxwell, 2019; Mead, 2003). Significantly, the holistic, person-centred framework which is elucidated in a palliative care system resonates with Māori models of health and wellbeing

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[4] People of the land; Indigenous people.

[5] Foreigner; non-Māori; person from afar.

[6] The Treaty of Waitangi.

[7] Culture, custom, method.

[8] Māori knowledges.

such as Whare Tapa Whā (Mason & Moeke-Maxwell, 2019). As Mason and Moeke-Maxwell (2019) discuss, the palliative care system within Aotearoa positions palliative care as a process which includes more than simply health professionals, placing importance on the role whānau play in supporting and providing palliative care. Importantly, population changes amongst Māori, particularly increasing age, has the potential to have a profound impact on how Māori access and experience palliative care and the intersection between whānau support and formalised care (Kerse et al., 2017; Mason & Moeke-Maxwell, 2019).

The importance of tikanga and mātauranga Māori continues to be demonstrated, even within more Westernised palliative care paradigms. Within the whānau role and alongside more general care and support, caregivers can incorporate a range of traditional Māori cultural customs such as rongōa māori[9], mirimiri[10], waiata[11], and karakia[12] whilst also engaging with core Māori paradigms (Angelo & Wilson, 2014; Johnston Taylor et al., 2014). Engagement in these cultural practices can sustain and strengthen whānau which provides them with resilience to navigate through the difficulties inherent to the end of life as well as the additional sociocultural, economic, structural and systemic issues Māori face (Moeke-Maxwell et al., 2014).

The whānau caregiver role can be impacted by several different concerns. Whānau capacity can differ greatly between families, a concern further mediated by the relative physical proximity of Māori to their whānau networks (Johnston Taylor et al., 2014; Moeke-Maxwell & Nikora, 2015; Moeke-Maxwell et al., 2014). Moreover, for some individuals, they may not wish for whānau to meet their palliative care needs (Moeke-Maxwell & Nikora,

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[9] Māori medicine; traditional treatment

[10] Massage.

[11] Song; chant.

[12] Incantation; ritual chant; prayer.

2015, 2018). This may be particularly salient for kaumātua[13] who may view the transition from a whānau leader to one requiring care as a challenge to their mana and sense of dignity (Oetzel et al., 2015b). Further, a deep concern for the burden that palliative care support can place on whānau may lead kaumātua to prefer non-whānau support (Gott et al., 2017; Moeke-Maxwell & Nikora, 2019).

Importantly, where whānau have the knowledge to navigate the healthcare space and services are flexible to the diverse needs of whānau, many whānau can positively engage with the palliative care space and ensure a collaborative, best-outcomes approach for their loved one (Mason & Moeke-Maxwell, 2019). Prior research has demonstrated that Māori experiences of palliative care services can be positive. For example, in a kaupapa Māori[14] qualitative study examining Māori perspectives of hospice care in the Wellington region, Johnston Taylor et al. (2014) found that whānau have positive experiences to do with compassionate staff, access to information and equipment when needed, respite care, bereavement and grief support, and spiritual care. Similarly, Slater et al. (2015), in a study of Māori cancer patients' and their families, had findings consistent with those of Johnston Taylor et al. (2014), further adding the positive impact of the responsivity of hospice inpatient units to whānau needs, continuity of care, after hours support, the inclusion and support of whānau, support with funeral arrangement, assistance for accessing benefits, and quality communication.

Nonetheless, there exist gaps in the provision of palliative care for Māori and their whānau, gaps that are exacerbated by limited resources and poor health literacy (Mason & Moeke-Maxwell, 2019). Research has demonstrated that a lack of awareness of palliative

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[13] Elders; a person of status within the whānau

[14] Māori approach; Māori principles

care services, barriers to accessing appropriate, accurate information, and misconceptions around what palliative care entails can drive poor uptake of palliative care services by Māori (Frey et al., 2013a; Johnston Taylor et al., 2014; Penney et al., 2009). Kidd et al. (2018) found that a disregard for the importance of tikanga, whakawhanaungatanga[15], and reciprocity can drive late access of palliative care services. Connectedly, the lack of clear, respectful, and culturally sensitive communication has been identified as a barrier for Māori and their whānau navigating the palliative care space (Moeke-Maxwell et al., 2014; Oetzel et al., 2015a; Penney et al., 2009). Finally, prior experiences of racism within the healthcare system alongside fears of discrimination derived from the experiences of others are a significant concern for Māori and their whānau when accessing palliative care (Frey et al., 2013a; Moeke-Maxwell et al., 2014; Penney et al., 2009).

In recognition of these issues, as well as broader concerns about the legacy of colonisation, and the unique position Māori hold as tangata whenua, processes and policies have been developed to address disparities for Māori in the palliative care space in Aotearoa. Building on previous publications, references to the unique needs of Māori are interwoven into the most recent Hospice New Zealand Standards for Palliative Care, making explicit how the Standards can be interpreted and applied within a Māori context to ensure best outcomes (Hospice New Zealand, 2019). Connectedly, Totara Hospice (South Auckland) alongside Mary Potter Hospice (Wellington) and in partnership with Te Ohu Rata o Aotearoa (Te ORA, Māori Medical Practitioners Association), developed Mauri Mate, a Māori palliative care framework designed to guide hospices in addressing the previous discussed issues for Māori and whānau in the palliative care space (Te Ohu Rata o Aotearoa, 2019).

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[15] Process of establishing relationships.

Fundamentally, this discussion of Māori experiences of palliative care demonstrates how the acknowledgement of specific community needs in the Strategy can be applied and realised. By acknowledging the concern, conducting appropriate and robust research, and creating quality resources and publications, specific community needs, and the health disparities they can represent, can be responded to (Muircroft et al., 2010). It is important to acknowledge that Māori possess unique rights as stemming from te Tiriti o Waitangi and it is not the intent of this thesis to imply the Rainbow community possess those same rights by nature of being a marginalised community. Rather, I contend that the Strategy and other core documents include provision for specific community need, and the experience of Māori demonstrates a real-world application of this, which sets a precedence and establishes capability to accomplish such work for other communities. Hence, this research places itself within the beginning of this process of responding to the needs of the Rainbow community.

3.4 Rainbow experiences of palliative care

As has been mentioned, there is a dearth of localised literature pertaining to Rainbow experiences of palliative care in Aotearoa New Zealand. Whilst there is recognition of the specific needs of the Rainbow community (e.g., Ministry of Health, 2017), there has been no formal exploration of the intersection between Rainbow identity and palliative care trajectories. This is significant as there are aspects of the local context which may have an impact of palliative care experiences such as the structure of the New Zealand healthcare system. As mentioned in Chapter 1, this underscores a key purpose of the present study, to begin the creation of knowledge in this area, given the gap in existing literature. Hence, it is important to briefly situate this research within the broader extant literature pertaining to Rainbow experiences of palliative care. This serves the purpose of illustrating the research gap that exists in New Zealand whilst also allowing for comparisons.

International research has demonstrated inequities in palliative care for members of the Rainbow community and their families (Berkman et al., 2023; Bristowe et al., 2016; Haviland et al., 2021; Rosa et al., 2023; Rosa et al., 2024). A lack of education and cultural competency training for service providers has been highlighted as contributing to these disparities (Maingi et al., 2018). This is compounded by a general lack of awareness, the presence of conscious and unconscious biases, and an overreliance upon cis-heteronormative assumptions amongst providers, all of which impede effective and culturally responsive care (Candrian & Lum, 2015; Cloyes et al., 2018). Furthermore, broader concerns about potential discrimination and the fear of revealing Rainbow identity status are recurrent themes within the literature (Maingi et al., 2018). These themes can be particularly salient within the context of home-based care as homes often represent safe spaces in which patients can be their most authentic selves, meaning the potential for non-affirming interactions may lead to either a hiding of Rainbow identity or a lack of engagement with such services (Candrian & Lum, 2015; Cloyes et al., 2018). Moreover, it is not just the fear of discrimination which can negatively impact palliative care outcomes for Rainbow patients but also direct experiences of disrespectful practice including homophobic or transphobic comments, the use of derogatory language, the disrespectful and dismissive treatment of partners and loved ones, and the prioritisation of the bio-legal family against patient wishes (Berkman et al., 2023; Cartwright et al., 2012; Higgins & Hynes, 2019; Stein et al., 2020).

Nonetheless, there is also literature demonstrating positive experiences for Rainbow people in the palliative care space. Palliative care environments with explicit non-discrimination policies combined with providers who engage in affirming communication and behaviour has been associated with improved quality of care, sense of well-being for patients, and treatment-goal alignment (Acquaviva, 2017; Cahill & Makadon, 2013; Cahill et al., 2014; Cloyes, et al., 2018). Roberts et al. (2022) found that the development and distribution of inclusive information, continuing engagement with the Rainbow community, comprehensive staff training, and the fostering of inclusive service delivery were all positioned as enablers of access to and engagement with palliative care services amongst Rainbow community members. Cloyes et al. (2018) made similar recommendations of best practice as well as including considerations for inclusive education curricula, models that incorporate history and context, comprehensive bereavement services, safe opportunities for self-disclosure, and embedded continuity of care.

3.5 Chapter summary

In summary, this chapter has introduced palliative care as it pertains to the localised, Aotearoa New Zealand context. I described the development of palliative care in New Zealand as emerging from primarily religious organisations. Following this, the delivery of palliative care in New Zealand was discussed. This included reference to the broader health system in which palliative care is provided as well as the concept of a palliative care system. Definitions for specialist palliative care and primary palliative care are provided. Hospice New Zealand is identified as a foremost palliative care organisation in Aotearoa, including recognition of the organisation’s importance in the creation of relevant policies and documents. Māori experiences of palliative care illustrate a specific community’s experience of palliative care including the tensions and unique considerations which must be made to ensure appropriate, high-quality care. I suggest that recent responses to the specific needs of Māori may provide a precedent for similar work for other groups, such as the Rainbow community. Finally, the extant literature pertaining to Rainbow experiences of palliative care provides a means to situate this research within existing literature, revealing a need for research into experiences of Rainbow people accessing palliative care in Aotearoa New Zealand.

Chapter 4: Research approach and methodology

This chapter outlines my research approach which was designed with community care, participation, and aroha at its core. To begin, I discuss the theoretical framework that forms the foundation of my research which consists of the socio-ecological model of health and aroha as a guiding principle of research engagement. Following this, I will discuss the ethical framework which informs my research. This section covers the emic/etic paradigm, positionality, relational ethics, and the ethical oversight of this study. The next section will introduce case study design as the qualitative methodology employed in this study. Subsequently, I discuss recruitment including the recruitment procedures I undertook, difficulties I experienced, and the solutions I employed. Next, I provide a brief profile on my participant. I then explain my interview procedure including interview transcription. Following this, I introduce several key documents and explain the way in which they are utilised in this thesis. Finally, I describe my analysis process which includes qualitative analysis of my interviews, analysis of the key documents, and the interaction between the two.

