Healthcare Professionals' Perspectives on End-of-Life Care for Metastatic Prostate Cancer in Aotearoa New Zealand: A Reflexive Thematic Analysis

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A thesis submitted to
Auckland University of Technology
in partial fulfilment of the requirements for the degree
of

Master of Arts (Psychology)

2026

School of Social Sciences and Humanities
Faculty of Culture and Society

Abstract

Background: Metastatic prostate cancer (mPCA) is an incurable, life-limiting illness that presents significant physical, emotional, spiritual, and relational challenges to patients and their whānau. Despite growing research on end-of-life (EOL) care, there remains a limited understanding of how healthcare professionals (HCPs) in Aotearoa New Zealand (NZ) navigate the relational, cultural, emotional, and structural complexities of providing EOL care.

Method: The study investigated experiences of HCPs providing EOL care to men living with mPCA. Seven HCPs representing oncology, hospice, primary care, community nursing, psychology, and theranostics participated in semi-structured interviews. The data were analysed using reflexive thematic analysis.

Findings: Participants understood EOL care as a relational, culturally situated, and systemically influenced experience. Four interconnected themes were identified: (1) Whanaungatanga – Relational Care and Whānau Involvement at End of Life; (2) Wairuatanga and Manaakitanga – Cultural Responsiveness and Making Meaning of End-of-Life; (3) Rangatiratanga – Autonomy, Identity, and Ethical Care; and (4) Ōritetanga (Equity) – Structural Inequities and Access to End-of-Life Care. Across the interviews, participants identified challenges in balancing clinical responsibilities with the emotional, spiritual, and cultural needs of patients and whānau while navigating difficult workforce pressures, fragmented service delivery, and inequitable access to care.

Conclusion: The quality of EOL care provided to men living with mPCA is influenced by relationships, shared decision-making, spirituality, meaning-making, and culturally responsive care. However, workforce pressures, fragmented services, and persistent inequities within health systems hinder the delivery of whānau-centred care. Improving the equitable provision of EOL care requires investment in workforce wellbeing, service integration, culturally responsive practice, and addressing ongoing inequities within the healthcare system. Further research involving Māori and Pacific HCPs is needed to enhance understanding of culturally responsive EOL care in NZ.

Keywords

Healthcare professionals; end-of-life care; metastatic prostate cancer; Māori concepts; cultural safety; whānau-centred care; reflexive thematic analysis

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Acknowledgements

The completion of this thesis would not have been possible without the generosity, guidance, encouragement and support of many people.

Firstly, I thank God for providing me with the strength, wisdom, and perseverance to complete this journey.

To both my supervisors, Associate Professor Liesje Donkin and Professor Jason Landon, thank you for all your direction, cultural knowledge, thoughtful critique and unwavering support throughout this entire process. Your mentorship has influenced the study's overall direction and scope and ensured it is grounded in both academic and cultural contexts.

I acknowledge Auckland University of Technology (AUT) for the institutional support and academic environment that were essential for the completion of this work.

To the healthcare professionals who participated in this study, thank you for sharing your time, skills, and reflections with me; you have given this research purpose.

I want to acknowledge Hospice West Auckland for their assistance in facilitating the recruitment of study participants.

To my friends and fellowship group, thank you for your encouragement, prayers, understanding, and support during this journey. Your friendships have supported me at times of struggle, and I am deeply grateful for your unwavering support, kindness and faithfulness.

To my extended whānau, Karena, Fee, Marsh and Koro, thank you so much for your aroha, manaakitanga, and unwavering support throughout this journey. I am grateful for your friendship, encouragement, and all the ways you have supported, encouraged, and uplifted me.

To my parents, Mum (Madalein), Dad (James) and my step-Mum (Dianne), thank you for your never-ending support, love and encouragement throughout this process. Thank you for believing in me and for being there through every challenge and success I faced; I am deeply grateful for all that you have done for me!

To my sister, Tyra, thank you for your love, support, and encouragement throughout this journey. I am grateful for your friendship, your faith in me and the special bond we share as sisters.

To my daughter, Samantha, thank you for your constant love, support and encouragement throughout this process. I will always be grateful for the love and support you have given to me.

Finally, to my husband Chris, thank you for carrying more of the load at home, for the late-night cups of coffee and quiet pep talks, and for helping me protect my writing time, often at the cost of your own plans. Your constant belief in and support for me, patience, humour, and behind-the-scenes contributions have made this possible. You have been my sounding board, my reality check, and have given me your full support as I have juggled my home, study, and work commitments. This thesis would not have been possible without you.