4.1 Theoretical framework

The socio-ecological model (SEM) of health asserts health is influenced by the interaction of factors occurring at the individual (microsystem), interpersonal (mesosystem), communal (exosystem), and societal (macrosystem) levels, and acknowledges the interrelationship between these factors (Kilanowski, 2017; Roberts et al., 2022). Additionally, the SEM considers the impact of time and historical context, including the influence of policy, within the chronosystem (Kilanowski, 2017). It has been demonstrated that the SEM can be beneficial in conceptualising and framing research pertaining to social justice and health, an intersection where this thesis inherently sits (Henderson & Baffour, 2015). Further, the SEM has been utilised to understand the barriers and facilitators to health and well-being within a contextualised framework (Ma et al., 2017). Within the palliative care space, the SEM has been used to examine the relationship between palliative care and cultural diversity, providing a framework to explore how factors at each level of the SEM can influence palliative care services (Davidson et al., 2016). Additionally, Roberts et al. (2022) utilised the SEM to explore the palliative care experiences of Rainbow people in New South Wales, Australia, situating perceived barriers and enablers within a socio-ecological paradigm. This thesis deliberately works to embed the SEM within its radical potential by connecting the individual to the broader social context and situating my findings within the historical timeline. The idea of entrenching this research within radical potentialities of frameworks is further shown in my utilisation of aroha as a theoretical paradigm.

The concept of aroha forms the second theoretical pillar of this research. Aroha is popularly understood in the public sphere as meaning love and is most often translated as thus (E Tū Whānau, n.d.). However, as can happen when indigenous concepts are translated, this reading of aroha neglects the depth of meaning inherent in the original, te ao Māori-grounded conceptualisation (E Tū Whānau, n.d.). When re-contextualised into/returned to mātauranga Māori, aroha encompasses an emotional experience, abstract concept, and way of being (E Tū Whānau, n.d.). It is grounded in notions of empathy, compassion, respect, and concern (Barlow, 1991). As Young et al. (2020) discuss, aroha extends beyond a concept or feeling and includes an active component; it is not simply a question of feeling aroha but doing aroha. Case et al. (2022) situate aroha as a form of power with the ability to generate theory and underscore practice. Further, Case et al. (2022) articulates the intentionality of aroha and its ability to challenge as well as to comfort. As such, aroha can act as a basis for liberation (Case et al., 2022). This conceptualisation of aroha underscores the co-construction of knowledge, and meaning as it necessitates respectful, attentive, and mutual consideration (Young et al., 2020).

From the understanding of aroha evoked above, I am led to its radical potential. By situating aroha as an active process, it follows that actions completed in service of others are a manifestation of aroha. The liberatory potential of aroha is vested in the questions it asks of us and the duty to others it evokes; it is a call to collective humanity. Therefore, I situate this research as an act of aroha. I position aroha as part of my theoretical framework as it scaffolds my research and provides a lens through which to view it. I have articulated that my research begins and ends in a place of aroha, and it is aroha that guides it. By grounding my work in aroha, it ensures I am thinking at every stage of the wellbeing of my community, from the interpersonal moments with my research participant, to the organisations I choose to ally myself with, to the ways I speak to my research in my written thesis. While I cherish and uplift the moments of Rainbow peace and joy, I recognise that resistance has constituted a core part of the Rainbow experience (Fitzgerald & Grossman, 2018; Sligo et al., 2023). I place my research within this ethic of resistance as an expression of aroha.

4.2 Ethical framework and positionality

Central to the ethical framework of this research is the recognition that qualitative research is an inherently contextualised research paradigm. In contrast to research methods that seek to uncover some form of objective, knowable ‘reality’, this current research is constructed to investigate a series of realities embedded within the contexts from which they emerge (Braun & Clarke, 2013; Laurence, 2020). As the researcher, and thus the architect of this research, I am a part of the research context; I establish the boundaries, inhabitants, and purpose. This manifests in the way I have constructed, completed, and engaged with this research, its topics, challenges, participants, and collaborators. Therefore, who I am intrinsically shapes this research; I cannot be separated from my own reality and thus cannot assume objectivity (Laurence, 2020). Hence, it is important to locate myself at the intersection of my social identities as these underscore the subjectivity I bring to this research.

I am a member of the Rainbow community and self-identify as queer. In many ways, this is the most significant of my identities in the context of this research. Indeed, I would have been unlikely to focus my research on the Rainbow community had I not been a member; we are often drawn to the topics of most relevance to us (Laurence, 2020). I connect this directly to my earlier discussion of enacted aroha and its connection to the ethic of resistance apparent throughout Rainbow history. Therefore, my research is written both as a researcher and as a Rainbow person. I have a vested interest in this research as it concerns something of direct significance to me: whether, upon approaching death, I will be supported to live with health and wellbeing. Therefore, as I write, I straddle these two identities I bring, researcher and community member. The implications of this can be discussed through the emic/etic paradigm (Mostowlansky & Rota, 2020).

Emic and etic refer to complementary positional standpoints for constructing and analysing social research. Emic is ‘insider’ research whereby the research standpoint is from within the community, analysing behaviour, culture, and significance as is understood by the community (Mostowlansky & Rota, 2020). Conversely, etic is ‘outsider’ research whereby the research standpoint is from outside the community, analysing behaviour, culture, and significance through externally mediated paradigms (Mostowlansky & Rota, 2020). It is important to note that mere membership to a community does not inherently mean a researcher conducts research from the emic position. They may utilise external ideas, technologies, methods, and insights and adapt them to the local context which is consistent with an etic position as described by Hodgetts et al. (2020). While there are strengths and weaknesses to both positions, it is routinely acknowledged that a symbiotic combination of both allows for greater insight (Galperin et al., 2022; Hodgetts et al., 2020; Mostowlanksy & Rota, 2020; Xia, 2011). Hodgetts et al. (2020) describe how the emic position can offer localised concepts and knowledge that may be otherwise missed while the etic position allows for comparison across contexts.

Within this research, I occupy both emic and etic positions. As a Rainbow person who occupies that position actively and openly in this research and who derives meaning from this insider perspective, I occupy an emic standpoint. Concurrently, I possess no direct experience or membership to the palliative care space and community. My understanding of that space is mediated by external factors which positions me as etic. Therefore, when conducting this research, I am cognisant of this dual position I occupy and the relevant benefits and concerns it affords me.

The approach to navigating ethical considerations within this research was also shaped by relational ethics, particularly with regards to interactions with my participant. Relational ethics as a framework decentralises epistemological concerns on the nature of knowledge, focusing instead on how and why knowledge is created and used (Hodgetts et al., 2022). A relational framework highlights relationships between researchers and participants, incorporating contextualised understandings of power dynamics and imbalances and privileging notions of respect, reciprocity, dialogue, collaboration, and mutual responsibility (Hopner & Liu, 2021). Further, relational ethics considers who benefits from the production and usage of knowledge, stressing the importance of mutual benefit for researcher and participant/community and challenging more extractive, transactional methods of knowledge production characteristic of legalistic ethics (Hodgetts et al., 2022; Hopner & Liu, 2021; Svane & Frandsen, 2024). By deploying relational ethics within the concept of aroha, I grounded the research within my broader commitment to the Rainbow community and producing research that could inform more inclusive care.

In addition to my own ethical commitments and reflective approach to my position as researcher, this research, including its materials and procedures, were reviewed and approved by the School of Psychology Human Research Ethics Committee at the University of Waikato. It was conducted pursuant to (HREC(Health)2023#49) and in line with the University of Waikato Ethical Conduct in Human Research and Related Activities Regulations (https://www.waikato.ac.nz/about/calendar/research-assessment-graduation/ethical-conduct/). Specific ethical considerations included protecting the welfare and dignity of research participants, informed consent, ensuring that methods minimise the risk of harm to my participant, and privacy and confidentiality. Considering my commitment to ethical research and ethical code above, I informed my participant of his right to withdraw from the research at any point during an interview, or later in the research process. During our interviews, I was careful to ensure he felt safe and supported and remained vigilant for signs of distress. In addition, I committed to providing my participant with copies of his transcribed interviews before using his account within my thesis, giving him control and ownership of his story. I took care to respect privacy and confidentiality which will be further discussed in the forthcoming participant profile. Further, the steps I took to ensure informed consent are discussed in the later interview procedure section.

4.3 Case study design

From the outset of this research process, I committed to employing a research design which allowed for rich discussion and centred depth of analysis and knowledge, as opposed to a focus on engaging with as many participants as possible. This is in line with the theoretical and ethical frameworks discussed prior, particularly the commitment to the enacting of aroha. Further, due to logistical considerations around time constraints and realistic recruitment expectations, employing such an approach allows for proportionately more time dedicated to the exploration of cases than to the recruitment of participants. Consequently, this research uses a case study design.

A case study design allows for in-depth description, exploration or investigation of contemporary phenomena in the real-life context in which they occur (Crowe et al., 2011; Yin, 2009). In contrast to experimental designs which deliberately manipulate variables, case studies focus on knowledge pertaining to how, where, and why phenomena occur allowing researchers to gain understanding of the shape, complexities, and dynamics of said phenomena (Crowe et al., 2011; Orum et al., 1991). This research is not positioned as providing a comprehensive investigation of Rainbow experiences of palliative care. Rather, it utilises a case study design, grounded within a theoretical and ethical framework, to explore a phenomenon not previously studied within the Aotearoa New Zealand context. That is, the case study provides a lens into the phenomenon.

4.4 Recruitment

Recruitment was initially open to two groups of people: members of the Rainbow community who have received/are receiving palliative care and family of Rainbow community members who have received/are receiving palliative care. The delivery of palliative care needed to be within Aotearoa New Zealand as this study focused specifically on the local context. Family is a diverse and dynamic concept that can manifest in a multitude of different forms (Widmer, 2010). Initially, as can be seen in the recruitment materials included in Appendix A, family was articulated as whānau. I chose to use whānau due to the potentially narrow understandings of the word family which prioritise and privilege the bio-legal, nuclear family (Goldberg & Allen, 2012; Levin et al., 2020; Widmer, 2010). As will be discussed, conceptualisations of family within the Rainbow community can challenge these notions, in part due to family estrangement and the creation of families of choice (Huynh, 2023). The idea of found families or chosen families, of which membership is determined by mutual care and support as opposed to biological or legal (bio-legal) ties, is an enduring experience in the Rainbow space (Levin et al., 2020). These families of choice function as bio-legal families are expected to, providing emotional, financial, physical, and spiritual support. Therefore, where brevity was important, such as in recruitment materials, I chose to use whānau to be inclusive of these different familial structures and arrangements. However, I have since chosen to also use family. The reason for this change is three-fold.

First, relevant literature uses family, including both international and domestic. Whilst whānau is increasingly used alongside family within domestic documentation, family remains the most consistently used term, particularly when utilised as a descriptive noun such as in the phrase ‘family health care’. Hence, utilising family as a descriptor aids efficient and accessible comparison. Second, due to the ubiquitous nature of chosen family within the Rainbow community, it is likely that potential participants would be aware of the dynamic nature of family and could infer their relevance to the research accurately. Third, as a non-Māori researcher, I have hesitancy utilising a concept from te ao Māori that I do not possess a comprehensive cultural understanding of. Moreover, there is cultural danger in removing said concept from its cultural grounding and using it to refer to something else, particularly another concept with Western roots. Consequently, I took an inclusive approach, deploying both family and whānau.

For participants who are family members, this includes those whose person is currently accessing care and those who have previously accessed care, including family members who may be bereaved. Family members need not be Rainbow community members themselves. It is important to note that a potential participant may share characteristics of both groups. For example, a person may be a member of the Rainbow community and be fulfilling the family role for someone else. Similarly, someone may have previously fulfilled that family role but are now experiencing their own journey with palliative care. These complexities were acknowledged and welcomed as they reflect the layers inherent to lived realities. Due to recruitment difficulties which will be discussed further, these two groups were broadened to include all Rainbow persons who have been in contact with the palliative care services whether they were themselves a patient or not. This may include nurses, support workers, and Rainbow family members of palliative care patients. It was my belief that these widened eligibility requirements would still allow for rich exploration of the intersection of being a member of the Rainbow community and palliative care services.

My intention was for recruitment to primarily be conducted through collaboration with stakeholder groups. I approached relevant groups and organisations such as Gender Minorities Aotearoa, the Burnett Foundation (formerly New Zealand AIDS Foundation), and hospices and provided them with advertising materials. This collaboration was important as it demonstrated a level of community validity which could reassure participants of the intent of this research (Reimer et al., 2020). Logistically, collaboration was of benefit as these organisations have broad reach within the Rainbow community and palliative care spaces meaning my recruitment materials could be viewed and accessed by a wider population. Further, as there is no currently existing central authority for palliative care within the Rainbow community, these organisations provided the best opportunity to reach potential participants. Nonetheless, word of mouth was also important as simply talking with people in the Rainbow community helped to access informal community networks.

Despite casting a wide net, I encountered difficulties in recruitment. The timing and relatively short length of my recruitment period, from mid-November 2023 to the end of January 2024, presented logistical challenges as many people were on holiday for the Christmas/New Years period. This impacted the organisations I approached for collaboration as fewer staff were available. Community members were also less available as they prioritised spending the holiday period with family and whānau. Additionally, it is a simple reality that this research explores a difficult topic which some may not feel prepared to discuss. Furthermore, palliative care journeys can be emotionally draining and time consuming, leaving patients and their families without capacity to engage in additional commitments such as this research (Jordhøy et al., 1999). Even with precautions taken to ensure the well-being of participants, engaging in research likely would not be a priority for many potential participants. Unfortunately, with the time constraints inherent to this level of study, it was outside of my capabilities to establish the mechanisms necessary to make recruitment truly comprehensive in this regard. Consequently, I struggled to recruit participants. Ultimately, a family friend, Tim, agreed to participate having discussed this research with me. Tim will be introduced in more detail in the next section.

It is notable that, throughout my recruitment process, I had numerous people inform me of their interest in and support of my research. When advertising in Rainbow social media spaces, I had several people reach out to offer their support and assistance. Even when they were not suitable for participation, they nonetheless offered their help. Further, the comments I received on my posts demonstrated a considerable amount of support for my research, indicating that members of the Rainbow community felt this sort of research was significant, important, and necessary. They articulated potential inequities that Rainbow people face in the health system and the need to conduct formal research to clarify these. Therefore, although I encountered difficulties in recruitment, it seems unlikely this was due to community hesitancy. Supportive responses from those learning about my intended research motivated me to pivot my research when I encountered recruitment difficulties. My commitment to ensure I would produce something that would be of utility to the community echoed my reading of aroha as theory and practice. Moreover, I also received support from outside the Rainbow community including from nurses and other healthcare providers and hospice staff. For providers and staff, there was recognition that this was an area that they were not knowledgeable about and recognised a need to increase their knowledge. This reinforces the rationale for this research.

4.5 Participant profile

As mentioned, my participant was a family friend. Tim and I have known each other for several years and have formed a friendship despite our generational gap. I had discussed my research with Tim from the beginning stages of formulating my idea through to obtaining ethics approval. He was aware of my recruitment difficulties and offered to participate. He had previously supported his late partner through a palliative care journey in 2010 and felt he could offer insights for my research. Tim is a Pākehā/New Zealand European, cisgender gay man as was his late partner. At the time of his death, Tim's partner was 55 years old and was a practicing general practitioner. He had engaged with hospice services during his palliative care journey. Tim and his partner were in a long-term relationship which was known to both their family and community. Tim offered to participate of his own volition and with no pressure or expectation from myself. Nonetheless, there are ethical considerations to be made due to our dual relationship as friends and researcher/participant. These considerations were guided by the relational ethics framework discussed above in the chapter section on ethics. A key concern when dual relationships are present in research is the impact of power imbalances emerging from the typically hierarchical relationship between researcher and participant (Bourdeau, 2000; Gabriel, 2005). Considering this, I made every effort to construct the interview space as a reciprocal and collaborative environment wherein Tim was the expert, facilitated by respectful communication, appropriate anecdotal sharing, and deference to Tim's status as knowledge sharer.

One issue I needed to consider, particularly in light of the sensitive topic of this research, is participant confidentiality. The protection of identities helps to create safety for participants to share in an authentic way and recognises their right to autonomy (Giordano et al., 2007; Wiles et al., 2008). Nonetheless, for some participants, openly claiming their stories can be an empowering and cathartic experience, particularly for those who belong to communities that have been marginalised, ignored, and silenced (Giordano et al., 2007; Wiles et al., 2008). Tim made the decision to be identified in this research by way of using his real name. However, he did ask for his partner's name to be kept confidential as, in his words, he had given permission, but his late partner had not and could not. To respect this, I have sought to keep information about his partner vague and have removed some identifying information for Tim. This approach allows balance between Tim's right to be identified and the protection of his loved ones. I made sure to discuss the implications of identifying himself in this research with Tim, including the potential for his partner to be recognised through context clues.

Tim has an extensive work history in organisations centred around community engagement and advocacy. This includes victim support, suicide prevention, family violence support, HIV/AIDS advocacy, and restorative justice. This background is relevant as it provided Tim with a keen understanding of social inequality and power dynamics as well as affording him a high level of health literacy. These were apparent in our interviews and informed what information he communicated and how he did so, particularly the concepts and language he employed.

4.6 Interview procedure

Upon Tim expressing his interest in participating in my research, I provided a brief description of the aim and objectives of the research to ensure clarity. Once Tim indicated his continued interest in participating, I provided him a full participant information sheet (see Appendix B). The information sheet clarified his rights, my responsibilities as a researcher, what participation would entail, potential risks, confidentiality and privacy, and the provision of koha. Koha[16] comprised of a $50 voucher to a local restaurant. Having read the information sheet, Tim agreed to participate in an initial interview as well as a follow-up interview if needed.

I completed two interviews with Tim, both of which were conducted face-to-face in locations of Tim’s choosing, allowing him to select a space he felt comfortable to share his story in. I provided refreshments in recognition of Tim’s time and contribution, in the spirit of reciprocity and aroha. At our initial interview, I went over the information sheet again,

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[16] Contribution; physical demonstration of appreciation

particularly Tim's rights and my duties as a researcher, giving Tim the opportunity to ask questions. When he felt comfortable doing so, Tim provided written consent through a consent form (see Appendix C). After our initial interview, Tim agreed to a follow-up interview. At our follow-up interview, I again gave Tim space to ask questions and was able to talk through any concerns he had. This was important as, until an interview has been conducted, participants cannot be certain of how the experience will be for them. Re-checking with Tim recognised that his understanding of the research would have increased following our initial interview.

The interviews were semi-structured in nature. While I compiled a list of topics and questions as interview guidelines which could function as conversation starters (see Appendix D), I allowed Tim the space to tell his story in the way that was meaningful to him, and I did not limit him in what he chose to discuss. My reasons for this are two-fold. First, within a relational ethics paradigm, this empowered Tim to articulate and share his story as he felt appropriate and ensured I was not prioritising knowledge I deemed valuable or relevant. In this way, I was enacting a respectful research relationship grounded in aroha. Second, my positioning as etic in the palliative care space meant that Tim, as the more knowledgeable in this context, was in a better position to guide what knowledge he deemed most important, necessary, and relevant. This participant-led interview structure also supported the deeply exploratory nature of this research.

Each interview was audio-recorded using a generic voice recording application on my personal smartphone. These were uploaded to secure digital folders with the raw audio files being deleted. Full, verbatim transcripts were created using the audio to text function on Microsoft Word. I manually checked each transcript, editing where necessary to ensure accuracy to what was recorded. Once the transcript was finalised, I emailed it to Tim so he could read it and make amendments. This also allowed for him to recalibrate prior to our follow-up interview, giving him the opportunity to bring topics of discussion and concerns to the second interview.

It should be noted that Tim found reading the transcript of our first interview disconcerting. We discussed this experience in our second interview where it became apparent that this feeling emerged from the relative strangeness of reading verbatim spoken speech. Unlike written text which can be edited and refined, spoken speech can be repetitive, imprecise, and situationally grounded. It is likely that Tim was not aware at the time he was speaking the way he did, particularly given the personal narrative he was sharing, and so to see the reality of his words, unedited, was disconcerting. Crucially, his concern was not about the content of the interview, as he made no amendments, but rather the experience of reading it back. He noted that, in the future, it would be beneficial to communicate this to future participants who may also find reading a verbatim transcript strange. It is valuable for qualitative participants to be able to see and hear themselves within their narratives. Hence, this was a learning moment which I have reflected upon. In addition, Tim felt comfortable communicating his discomfort, suggesting that our research relationship was one of trust and mutual respect; he felt he could safely raise the issue with me because he trusted in my respect for him and his opinions.

4.7 Documents for analysis

In addition to the fine-grained analysis of lived experience, afforded by my case study, I conducted an analysis of pertinent documents. The theoretical framework of this research, specifically the socio-ecological model, required examination of the broader structures that construct, mediate, and inform the palliative care space in Aotearoa New Zealand. As a method of investigating these structures, I examined several documents that shape the provision of palliative care, displayed in Table 1 (see p. 42). This selection is not intended to be an exhaustive list of every strategy, action plan, policy, or publication that has an impact on palliative care in New Zealand, which would extend far beyond the capabilities of this thesis. Instead, the documents selected introduce key empirical materials which have the most direct impact on the design and delivery of palliative care. Table 1 indicates some key documents that served as data for understanding how palliative care is conceived as a system by key organisations and bodies governing the planning and delivery of palliative care in Aotearoa.

I collated these documents by searching the websites of relevant organisations, namely the Ministry of Health (Manatū Hauora), Health New Zealand (Te Whatu Ora), and Hospice New Zealand. Through my review of relevant New Zealand literature, the documents included in Table 1 emerged as particularly important and influential documents within the local palliative care space. As such, they formed a network of resources which provided an overview of the structure of palliative care in Aotearoa New Zealand.