Ethics Approval

Ethics Approval was granted by the Auckland University of Technology Ethics Committee (AUTEC Approval No. 25/38) on 16 April 2025. (See Appendix A)

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Glossary

Abbreviations

Abbreviation	Definition
ADT	Androgen Deprivation Therapy
EOL	End-of-Life
GP	General Practitioner
HCPs	Healthcare professionals
mPCA	Metastatic Prostate Cancer
NZ	Aotearoa New Zealand
PSA	Prostate-Specific Antigen
Lu-177 PSMA	Lutetium-177 prostate-specific membrane antigen
RTA	Reflexive Thematic Analysis
QoL	Quality of Life
WHO	World Health Organization

Te Reo Māori Terms

Many te reo Māori terms have multiple meanings and complex interpretations. The definitions below are the meanings assigned for the purposes of this thesis.

Māori term	Definition
Aotearoa	The Māori name for New Zealand
Hapū	A subtribe, clan, or extended kinship group
Hui	Gathering, meeting, or assembly, often for discussion or decision-making
Iwi	Tribe or extended kinship group
Iwi-katoa	All iwi, the collective Māori population, social structures or all tribal groups
Kaiārahi	Guide, navigator, mentor, advocate, or leader
Karakia	Prayer used to open or close gatherings or provide spiritual support
Kaumātua	Respected tribal elder recognised for wisdom, knowledge, and cultural leadership
Kaupapa Māori	A Māori-centred philosophy and research approach grounded in Māori values, knowledge, and aspirations
Koha	A gift, donation, or contribution given as an expression of respect or gratitude
Mana	Prestige, authority, dignity, influence, or spiritual power
Manaakitanga	Care, hospitality, generosity, respect, and kindness towards others
Mauri	The life force or vital essence present in all living things
Mauri Mate	A Māori framework supporting culturally responsive palliative and end-of-life care
Ōritetanga	Equity
Rangatiratanga	Self-determination, autonomy, leadership, and authority
Taha hinengaro	Mental and emotional wellbeing
Taha tinana	Physical wellbeing
Taha whānau	Family wellbeing
Taha wairua	Spiritual wellbeing

Taiao	Environment
Tangata whenua	The Indigenous people of Aotearoa New Zealand (Māori), who have ancestral connections and authority (mana whenua) over a particular area through whakapapa (genealogy)
Tangihanga	Traditional Māori funeral rites and ceremonies
Tapu	Sacred or restricted, often in a spiritual or cultural context
Tauiwi	Non-Māori
Te Ao Māori	The Māori worldview, encompassing language, culture, values, and beliefs
Te reo Māori	The Māori language
Te Tiriti o Waitangi	The Treaty of Waitangi
Te Whare Tapa Whā	A Māori model of health that recognises four pillars: taha tinana (physical), taha wairua (spiritual), taha whānau (family), and taha hinengaro (mental and emotional wellbeing)
Tikanga	Māori customs, values, protocols, and culturally appropriate ways of doing things
Wairua	Spirit or soul; an essential dimension of health, wellbeing, and connectedness
Wairuatanga	Spirituality and connection with the spiritual realm
Whakapapa	Genealogy and ancestral connections that link people to whānau, ancestors, and whenua (land)
Whakawhanaungatanga	The process of establishing, strengthening, and maintaining relationships and a sense of belonging
Whānau	Family, extended family or a wider network of people related through kinship, common relationships, care, and belonging
Whanaungatanga	Relationships, kinship, connectedness, and a sense of belonging through shared relationships and responsibilities
Whare	House

Chapter 1: Introduction

Purpose of the Research

Metastatic prostate cancer (mPCA) is a progressive illness characterised by prognostic uncertainty and an increasing symptom burden. As men approach the end of life (EOL), they face complex physical, emotional, and psychosocial challenges (Collins et al., 2019; Onishi, 2021). In addition to disease progression, other factors shape the dying experience, including cultural and spiritual beliefs, whānau (family) connections, and relationships with the healthcare system. In Aotearoa New Zealand (NZ), Māori experience a disproportionate burden of prostate cancer and persistent health inequities, making equitable and culturally responsive EOL care an important healthcare priority (Obertová et al., 2015).