Table 1

Documents included for analysis

Title	Year	Author/Organisation
New Zealand Palliative Care Strategy	2001	Ministry of Health (Manatū Hauora)
Referral Criteria for Adult Palliative Care Services in New Zealand	2014	Palliative Care Council of New Zealand (dis-established 2015)
New Zealand Palliative Care Glossary	2015	Originally Palliative Care Council of New Zealand, now the responsibility of the Ministry of Health (Manatū Hauora)
Review of Adult Palliative Care Services in New Zealand	2017	Ministry of Health (Manatū Hauora)
Palliative Care Action Plan	2017	Ministry of Health (Manatū Hauora)
Hospice New Zealand Standards for Palliative Care	2019	Hospice New Zealand
Māori and Palliative Care: Literature review report for Te Ohu Rata Aotearoa	2019	Kat Mason and Dr Tess Moeke-Maxwell (on behalf of Te Ohu Rata Aotearoa)
Mauri Mate: A Māori Palliative Care Framework for Hospices	2020	Totara Hospice and Mary Potter Hospice (commissioners); Te Ohu Rata Aotearoa Māori Medical Practitioners

4.8 Analysis process

Qualitative data analysis of the interviews with my participant was interpretivist in nature. Within case study designs, an interpretative approach seeks to understand meaning at both the individual and social levels which connects to the SEM framework of this thesis (Crowe et al., 2011). Through repeated close reading of the interview transcripts, I identified events and themes which were significant to Tim and his partner’s experience of palliative care. I considered each of these events and themes within the theoretical framework of this thesis, particularly the SEM, and concurrently with the documents identified in the preceding section. This allowed me to consider how my case study was positioned within broader systems, connecting the individual level experience of my participant to the wider systemic levels which structure palliative care. Furthermore, given the central tenet of this thesis pertains to the relationship between palliative care and good death within the context of the Rainbow community, I remained conscious of these concepts during my analytical process.

Analysis of the documents was conducted by thorough, repeated readings in which I considered how the values, beliefs, and assumptions observable within the documents underscore the palliative care space in Aotearoa. This included identifying specific quotes which most clearly illustrated this from which I created a detailed mind-map clarifying the relationships and interactions within and between the documents. By engaging in this analytical process, I gained understanding of the macrosystem, within which patients and families experience palliative care. When considered in conjunction with the qualitative knowledge that arose from my interviews, the documents elucidate a rich picture of how palliative care in Aotearoa functions as a system. Plainly, the documents explain the broader levels of the SEM whereas the interviews speak to the more intimate levels. My analysis of these documents, when situated within the theoretical framework of this thesis, provides me a pathway to examine how understandings of palliative care at the macrosystemic level impacts the experience for individuals at the micro- and mesosystemic levels. Furthermore, I can see the connections across and within each level of the SEM by examining interactions between the documents framing palliative care services in New Zealand and the experiences explored in the case study.

4.9 Chapter summary

In summary, this chapter has described the research approach and methodology of this thesis. This includes the theoretical and ethical frameworks, case study design, recruitment process, interview procedure, and analytical process. Further, I provided a brief introduction to my participant and presented the documents which form a pillar of data in this research alongside the qualitative data sourced from the interviews I conducted.

Chapter 5: Caregiving: Navigating transitions, support, and autonomy

This chapter introduces the theme of caregiving. Tim's understanding and recollections of his partner's journey with palliative care were shaped, unsurprisingly, by his experiences navigating his role as primary caregiver for his late partner. Through our interviews, it became clear that Tim's experience was shaped by transitions in care, dynamic support, and expressions of autonomy. These key ideas are interwoven throughout the chapter in recognition of the complex, multilayered experience that is caring for a dying loved one.

There were initial attempts to treat Tim's partner's cancer using chemotherapy although it was not certain whether it would cure the cancer or slow its trajectory. Tim mentioned how, given his partner's experiences as a GP, "he was able to decide about treatment and support he wanted" and so was able to make the informed decision to pursue treatment. Tim recollected how difficult that period was for him and his partner, saying:

> That treatment was horrible … he'd go for that treatment which lasted a day each time and he'd come back from that, and he'd be really high, with all the steroids, and then he'd be really flat and really ill afterwards.

This period of active, curative-focused treatment was challenging for both Tim and his partner. While his partner was experiencing the deeply unpleasant physiological side effects of the chemotherapy treatment, Tim was a witness to his pain and did not have a direct course of action to ease his suffering. His partner’s illness was something out of his control. Hence, this period was one of uncertainty, characterised by the difficulty of bearing the burden of chemotherapy as both patient and loved one. This was compounded by the fact that, prior to treatment, Tim describes how his partner “wasn't ill, wasn't presenting as ill” except for some minor fatigue. Thus, seeing his partner suddenly enduring the chemotherapy side effects was hard for Tim as he had previously “no real illnesses, [no] signs or symptoms”. The change was abrupt and came without warning or time for preparation, particularly given the time constraints his partner’s prognosis established. As such, Tim suddenly found himself having to bear witness to his partner’s struggle. This changed once the decision was made to stop treatment.

Following “two or three sessions”, Tim described how “the results showed that the treatment had had no impact on the growth” of his partner’s cancer. Given the toll the treatment had taken with little redeeming effectiveness, the decision was made to stop curative treatment. Instead, the focus would shift towards home-based palliative care with treatments centred on symptom management. Tim reflected on that decision saying, “once that decision was made, we were all good”. There was a sense of acceptance with making the decision to transition to palliative care. Where the curative period had been marked by a lack of surety, the movement to this new stage brought a sense of certainty. There was an acceptance that Tim’s partner was dying which allowed for Tim and his partner to recalibrate and enter a stage of preparation. Furthermore, Tim recalled how his partner had previously expressed a desire to pursue work within a hospice setting, seeing it as “a worthwhile, useful, positive thing to do, … to be in that space.” Hence, he “was aware of what was likely to happen and what he was likely to need”.

Once it was determined that his partner was terminally ill, Tim transitioned into the role of caregiver. Initially, this did not require significant hands-on care. His partner "remained quite well" at the beginning of his palliative care journey and so was able to exercise autonomy and independence. This included informing loved ones of his condition, where they "[decided] to go around and tell people face to face if possible". This speaks to how important a sense of social connection was during the palliative care journey. Tim specifically remembered the process of informing his partner's two grown daughters of his illness, an experience he described as "heart-breaking". Outside of close friends and family, Tim took on much of the responsibility of telling people of his partner's diagnosis at his partner's behest. He described this as giving him a purpose, an avenue for him to be productive and supportive. This contrasted with his prior experience of when his partner was receiving chemotherapy. Tim described this initial period as being a "journey [they] embarked on" which echoes a sense of palliative care as a process marked by personal change and as a series of transitions and developments.

As his illness progressed, Tim's partner became increasingly more visibly ill which saw Tim begin to administer more hands-on care. A significant moment came when his partner required surgery to remove a blockage in his stomach. The decision to operate was made to ensure Tim's partner retained quality of life. However, the experience of entering hospital solidified for him that he did not wish to be hospitalised, rather preferring to be at home. Tim recalled this, saying "he came home, and he complained about the hospital because it wasn't clean, and he didn't like it. He didn't want to be there. And so, he came home, and everything was fine." Tim's partner found the clinical environment of the hospital to be incompatible with the way he wished to spend his limited time. The experience of being at home provided a sense of comfort which was not possible in the medicalised environment of the hospital. At home, Tim's partner had greater access to his family, including his mother who lived with the couple at the time. Further, he was able to navigate this new stage of his life with the security, familiarity, and comfort that being in his own home provided. This desire to be at home is echoed strongly in other accounts of patient wishes (e.g., Hanratty et al., 2013; Sandsdalen et al., 2015) as well as in documents from providers, including Hospice New Zealand. This moment became one in which Tim's partner could exercise his autonomy. His desire to remain at home became paramount with the various branches of his care network, including Tim and hospice staff, orienting themselves to ensure his wishes were met. Consequently, Tim's importance as primary caregiver became more pronounced.

During this time, Tim discussed how he felt he became the "gatekeeper" for his partner. Due to his partner's increasing symptoms, he "spent more and more time in bed". Hence, Tim became the access point for the "people [who] wanted to come in and see him". Whilst his partner focused on his own journey, Tim became responsible for balancing his partner's desire for continuing social connection and the wishes of his loved ones to reaffirm their relationship with the practicalities of his partner's limitations. This was particularly difficult given his partner's status in the community having been a doctor who had positioned himself as deeply community engaged. As such, "[Tim] became the person that would say yes or no, [would say] we need to have some time now." He had to make the difficult decisions on who was "coming and not coming in, who [he] would let in and when they were allowed." At times, this meant declining social calls as his partner was simply too unwell and required rest. Nonetheless, Tim recognised how important continuing social connection was for his partner and that there would be many who would want to express their well wishes and reaffirm their relationship with his partner. As an alternative, Tim used notebooks to create a bridge between his ailing partner and those who wanted to reach out.

> I got a set of books like you get in a hotel or something. You know, for comments. And then took them into [his partner's surgery]. So, they were in the surgery on their reception desk. People would fill all those in. … That also gave people a way of saying goodbye or to say what they needed to say.

By sourcing an alternative, Tim was able to balance his partner's need for rest with the need to connect with others, recognising that connecting with Tim's partner was important to those in their wider social circle.

Another detail which Tim recalled as being something he had to navigate was around his partner's nutritional needs. Tim describes how, "when he came out of hospital, [his partner] really wasn't interested that much in eating or meals and stuff like that." This created some tension as Tim, in his role as primary caregiver, felt he had a duty to ensure his partner was receiving the nutrition he needed despite his partner's apathy towards eating. Hence, it became a balancing act between his partner's autonomy and thus right to refuse food and the reality that, without proper nutrition, his quality of life may diminish. This was a transition Tim had to navigate, that of going from being an equal partner to having the responsibilities of a caregiver. Given his partner was able-bodied prior to his illness, this difference was particularly pronounced. Tim described this transition as "a difficult time, balancing [his partner's] needs above [his] and other peoples and trying to keep the environment as stress-free as possible."

The idea of autonomy became apparent again when Tim described his interactions with hospice. Further, it also speaks to the theme of support as hospice supported him to be autonomous in his partner's care wherever possible. Hospice staff began providing home-based support around the time Tim's partner became apathetic towards food. Staff would come to their home to administer his partner's medication and to check how he was doing.

Over time, his medication needs became such that a pump was installed. This allowed for him to receive the medication he needed to combat his symptoms whilst remaining at home which was his ultimate expressed wish. As Tim said, “he was able to be at home all the time, which was lovely.” The installation of the pump also meant that Tim was able to take over responsibility for his partner’s medication after receiving training from hospice on how to do so. Hence, this became a moment of autonomy for Tim as he was able to respond directly and in real time to his partner’s needs. Further, it supported his partner’s sense of autonomy by allowing him to remain at home and it was the direct support of hospice that enabled this. Tim recalled how, despite the training, “[his] concern was whether [he] was over medicating or under medicating.” To ease his worry, Tim was able to talk to hospice staff and receive reassurance that he was administering the medication correctly. Thus, the hospice staff helped create an environment where Tim and his partner could focus on what was important to them whilst providing support as and when needed.

By being at home and receiving the support from hospice there, Tim and his partner were able to prepare for his impending death. They had time to discuss funeral arrangements, including liaising with the funeral celebrant and funeral home, which meant Tim’s partner could both express his wishes and streamline the process after his death. Tim “had a casket woven for him in the South Island which [his partner] also got to see.” Family members were able to be included in the conversations and contribute their ideas which Tim described as “really, really nice.” These experiences were important to Tim and his partner and helped to ease a difficult and emotionally taxing time. As Tim said, “[his partner] was able to be really involved. That made a huge difference, that it was his wishes. He was part of it all.” Tim’s partner was able to prioritise preparation and social (re)connection because of the responsibilities Tim undertook and the support hospice provided.

In addition to the hospice workers, further support was provided by staff at the practice Tim's partner worked at, completing the care network of primary palliative care providers, specialist palliative care providers, and family caregivers. Tim remembered how helpful it was to have this additional branch of support, saying "the other doctors [at the practice] were really good. They were on call as well, if I needed them or if I needed any support." As they worked at his practice, the other doctors "were people that [Tim's partner] worked with, so he knew them. He knew who they were and how they worked. So that was a comfort for him. He knew them, and he could tell them what he wanted." These pre-existing relationships meant Tim's partner was able to cultivate his support network with a sense of security; he could select those he felt most comfortable with. Similarly, Tim's partner was able to approach hospice with a sense of familiarity as "he'd worked with hospice and people like that already through his practice and so he already knew who he wanted to have." Overall, this meant the coordination of care for Tim's partner was streamlined, allowing the focus to turn to supporting him on his palliative care journey. Further, this had the added benefit of easing Tim's burden as caregiver as he also had a pre-existing, albeit less direct, relationship with the other doctors. Moreover, knowing his partner's trust in them was reassuring.

With the support he received from his care providers and the caregiving role Tim undertook, Tim's partner was able to realise his desire to remain at home until his death. In doing so, he remained close to his family and loved ones, re-affirming those relationships and the place he held in their lives. Tim reflected on his partner's death in a positive light, saying "he died in my arms, which was lovely … it was a really nice way to die for him, hopefully. But for me as well." The peacefulness of his partner's final moments appeared to Tim to be the best possible outcome of his palliative care journey. He had died without pain and minimised suffering, near his family and loved ones, at home as he wished, and with the knowledge that his affairs were in order. All of these were important to Tim's partner and so for the wishes to be realised suggests the support he received was successful in its endeavours. Further, it is important to recognise the significance for Tim. In his role as both partner and caregiver, Tim had supported and cared for his partner whilst going through his own experience of watching his life partner pass away. Hence, his partner's death represented an ending for Tim and the beginning of a new stage in his life, that of bereavement. As has been discussed, death is an inherently social experience. Whilst he did not experience the physical reality of it, Tim bore witness to his partner's death and had to deal with the aftermath. Hence, there is a poignancy and significance that Tim found his partner's death to be "a really nice way to die". He was able to carry comfort that he had helped his partner realise a good death given the circumstances.

Tim recognised that his ability to undertake the caregiver role and the ease with which he navigated the responsibilities and relationships that the role garnered was directly aided by the acceptance of his and his partner's relationship. For Tim, their status as a same-sex couple appeared to have no impact on the care his partner received or the support Tim himself received, as his partner's caregiver. In his words, "I think that so far as the hospice and the care [his partner received], the fact of him being gay or us being the gay couple didn't have any bearing or not that I was aware of."

Being "the gay couple" became an almost non-entity from Tim's perspective. His partner's care providers understood the nature of their relationship and accepted it without question. This allowed Tim to easily step into the caregiver role as his status as his partner's life partner was neither questioned nor undermined. However, Tim also recognised that "it had no bearing on any treatment because, as I say, [his partner] picked the people he wanted.” His partner’s ability to select his care team, due to his pre-existing relationships and occupation, ensured his team would operate from a place of acceptance and safety. The significance of this will be discussed later in Chapter 7.

Importantly, Tim believed the fact his partner was openly gay, and engaged with his community from that position, also contributed to ease on his palliative care journey.

> He was a very recognised and well known and out gay. … there was no sort of pussy footing around the relationship. There was nothing that felt awkward about that. Everyone was aware, yeah. So, it wasn't like meeting people for the first time and having to explain the relationship or who he was.

His partner’s status as ‘out’ removed uncertainty and, as Tim recognised in the above quote, ensured they did not have to expend energy explaining his identity or their relationship. Thus, being known as gay made it easier for his care team to meet him where he was, compounded by the pre-existing relationships he held with them. When asked whether he felt it may have been an issue if his partner was not openly gay or their relationship was not known, Tim said he thought “it could be a huge issue.” Significantly, this suggests a tension surrounding being openly Rainbow in the context of palliative care, an idea which will be developed in the following chapter.

5.1 Chapter summary

This chapter explored the theme of caregiving, developed through an examination of Tim’s experience as caregiver for his partner. Transitions are identified as an important aspect of Tim and his partner’s experience of terminal illness. Specifically, the impact of the transition from curative treatment to palliative care and the corresponding transition in Tim’s role as caregiver. Connectedly, Tim’s experience navigating the responsibilities and tensions of being his partner’s primary caregiver emerges. Tim’s autonomy as a caregiver and his partner’s autonomy as a patient form important themes in Tim’s account. Further, Tim expresses the idea of expert support, specifically hospice support, as facilitating autonomy.

Chapter 6: The impact of discrimination: Considering history and legacy

This chapter introduces the second key qualitative finding of this study, the impact of discrimination. This includes both past and present experiences with discrimination, demonstrating how events occur within the chronosystemic dimension of the SEM. To begin, the chapter covers a specific experience Tim and his partner faced where the lingering traumatic impact of the AIDS crisis was made explicit. Following this, the burden of educating is discussed. Finally, the chapter describes how, due to historical experiences, a fear of discrimination can shape the actions and experiences of Rainbow people in the palliative care space.

People and events are located in a historical timeline that flows from the past through the present and into the future. While moments can appear to be distinct snapshots in time, they instead emerge as a historically contextualised event whereby each socio-ecological level is shaped by moments of change and continuity across time (Bronfenbrenner, 1986). Simply put, situations do not emerge out of a vacuum but rather, our past shapes our present shapes our future. As discussed in the preceding chapter, Tim’s experience supporting his partner during his palliative care journey was a largely positive one. He found the hospice staff and other care providers to be supportive and attentive to his and his partner’s needs. Nonetheless, a significant moment Tim recounted was the experience of a nurse spreading rumours about his partner’s illness, specifically that he was dying of AIDS-related complications.

> But there was a nurse that had done some bank nursing for him or, you know, helped him occasionally, and hadn't got a job when a job came up at his practice, and so she apparently told people that he was dying of AIDS. So, then there's that whole thing about, you know, it's bad enough that someone's dying, but then to have that and the possible ramifications of that.

During the AIDS crisis, the devastating physical and emotional toll of the disease was compounded by pervasive discriminatory, anti-Rainbow rhetoric (Lutz & Ehrlich, 2023). Hence, the experience of having a nurse spread such rumours about his partner was deeply upsetting for Tim. It served as a reminder of a time in his life where many friends and loved ones died under the shroud of significant stigma, uncertainty, and misinformation. Tim acknowledged that, whilst AIDS "was not such a scary, scary thing" in 2010, there were nonetheless enduring misrepresentations which continued to be harmful to Rainbow people such as "the fact that someone was gay and dying meant that it had to be AIDS." This echoes the discriminatory rhetoric that was present during the crisis that positioned AIDS as an inherently Rainbow disease (Ruel & Campbell, 2006).

This experience illustrates how historical values and attitudes can continue to influence the present day as described by the chronosystem. Tim is a member of the demographic who survived the AIDS crisis and has thus borne witness to its legacy. He speaks from a place of lived experience – he knows the danger these myths hold because he has experienced the consequences of them. Further, the fact he mentions there continue to be myths suggests the impact of the AIDS crisis endures to the present day. Although implicit, Tim recognises that such misinformation continues to do harm. Hence, Tim's experience with the nurse demonstrates a need for understanding how historical events can shape specific demographic concerns. For those of Tim's age and generation, the AIDS crisis was a monumental community trauma which shaped their lives; the impact it continues to have cannot be underestimated. For example, de Vries et al. (2019) found that the legacy of the AIDS crisis continues to shape how older Rainbow adults perceive and engage with end-of-life care preparation. Further, whilst the AIDS crisis was central to how Rainbow men approached end-of-life care both individually and collectively, Rainbow women also related their perspectives back to the AIDS crisis, specifically their experiences of being caregivers during that time (de Vries et al., 2019). Thus, not only does the legacy of the AIDS crisis resonate within persistent albeit diminishing discriminatory attitudes, it also shapes the very behaviours and perspectives of older Rainbow people when approaching the end-of-life.

Importantly, whilst the nurse was not a part of Tim's partner's care team, she nonetheless was a medical professional who may be involved in the palliative care journeys of other Rainbow people. While her intentions in sharing the rumours cannot be ascertained beyond Tim's belief it was done vindictively, the nurse's actions were deeply inappropriate. By reiterating anti-Rainbow rhetoric, the nurse contributed to its perpetuation. Further, Tim mentioned how these sorts of rumours can do harm to reputation and livelihood due to the stigma surrounding HIV/AIDS, issues which are particularly relevant for his partner given his status as a healthcare professional.

Interestingly, Tim found confronting the nurse for her actions was an outlet for the anger and negative emotions he felt during the early part of his partner's palliative journey.

> She was a person that I was able to get really angry with. I phoned up the practice that she was working at and made an official complaint, I went round there, spoke to them about it, met with her, told her exactly what I thought and how damaging that was, and how damaging it could be spreading false information.

For Tim, being able to focus his energy on his complaint was cathartic. As discussed in the previous chapter, the early stage of his partner's illness was marked by uncertainty. Hence, having a definitive focus was stabilizing for Tim and served as a productive outlet for the negative emotions he was experiencing at the time. Although this specific experience was cathartic for Tim, he highlighted how stressful it can be for members of the Rainbow community to be educating people and advocating for themselves and their loved ones.

Tim emphasized how, when people are not knowledgeable on the Rainbow community and the complexities of their lived realities, Rainbow people must advocate for themselves and educate others to receive the same standard of care as their non-Rainbow peers. Within the palliative care space, this can be particularly taxing as many Rainbow people, patients and family members alike, wish to focus their time and energy on preparing, (re)connecting, and making memories (Higgins & Hynes, 2019). As Tim said, "it's really hard that you have to have that battle each time … it's not necessarily the time when you want to be educating people."

Tim was able to be an advocate for his partner and chose to take upon that responsibility, using it as an outlet for his frustration and anger at the situation. Given his history working in the community and social sectors, he was particularly equipped to navigate those conversations and understand the processes which needed to be followed. However, despite his ability and willingness to do so, Tim recognised that advocating for his partner and educating the nurse should not have been something he needed to do. As such, this represents an inequity within the palliative care space. There is a disparity between the aspirations of the palliative care model to be inclusive and culturally responsive and what is experienced on the ground by patients and their families. The burden of having to educate serves as a potential impediment to the experience of a good death, thus undermining a core value of the palliative care model in Aotearoa.

The potential need for Rainbow patients to educate staff also reveals a possible deficit in comprehensive Rainbow-inclusive training and education. Sanchez et al. (2017) found that, in a survey of medical schools in Australia and New Zealand, there was limited inclusion of Rainbow-related health content with an overemphasis on sexuality. This suggests that medical professionals and practitioners are not being properly educated on the specificities of Rainbow health and, more broadly, Rainbow identity. Whilst it is entirely likely that there are individual professionals in Aotearoa New Zealand practicing with a high degree of cultural literacy, when the educational foundation of practice is lacking in Rainbow related content, Rainbow people and their unique needs become comparatively invisible. This becomes embedded structurally in the wider health system and, more specifically, the palliative care space, ultimately impacting Rainbow experiences of palliative care at the point of delivery. Hence, this suggests a need for more comprehensive Rainbow curricula. Maingi et al. (2018) and Cloyes et al. (2018) both reference the need for better developed education in their discussions on best practice for Rainbow inclusive palliative care.