Healthcare professionals (HCPs) working across oncology, primary care, community nursing, palliative care, and theranostics play a pivotal role in supporting men living with mPCA and their whānau throughout this journey. HCPs are required to balance complex clinical decision-making with compassionate communication, cultural responsiveness, ethical practice, and the realities of increasingly constrained health services. Delivering high-quality EOL care extends beyond symptom management to encompass effective communication, active listening, relational care, shared decision-making, emotional support, and respect for patients' and whānau cultural and spiritual values (Carey et al., 2026; Gott et al., 2023; Schill & Caxaj, 2019).

Despite the importance of person-centred and culturally safe care, few studies have examined HCPs' experiences of navigating the competing relational, emotional, cultural and organisational influences in providing EOL care to men living with mPCA in NZ. Gaining a greater understanding of these experiences may support the development of culturally responsive practice, identify workforce support needs, and improve service delivery to patients and whānau affected by mPCA.

This study explores HCPs' experiences providing EOL care to men using a qualitative research approach. Guided by principles of manaakitanga (care, respect, and generosity), whanaungatanga (the importance of relationships and connectedness), and rangatiratanga (self-determination, autonomy, and leadership), the study examines how communication, relationships, and cultural and organisational contexts affect the provision of EOL care in NZ (Durie, 2004; Pitama et al., 2007; Te Ohu Rata o Aotearoa [Te ORA], 2020). These principles guided the analytical framework and the interpretation of the participants' accounts, facilitating a culturally grounded understanding of the factors influencing EOL care.

By foregrounding HCPs' perspectives, this study aims to deepen understanding of the relational, cultural, emotional, and structural influences that shape EOL care for men living with mPCA. The findings contribute practice-informed knowledge to support culturally responsive, equitable, and person-centred EOL care for men living with mPCA within oncology and palliative care services in NZ.

Research Background and Rationale

Clinical and Systemic Context

Prostate cancer is one of the leading causes of cancer-related death for men both globally and in NZ (Ministry of Health, 2022; Sung et al., 2021; Te Aho o Te Kahu, 2024). Improvements in diagnostic imaging and radionuclide therapies, along with systemic treatments, have significantly increased survival rates and transformed mPCA from an acute disease into a chronic, life-limiting illness (Collins et al., 2018; Goncalves et al., 2025). These advancements have increased life expectancy; they have also introduced new challenges regarding when a patient may be approaching the final stage of life. This uncertainty can make it difficult for HCPs to determine when to refer a patient to specialist palliative care services (Bernacki et al., 2014; Smith et al., 2022).

As part of their responsibilities to prepare patients and whānau for their future care needs, HCPs must frequently balance EOL planning with the need to maintain hope. This requires timely, honest, and compassionate conversations regarding prognosis, goals of care, and advance care planning with their patients and whānau (Bernacki et al., 2014; Smith et al., 2022). International research has highlighted the importance of early discussions about patients' quality of life (QoL), preparation for shared decision-making with health professionals, and the provision of care consistent with patients' wishes (Detering et al., 2010; Paladino et al., 2019). However, palliative care has not been equally supported or integrated with oncology services in NZ (Young et al., 2025).

The clinical challenges associated with mPCA are compounded by ongoing pressures within the NZ health system, including rising demand, workforce shortages, and limited resources. These pressures continue to affect the delivery of palliative care services and increase demand for them as the population ages and the prevalence of chronic illness rises (Duhoux et al., 2024; Egan et al., 2020). HCPs are also impacted by these systemic pressures. Limited resources and barriers to providing relationally focused and culturally responsive care may prevent HCPs from establishing therapeutic

relationships with their patients and whānau, thereby increasing professional stress and moral distress (Hunter & Cook, 2020; McCracken et al., 2021).

Cultural Dimensions of End-of-Life Care

Culturally influenced understandings of illness and dying profoundly affect how illness, dying and support are understood, and our expectations about the care and support we are provided in the latter part of a person's life (Schill & Caxaj, 2019). To provide culturally responsive EOL care in NZ, HCPs must understand both the diversity of values and beliefs that shape the health and wellbeing of those experiencing a serious illness, and the unique status of Māori as tangata whenua (Indigenous people of NZ) and the associated Crown obligations under Te Tiriti o Waitangi.

Many Māori draw on holistic models of health and wellbeing that incorporate physical, emotional, spiritual, relational, and environmental dimensions of life. Māori models of health such as Te Whare Tapa Whā (Māori model of health), the Meihana Model, or Mauri Mate situate whānau connections, wairua (spirit or soul), whakapapa (genealogy), and cultural identity within a construct of wellbeing, both throughout life and as part of the EOL process (Durie, 2004; Hospice New Zealand, 2020; Pitama et al., 2014). These models indicate that the EOL journey is collective, involving relationships, cultural identity, and the continuation of spiritual connection, rather than merely an individual clinical event (Carey et al., 2026; Moeke-Maxwell et al., 2019; Nikora et al., 2012).