In the previous chapter, it was discussed that Tim and his partner being openly Rainbow facilitated positive engagement with the palliative care team. The ability to live authentically in the last stage of his life contributed to Tim’s partner’s experience of a good death. However, as discussed previously, there were contextual circumstances that contributed to Tim and his partner being openly Rainbow, namely that they were both well-known in their Rainbow identities prior to Tim’s partner’s illness and that his care team were known to them. In our interviews, Tim recognised that the decision to reveal one’s Rainbow identity is not without its danger. Despite social advances towards acceptance and inclusion, homophobia and transphobia persist within New Zealand society, leading to Rainbow people experiencing discrimination, prejudice, and violence (Schimanski & Treharne, 2019). Hence, a fear of discrimination can cause Rainbow people to refrain from being open in their identities. As Tim said,

> For people who are not able to be themselves, the fear of coming out is huge and that can be paralysing for some people. … What you can't make sense of is that you're no different the minute before you tell someone than the minute afterwards. But there's that fear of people treating you differently.

Within the palliative care context, that fear of people treating you differently, of potentially being discriminated against, can lead to Rainbow patients refraining from communicating their identity or delaying interacting with medical professionals (Candrian & Lum, 2015; Cartwright et al., 2012; Maingi et al., 2018). A lack of visibility and accountability can exacerbate pre-existing vulnerabilities and increase the potential for discriminatory treatment (Candrian & Cloyes, 2021). Furthermore, there may be compounding concerns for patients whose identities are comparatively more marginalised, such as transgender and gender diverse people. Tim reflected on this, saying:

> I think now that could be an issue for people who are different, who present as different. Because they can be treated differently by the organisations, by hospice, by doctors, by hospitals, by funeral homes. You know, all that sort of thing, even down to the fact that when someone phones you, [they] think you're a man or a woman.

This demonstrates that the Rainbow community is not a monolith but a diverse community with varied needs. As such, generalised approaches which do not consider individual context and need are ultimately inadequate. In the context of palliative care, this speaks to how important it is that care is rigorously person-centred rather than based upon generalised assumptions of what Rainbow patients and their families need.

6.1 Chapter summary

This chapter explored the impact of discrimination. An experience Tim had with a nurse saying his partner was dying of AIDS demonstrated how the legacy of the AIDS crisis continues to impact the present day. This was illustrated through the way in which it continues to shape attitudes and assumptions as well as the behaviour and perspective of older Rainbow adults who survived the crisis. Tim reflected on how advocating for his partner in that situation was empowering and cathartic but also should not have been required of him to ensure his partner received equitable care. Connectedly, Tim discussed how the burden of educating can detract from the palliative care experience. Finally, the impact of anticipated discrimination was explored alongside the dynamics of being openly Rainbow.

Chapter 7: Discussion

The primary research objective of this study was to explore Rainbow experiences of palliative care in Aotearoa New Zealand within the context of the policies and values that construct the palliative care space. This chapter explores the qualitative findings of this study in relation to the documents outlined in Chapter 4 and the literature introduced in Chapters 2 and 3. Specifically, this chapter discusses the radical potential of palliative care as a model of care, possible systemic disconnection between aspirations and lived experience, the role of intersectionality in facilitating good death, and the complexities of being openly Rainbow.

I argue in this thesis that palliative care in Aotearoa New Zealand is founded upon values that can be compromised when the full diversity of human experience is not comprehensively considered. The documents that underscore and construct the palliative care model in Aotearoa New Zealand demonstrate radical potential due to the holistic focus and person-centred approach to palliative care that the model embodies. As discussed in Chapter 3, the palliative care model emerged as a model of care in contrast to the more de-personalised and de-humanised practices of the prevailing biomedical model (Mino & Lert, 2005). The grounding of the palliative care model in the re-humanisation of caring for the dying represents both a critique of the biomedical model, and a touchstone for a radical re-interpretation of care itself, one where patients rather than medical outcomes are at the core (Frey et al., 2013b; Radosta, 2021). This radical potential for shifting power to the patient is discernible in the documents which shape, regulate, and define the palliative care space in Aotearoa New Zealand, for example in the New Zealand Palliative Care Strategy (Ministry of Health, 2001). The New Zealand Palliative Care Strategy (Strategy) provides the first reference to the holistic approach and aspirations of the palliative care model in Aotearoa, and details the funding, shape and scope of palliative care provision. This is illustrated in the following quote from the Strategy executive summary:

> Palliative care is the *total care* of people who are dying from active, progressive diseases … Palliative care … *integrates* physical (tinana), social (whānau), emotional (hinengaro) and spiritual (wairua) aspects of care to help the dying person and their family/whānau to attain an acceptable quality of life [emphasis added] (Ministry of Health, 2001, p. 2)

This holistic approach is confirmed in subsequent documents including the New Zealand Palliative Care Glossary (Glossary), which sought to establish common understanding of language utilised in the palliative care space, specifically within the Aotearoa New Zealand context (Ministry of Health, 2015). The Glossary recognises that “the principles of palliative care are framed around holistic care and the interdependent physical, social, emotional, cultural and spiritual aspects" (Ministry of Health, 2015, p. 6). Though implied in preceding documents, the radical potential of the palliative care model is most developed in the person-centred approach conceptualised and articulated in the Palliative Care Action Plan (Action Plan). The Action Plan specifically (re)centres and (re)imagines holistic care as a person-centred and person-driven endeavour that forms the underpinning framework on which palliative care operates (Ministry of Health, 2017a). This represents a reinterpretation of medical intervention as medical care where person-led treatment goals are the foci as opposed to expert-led measurements of treatment effectiveness (Frey et al., 2013b; Radosta, 2021). This framing (re)-empowers patients and whānau to construct their own palliative care journeys and narratives, as is appropriate and meaningful to them and their contextualised identities.

In terms of the Rainbow community, the radical potential and empowerment expressed within the palliative care model is noteworthy as it suggests a system that could more aptly respond to the complex interplay of factors which contribute to Rainbow experiences of death and dying. Crucially, the person-centred approach espoused by the palliative care model provides a distinct opportunity for authenticity, a consideration made poignant for the Rainbow community due to the ongoing discrimination they experience (Tan et al., 2021). This opportunity emerges from the palliative care model's aspirational commitment to understanding and supporting patients within their contextualised realities (Ministry of Health, 2017). This is substantiated in the working models espoused in the documents, particularly the Action Plan (Ministry of Health, 2017a). Within such a framework, a Rainbow patient's lived reality becomes the lens through which the palliative care journey is understood and navigated thus elevating the treatment pathway beyond restrictive, cis-heteronormative prescriptions of care. One key example of this is the definition and interpretation of family as a concept and unit of care within the palliative care model.

The New Zealand Palliative Care Glossary defines family as “those closest to the [patient] in knowledge, care and affection” which can comprise “the biological family, the family of acquisition (related by marriage/contract), and the family of choice and friends (including pets)” (Ministry of Health, 2015, p. 5). As discussed briefly in Chapter 4, the concept of family within the Rainbow community can be one of fluidity whereby the presumed bio-legal paradigm of family is rejected or subverted in favour of ties grounded in mutual care, affection, and support, irrespective of formalised kinship ties (Levin et al., 2020). Families of choice, or chosen families, can present crucial networks of care when Rainbow people are rejected or otherwise ostracised by their families of origin (Hull & Ortyl, 2019; Levin et al., 2020). Even in contexts where bio-legal familial ties remain important in Rainbow understandings of family, the importance of chosen families continues to resonate with and be important to Rainbow community members (Hull & Ortyl, 2019). Hence, the dynamic and inclusive conceptualisation of family espoused in the palliative care model in New Zealand represents a significant opportunity for the affirmation of Rainbow understandings of families that exist beyond heteronormative bio-legal paradigms. Fundamentally, the positioning of family as a fluid, individually understood entity affords greater capacity for diverse and multilayered familial configurations. As such, it serves as a potential site of empowerment and self-determination for Rainbow people to determine what family means to them and who comprises that family, founded upon a radical recognition of the diversity of familial ties. In addition to the ability of Rainbow people to define their concept of family within the inclusive framing of the palliative care model in Aotearoa, it is important to recognise increasing willingness from practitioners and policy makers to directly acknowledge the needs of diverse communities, including the Rainbow community.

Significantly, the most recent edition of the Hospice New Zealand Standards for Palliative Care (4th ed., the Standards), released in 2019, explicitly addresses the Rainbow community, recognising that community members have specific needs which should be considered within context (Hospice New Zealand, 2019). Specifically, the Standards state that:

> Palliative care services for [Rainbow][17] people should be accessible and inclusive; they should be culturally appropriate, safe, respectful, non-judgemental, welcoming and acceptable to the person and their self-designated family, whānau, friends, carers and support networks (Hospice New Zealand, 2019, p. 19)

Furthermore, the Standards recognise the importance of understanding and using current terminology to combat harmful stereotypes and out-dated or derogatory language (Hospice New Zealand, 2019). This is important as international research in the palliative care space has demonstrated that the usage of non-inclusive language can lead to Rainbow patients and their whānau feeling unwelcome or unsafe (Cloyes et al., 2018). Connectedly, the Standards call for collaboration and consultation with Rainbow community members to ensure services are engaging in appropriate and safe practice (Hospice New Zealand, 2019). This recognises the Rainbow community as being the experts in their own lived realities, thus serving as a site for community empowerment.

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[17] The Standards utilise the umbrella term LGBTQI+ which I have replaced with Rainbow to encourage continuity in the context of this thesis.

It is notable that, despite the inclusion of the Rainbow community and the intentions expressed above to improve services to this group, the Standards also state that Rainbow people “continue to experience misunderstanding, prejudice, discrimination, isolation, marginalisation, harassment and abuse leading to reduced health and well-being” (Hospice New Zealand, 2019, p. 19). The negative experiences described could refer solely to the wider social context in which Rainbow are systemically disadvantaged, but the Standards follow these descriptions of discrimination with a recommendation for education and training for staff and volunteers working in palliative care settings. The recommendation for addressing prejudice implies that such concerns may resonate within the palliative care space and, specifically, in Hospice New Zealand’s areas of practice (Hospice New Zealand, 2019). This statement of intent to serve the needs of Rainbow people, followed by recognition of the need for responding to infringements of this intent within care settings, indicates tension between the aspirations of the Standards, and what Rainbow people receiving palliative care may experience.

Whilst the documents constructing the palliative care space in New Zealand are underscored by values, such as the commitment to patient-centred care, the provision of palliative care nonetheless exists within a wider macrosystem which continues to have an impact on providers and consumers. Previous research has demonstrated that there are systemic concerns surrounding health disparities more broadly for the Rainbow community in Aotearoa (González & Veale, 2024; Sanchez et al., 2017). These concerns have been linked to a lack of cultural competency by providers and experiences of mistreatment or discrimination within healthcare settings (González & Veale, 2024). Furthermore, despite advancements towards equality, cis-heteronormative values continue to permeate New

Zealand society, directly and systemically disadvantaging members of the Rainbow community (Carpenter & Lee, 2010).

Continued inequities in the health system for the Rainbow community will have implications for palliative care. Whilst the documents which shape the provision of palliative care have aspirations of universal access and appropriateness through person-centred practice, this can be disconnected from what is experienced at the point of care for Rainbow patients and their whānau. Utilising an SEM perspective, it is clear that, when discrimination and misinformation persist at the macrosystemic level, there are direct implications for each systemic level due to the interdependent nature of the system (Kilanowski, 2017; Roberts et al., 2022). As such, persistent anti-Rainbow values permeate the system, becoming embedded in each level, which can continue to undermine aspirations towards Rainbow inclusivity within the palliative care space. Given this, it is important to consider how positive experiences of palliative care can be facilitated.

In the case of my research participant, Tim, and his partner, the palliative care model was generally successful in achieving aspirations of what has been defined as 'a good death'. As discussed in Chapter 5, Tim's partner was able to die the way that he wished and Tim, as his partner and primary caregiver, felt supported and empowered. This demonstrates that, when the constituent parts of the palliative care system in Aotearoa are effective, the model can manifest the values and goals that underscore it. Nevertheless, when approaching Tim's case study with a critical lens, it is apparent that there were intersecting facilitators which enabled this demonstration of the palliative care model's radical potential. International literature has demonstrated that disclosure of one's Rainbow identity within the palliative care space can be beneficial, particularly when the environment is explicitly affirming, as it leads to more person-oriented, specialised, and authentic care (Cloyes et al., 2018). As previously discussed, Tim's partner was well-known in his community as a gay man. The fact that his sexuality was already known proved beneficial as his care providers possessed pre-existing knowledge of his lived reality, facilitating a straight-forward transition into his palliative care journey.

Tim and his partner's relationship was privately and publicly known, meaning there was no confusion or uncertainty about Tim's status as primary caregiver. Additionally, Tim and his partner's relationship was long-term, well-established, monogamous, and domestic. Whilst this does not negate the fact their relationship was same-sex and thus subjected to homophobic scrutiny, these characteristics constitute similarities between their relationship and expected relationship structures within the prevailing heteronormative framework (Goldberg & Allen, 2012). Their relationship could conceivably be comprehended more easily than other Rainbow relationship dynamics which deviate more explicitly from sociocultural expectations of monogamous heterosexuality (Kitzinger, 2005). Connectedly, Tim and his partner were both white, cisgender men which placed them at a nexus of privilege due to structural racism and anti-transgender rhetoric although they experienced systemic homophobia (Came et al., 2019; Tan, 2021). From an intersectional perspective, this demonstrates how multilayered, intersecting identities create complex networks of relative sociocultural power and privilege which shape individual experiences of simultaneous systemic advantage and disadvantage (Parent et al., 2013). Tim and his partner were positioned in such a way that their layered identities afforded them relative privilege that a non-white or gender diverse person likely would not have possessed (Lamble, 2008). Further, the benefit that Tim and his partner experienced due to them being openly Rainbow reveals a significant tension within the palliative care space as relating to the necessity of being 'out'.

As discussed, a sense of authenticity when experiencing palliative care can be of benefit to Rainbow people (Cloyes et al., 2018). The disclosure of Rainbow identity status to palliative care providers has been associated with higher comfort levels for patients and reported benefits to goal alignment, sense of wellbeing, and the experienced quality of care (Acquaviva, 2017; Cahill & Makadon, 2013; Cahill et al., 2014). Importantly, these benefits were heightened and compounded when care providers demonstrated explicit non-discrimination policies through affirming signage, resources, communication and provider practice and behaviour (Acquaviva, 2017; Cloyes, et al., 2018). Conversely, non-disclosure of Rainbow status is associated with negative outcomes for Rainbow patients and their families, undermining aspirations of good death experiences. A significant concern is, due to structural cis-heteronormativity, there can be heterosexist assumptions about sexual and gender identity (Maingi et al., 2018). Moreover, it can lead to a lack of recognition of chosen families, denying patients crucial care networks (Maingi et al., 2018). For chosen family members this can lead to experiences of disenfranchised grief wherein grief is not acknowledged or is seen as delegitimate (Candrian & Cloyes, 2018; Candrian & Lum, 2015). Therefore, if being openly Rainbow is of benefit to the palliative care model working, this creates an impetus to ensure patients can be open about their Rainbow identity. However, the mechanism and process through which the Rainbow status of patients becomes known can function as a site of tension. If the care environment and relationship established between providers and patients is non-affirming, this creates a barrier for Rainbow people to be authentic in their identities (Candrian & Lum, 2015). Simply put, if Rainbow patients do not feel safe, they will not disclose their identity, and this can compromise their care (Candrian & Lum, 2015).

A fear of discrimination from healthcare providers, gained either through prior negative experiences or shared community knowledge, and a general mistrust of healthcare settings can lead not only to non-disclosure but also to delayed engagement with healthcare services (Hash & Netting, 2007; Johnson et al., 2005; Maingi et al., 2018; Price, 2010). Whilst there may be benefit in providers being proactive, such as in collecting sexuality and gender identity information as a means in which to challenge cis-heteronormative assumptions and relocate the burden of disclosure off patients, unless this proactivity is supported by an explicitly affirming environment and competent practice, Rainbow patients may experience no benefit (Candrian & Cloyes, 2021). Therefore, this demonstrates the necessity of explicit Rainbow inclusivity within the palliative care environment, to facilitate safe disclosure of identity and ensure the full benefits of the palliative care model can be accessed.

Despite the intersecting advantages Tim and his partner experienced when navigating the palliative care system, and their largely positive experiences of disclosing their identities, their Rainbow identities did also expose them to an example of discriminatory behaviour. In Chapter 6, Tim's account of a nurse telling people that Tim's partner supposedly had AIDS was understood by Tim to be a reference to his partner's sexual identity, connecting his illness with a disease that has a specific, complex, and painful history for the Rainbow community (Lutz & Ehrlich, 2023; Ruel & Campbell, 2006). The example illustrates how Tim's partner's experience was interpreted through the lens of his perceived identity by the nurse, demonstrating how assumptions and negative biases can shape the actions of health professionals (Berkman et al., 2023). Furthermore, the example of the nurse's hurtful comments also illustrates how events situated within the chronosystem can impact individual experiences in the present day. The lingering trauma of the AIDS crisis meant that the nurse's comments were particularly salient for Tim, evoking anger and sadness that may not be present for those who did not experience the crisis. This demonstrates that issues relating to the historical legacy of events for communities hold continued relevance for some members of those communities, as well as being relevant to how others may perceive them. Shaping systems that better serve the Rainbow community requires acknowledgement of how past experiences for these groups may impact in the present period.

7.1 Key points

In summary, when considering the overall implications of this study through a socio-ecological perspective, several key points emerge. The qualitative case which forms the foundation of this thesis demonstrates that members of the Rainbow community who engage with palliative care in Aotearoa New Zealand may have experiences and treatment journeys which are similar, yet distinct from the non-Rainbow population. The case of Tim and his partner illustrates how, even with the structural advantages they possessed from an intersectional standpoint, there were issues that they encountered that related directly to their Rainbow identities. For example, the negative experience they had with the nurse, as described in Chapter 6, was directly related to their status as gay men and the persistent belief, as Tim described, that AIDS is an inherently Rainbow-related illness. Furthermore, although Tim and his partner were comfortable in being openly gay when engaging in their palliative care journey, the mere fact that disclosure could potentially be an issue is not an experience shared by cisgender, heterosexual couples. Connectedly, the Rainbow community can possess pre-existing concerns about potential discrimination or non-affirming practice due to prior experience or shared community knowledge. All these considerations can hinder aspirations of a good death as set out in the palliative care model.

The case of Tim's partner being falsely represented by the nurse, discussed above, indicates how barriers to inclusive care for Rainbow people may lie in the broader landscape of the health system and the macrosystemic context. Whilst the nurse in question was not a direct part of Tim's partner's palliative care team, she nonetheless works within the New Zealand health system, which interacts with the palliative care system, as described in Chapter 3. As such, she represents an example of how factors at the mesosystemic level interact with societal level values to impact individual experiences of palliative care. Palliative care exists within a macrosystemic context rather than a utopian space not subject to issues in the broader system. Therefore, there is an imperative to address systemic, structural concerns which undermine Rainbow aspirations of a good death within the palliative care model.

Chapter 8: Conclusion

This thesis explored Rainbow experiences of palliative care in Aotearoa New Zealand through the lens of a situated case study. This final chapter provides a summary of the thesis including key findings and conclusions. Further, it describes implications of the study and considers the importance of researching diverse Rainbow experiences within the palliative care space in New Zealand.

First, it is important to recognise that, at the time of the writing of this thesis, significant changes were in the process of being made within the healthcare sector in Aotearoa New Zealand. This is partly due to the change of government from the Sixth Labour Government to the Sixth National Government and the subsequent changes in healthcare policy this engendered. Specifically, the passing of Pae Ora (Disestablishment of Māori Health Authority) Amendment Bill, which disestablished Te Aka Whai Ora (Māori Health Authority) and the absorption of staff into Health New Zealand (Te Whatu Ora).

Additionally, Health New Zealand (Te Whatu Ora) is currently undertaking the National Palliative Care Work Programme, a series of working groups in partnership with communities, which aims to support a “nationally consistent approach to palliative and end-of-life care planning, funding, service delivery and outcomes” (Health New Zealand, n.d.). The programme, established in August 2023 with a 2-year timeframe, will provide key deliverables which may have an impact on how palliative care is designed, administrated, and delivered in Aotearoa New Zealand (Health New Zealand, n.d.). Therefore, whilst it is unlikely that there will be any major change in the delivery of palliative care in Aotearoa New Zealand in the immediate future, it is nonetheless important to locate this thesis in time in case it is in the future contradicted by up-to-date policies and documents.

8.1 Key findings

This thesis has demonstrated that the Rainbow community of Aotearoa New Zealand represents a unique subgroup of the population who possesses specific needs within the palliative care space. Whilst the palliative care model has the radical potential to more aptly address these needs, enduring issues within the broader social system prevents this potential from being fully realised. As such, whilst this disconnect persists, there may be barriers to Rainbow people experiencing a good death. Nonetheless, there is a burgeoning understanding of the necessity in addressing these needs to ensure equity within the palliative care space in Aotearoa New Zealand.

8.2 Implications and future research directions

The purpose of this study, as described in Chapter 1, was to respond to the dearth of literature pertaining to Rainbow experience of palliative care in the Aotearoa New Zealand context. As such, a motivation for this research was the creation of new knowledge within the palliative care space in Aotearoa New Zealand and the recognition of this as an area requiring further research, attention, and consideration. The significance of this study is that a fine-grained exploration of lived experience, contextualised by the socio-ecological model, provided insight into how palliative care unfolded within the lifeworld of a couple who are members of the Rainbow community. As such, this study has demonstrated the utility of fine-grained case study approaches, particularly when situated within frameworks such as the socio-ecological model which elevates the personal and connects it to broader, societal structures.

It is important to note that Tim's experience, whilst rich and engaging, is ultimately only one perspective from a diverse community. As such, there is a need for the exploration of other perspectives and positionalities to grant a more comprehensive and inclusive picture of Rainbow palliative care experiences in New Zealand. As has been discussed, Tim occupies a specific nexus of relative privilege within the broader sphere of Rainbow identity which facilitated his and his partner's positive experience of palliative care. Hence, Tim's experiences may not resonate with others in the Rainbow community, emphasising the need for additional research. For example, as both Tim and his partner were cisgender, an exploration of transgender and gender diverse experiences of palliative care in Aotearoa would be indispensable. This is particularly relevant given international literature has demonstrated that the transgender and gender diverse population have unique experiences within the palliative care space (e.g., Berkman et al., 2024; Higgins & Hynes, 2019; Stein et al., 2020).

It is important to explicitly position the scope of this research. Whilst this is a novel topic, this was a Masters-level project and as such its scope could only extend so far. Of particular concern were relevant time constraints which required a narrowing of focus and a prioritisation of goals. Furthermore, extenuating circumstances, including recruitment difficulties as discussed in Chapter 4, necessitated a reduction in scope. Hence, whilst this research presents new and valuable knowledge, it is not intended as an exhaustive or comprehensive exploration of Rainbow experiences of palliative care in Aotearoa New Zealand. Nonetheless, my findings have highlighted the need for additional research in this area to provide a comprehensive picture of palliative care experiences in the Rainbow community. Furthermore, given the findings of this study suggest a need for inclusive training and service development, additional research in this area would elucidate the specific gaps in knowledge and begin the process of developing best practice standards. At the time of writing, Te Ārai Research Group, an equity-focused palliative care research group based at the University of Auckland School of Nursing, is undertaking a Health Research Council of New Zealand supported research project exploring the palliative and end-of-life care needs and views of Rainbow[18] older adults (Health Research Council of New Zealand, 2023). This presents a significant opportunity to enrichen the knowledge base pertaining to Rainbow experiences of palliative care in Aotearoa, extending the work conducted in this study, with the potential of addressing inequities within the palliative care space for Rainbow people and their whānau. Further, this commitment to recognising and listening to the specific needs of the Rainbow community demonstrates a recognition of our shared humanity and thus is a profound manifestation of aroha.

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[18] The research project specifically uses the umbrella initialism TLGBTQI+ (Takatāpui, lesbian, gay, bisexual, transgender, queer, intersex, +). I have used Rainbow in text to aid consistency and the flow of reading.

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Appendices

Appendix A: Recruitment materials

EXPERIENCE WITH PALLIATIVE CARE?

There is currently little research on palliative care experiences of the Rainbow community and their whānau in Aotearoa. It is important we have the research to ensure the best outcomes for our community.

I am looking to speak to Rainbow persons who have accessed palliative care in Aotearoa as well as their whānau.

If you are over 18 and would like to know more, please send an email to **kb357@students.waikato.ac.nz** with the subject line **"Palliative Care Study"**.

This research is conducted pursuant to (HREC(Health)2023#49)


EXPERIENCE
WITH PALLIATIVE
CARE?

Appendix B: Information sheet

PARTICIPANT INFORMATION SHEET – WHĀNAU MEMBERS

Project title: Rainbow experiences of palliative and end-of-life care in Aotearoa New Zealand

Researcher: Kate Byrne kb357@students.waikato.ac.nz

Supervisors: Ottilie Stolte ottilie.stolte@waikato.ac.nz

Jaimie Veale Jaimie.veale@waikato.ac.nz

Kia ora! My name is Kate Byrne, and I am a postgraduate student at Te Whare Wananga o Waikato, the University of Waikato. As a member of the Rainbow community, the health and well-being of the community is important to me. In this research, I am exploring Rainbow experiences of palliative and end-of-life care in Aotearoa New Zealand. I am looking to interview Rainbow community members who have accessed palliative and/or end-of-life care as well as their whānau. This care may be formal, such as through hospice organisations, or informal, such as through community-led initiatives.

I am interested in researching this topic as there is little local research on what palliative and end-of-life care is like for Rainbow community members here in Aotearoa New Zealand. This means we do not have a clear understanding whether community members are being supported at the end of their lives. The purpose of this study is to address this gap in knowledge by giving participants the space to describe their experiences.

You have expressed interest in this study as a whānau member of a Rainbow palliative care patient.

Your participation

I will be conducting semi-structured interviews with participants which will last approximately 60 minutes. These will be audio-recorded. Following these interviews, you will receive an interview transcript for you to review. You do not have make amendments to the transcript if you do not wish to.

I will also be conducting follow-up interviews. These will also last approximately 60 minutes and will be audio-recorded. The general scope of these interviews will be influenced by what is discussed in initial interviews. As in the initial interviews, you will receive an interview transcript which you are invited to read and review if you choose.

As part of follow-up interviews, I am interested in a process called photo elicitation. This will consist of participants bringing photos which are of significance to them and their palliative care journey. This is entirely voluntary and is simply an option to make communicating your experiences easier. I am happy to provide extra information on this if you would like.

Interviews will be conducted in a location of your choosing which is quiet, private, and accessible. I am happy to discuss potential locations with you.

What will I be asked?

I am interested in hearing what you believe is important; this is a safe space for you to express your story in a way meaningful to you. Nonetheless, topics I may ask about include accessing care and support, attitudes and knowledge of care providers, availability of support groups and networks, the recognition of Rainbow identities in care, and your hopes for the future. If it would be beneficial for you to look at my interview guidelines, I am happy to provide this for you.

Are there any risks involved?

It is important to me that you feel safe and supported while participating. I understand that this research is of a deeply personal nature. It is likely we will discuss emotional topics which may be distressing. If you feel that participating in this research will cause you undue distress, it may not be in your best interest to participate in the study.

You are welcome to take breaks or end the interview at any time. You may ask for the recording device to be switched off. You do not need to answer any questions you feel uncomfortable with.

You have the option to bring a support person to the interview with you if you feel this would be more comfortable. You may bring items which may help you feel safe. I am happy to discuss what I can do to create a comfortable space for you.

What are your rights as a participant?

You have the right to stop the interview at any time. You can also ask to have the recording device turned off at any time.

You have the right to withdraw from the research up to three weeks from receiving your final transcript (initial or follow-up). You can do this by contacting myself, or you can contact the supervisors for this project. You do not have to provide any reason for withdrawal. All information gathered to that point will be destroyed.

You have the right to express concerns or complaints. You may do so by contacting the named supervisors for this project. Every effort will be made to respond to your concerns in an appropriate and sensitive manner.

Will my information be identifiable?

It is at your discretion to what level you wish to be identified.

As a default, your information will be anonymised. This includes the removal of identifying information (e.g., name, address). All data collected will be privacy protected. You will have the opportunity to choose your own pseudonym, or I can offer one with your approval.

However, given the relatively small pool of potential participants, you may be identifiable to those who are familiar with your story. I will take every precaution to keep descriptions as vague as possible (e.g., giving an age band over a specific age). I will consult with you regarding how to best protect your confidentiality in this research.

I recognise that claiming your story openly may be an empowering experience. You may choose to be identifiable in this research. It is important you understand that, in doing so, you will be identifiable to all consumers of my research including examiners, Rainbow community organisations with an interest in my research, and other researchers. I am happy to discuss this further with you.

What if I need to reschedule/cancel my interview?

I understand that you may need to reschedule or cancel and am happy for you to contact me if so. If you wish to cancel your interview, this is okay, and your participation will be removed from the research. If you choose to reschedule, we will organise a new time that best suits you.

Privacy

All data will be stored on a password-protected secure drive accessible only to myself. Consent forms will be digitised an uploaded to this drive; physical copies will be destroyed. Data will be anonymised before sharing with others.

Publication

The findings of this research will be submitted as a written thesis to fulfil the requirements of the Master of Applied Psychology (Community Psychology). Anticipated research outputs also include a potential community accessible document and an article for submission to a research journal.

Koha

In recognition of your time and sharing of knowledge, you will receive refreshments and a $15 voucher as koha.

This research project has been approved by the Human Research Ethics Committee (Health) at the University of Waikato as HREC(Health)2023#49. Any questions or concerns about the ethical conduct of this research may be sent to the Secretary of the Committee, email humanethics@waikato.ac.nz, postal address, Human Research Ethics Committee (Health), University of Waikato, Te Whare Wananga o Waikato, Private Bag 3105, Hamilton 3240.

Appendix C: Consent form

UNIVERSITY OF WAIKATO
FACULTY OF ARTS & SOCIAL SCIENCES

WHĀNAU PARTICIPANT CONSENT FORM

Name of person interviewed: ____

I have received a copy of the Information Sheet describing the research project. Any questions that I have, relating to the research, have been answered to my satisfaction. I understand that I can ask further questions about the research at any time during my participation, and that I can withdraw my participation at any time up to three weeks after the interview.

During the interview, I understand that I do not have to answer questions unless I am happy to talk about the topic. I understand that this interview will be recorded using audio recording equipment. I can stop the interview at any time, and I can ask to have the recording device turned off at any time. It has been explained that I will be provided a transcript of my interview which I can edit and amend at my discretion.

When I sign this consent form, I will retain ownership of my interview, but I give consent for the researcher to use the interview for the purposes of the research outlined in the Information Sheet. I understand that my identity will remain confidential in the presentation of the research findings except where I have indicated consent otherwise.

I understand that I will be provided with a summary of the research findings at the completion of the study.

I am aware that I have the right to complain about the conduct of the researchers and the process for doing so has been explained to me.

Please complete the following checklist. Tick [✓] the appropriate box for each point.	**YES**	**NO**
I consent for my name to be included in the research (if NO, a pseudonym will be used)		
I wish to receive a copy of the full written thesis.		

Participant : ____________________
Signature : ____________________
Date : ____________________
Contact Details : ____________________
____
____

Researcher : ____________________
Signature : ____________________
Date : ____________________
Contact Details : ____________________
____
____

Appendix D: Interview guidelines

Interview Guidelines for whānau members

The interviews will begin with introductions (which may take up to 15 minutes). During this time, KB will share her Rainbow identity and aspirations for the research. Participants will be welcomed to share details about themselves and their Rainbow person, if they are comfortable doing so.

The questions listed below are examples of topics which may be discussed. KB will decide what questions are appropriate to ask bearing in mind the flow of the conversation. The sharing of stories relevant to the participant will not be interrupted.

- What has been your experience of supporting a person with a terminal or life-limiting illness?
- How did their Rainbow identity impact this?
- Did your Rainbow person access formal palliative care? If so, what service(s) have they accessed?
- What was your experience of these services as a whānau member?
- Were these services accessible?
- As a whānau member, were you included in your person's care journey?
- **[For romantic partners]** How was your relationship understood and responded to by care providers?
- **[For romantic partners]** How has your relationship been recognised by care providers?
- What were the attitudes of care providers regarding your person's Rainbow identity?
- What knowledge of the Rainbow community did care providers have?
- In your view, how did being a member of the Rainbow community impact your person's palliative care journey?
- Do you have any positive experiences you would like to share?
- Do you have any negative experiences you would like to share?
- What would you like care providers to know about being a Rainbow patient?
- What would you like care providers to know about being a whānau member of a Rainbow patient?
- Have you received support from the Rainbow community?
- Are there any support groups you have accessed?
- What would you hope for Rainbow palliative patients in the future?
- What would you hope for whānau members of Rainbow patients in the future?

The questions listed below are topics which may be discussed in follow up interviews, in addition to those mentioned above.

- Following our previous discussion, is there anything you would like to share to begin?
- How did you feel after our previous discussion?
- **[For photo elicitation]** Could you explain the photo(s) you have brought today?
- **[For photo elicitation]** What is the significance of this photo to you and your person's palliative care journey?