Structural barriers, institutional racism, the lack of continuity between health services, and poor-quality care continue to negatively impact access to timely, equitable, and appropriate EOL services for Māori. This occurs despite Māori health frameworks and national commitments to equity for Māori existing (Came, 2014; Came et al., 2018; Gott et al., 2023; Waitangi Tribunal, 2023). These inequities include disparities in access to timely palliative care, specialist oncology services, culturally responsive care, and coordinated EOL support for Māori and other underserved populations. The inequities highlight the ongoing need to prioritise cultural safety, an ongoing process of critical reflection and recognition that the ultimate determination of culturally safe care rests with the person receiving care, rather than the person providing it (Curtis et al., 2019; Ramsden, 2002).

While Māori health frameworks were developed to improve outcomes for Māori, the relational principles underlying these approaches are relevant to all people in NZ's multicultural society, regardless of cultural background. Pacific communities share underlying principles of family involvement in collective decision-making, spirituality, and

faith or worship, which influence how their experience of EOL care (Foliaki et al., 2020). Understanding and acknowledging diverse cultural beliefs and values supports both culturally responsive and person-centred care for patients and whānau as they journey through the EOL process.

Communication is a key element of providing culturally responsive EOL care. Prognosis, advance care planning, and dying must be discussed with an awareness of the cultural beliefs, values, and practices that influence a patient's or whānau experiences and decisions about illness (Abdul-Razzak et al., 2014; Ekberg et al., 2021). HCPs need to practise with cultural humility and respect when providing EOL care in Māori contexts, recognising the importance of tikanga (customary practices), tapu (sacred or restricted), wairua, and the involvement of whānau throughout the dying process (Moeke-Maxwell et al., 2019).

Emotional and Ethical Complexities

Providing EOL care is emotionally challenging and often requires HCPs to manage uncertainty, pain, grief and loss while accompanying patients and whānau as they encounter some of the most difficult situations of their lives. This balancing act of fulfilling clinical demands while providing compassionate care can lead to an emotional burden and moral distress, especially when the HCP's professional values are contradicted by organisational expectations, resource constraints, or competing care decisions (Brook et al., 2020; Dijxhoorn et al., 2021; Koh et al., 2020). These tensions can lead to moral distress for HCPs when HCPs believe they are unable to provide care they perceive as morally appropriate due to systemic barriers and competing priorities (Hunter & Cook, 2020; McCracken et al., 2021). For Māori HCPs, these difficulties may be exacerbated by the competing expectations of their professional and cultural responsibilities within their respective communities (Hunter & Cook, 2020).

In addition to respecting and promoting individual autonomy, ethical decision-making at the EOL is influenced by relationships, cultural values, and whānau preferences. It often requires HCPs to negotiate individual wishes alongside collective decision-making processes (Gómez-Vírseda et al., 2020; Nikora et al., 2012). A relational understanding of autonomy acknowledges that decisions are rarely made in isolation but are shaped by family, culture, identity, and social context. A relational ethical perspective provides HCPs with opportunities to support autonomy while recognising the significance of sustaining dignity, preserving mana (authority) and respecting rangatiratanga throughout the process of EOL care (Gómez-Vírseda et al., 2020; Schill & Caxaj, 2019).

Research Gap and Need for Study

Most existing research has focused on the experiences of patients and their whānau, with comparatively little attention given to the experiences of HCPs providing EOL care for men living with mPCA. Research suggests that HCPs' communication, attitudes towards death, and approaches to care affect patients' preparedness, trust, and overall EOL experience (Braun et al., 2010; Ekberg et al., 2021; Walczak et al., 2016). However, little research in NZ has explored how HCPs navigate the intersecting clinical, cultural, emotional, ethical, and organisational demands of this work.

This study addresses this gap by investigating HCPs' experiences using qualitative methods and reflexive thematic analysis (Braun & Clarke, 2019, 2022). It explores the influence of relational, cultural, emotional, ethical, and structural issues on the provision of EOL care in a range of healthcare settings (Braun et al., 2010; Ekberg et al., 2021; Walczak et al., 2016). The following research questions guided this study:

1. How do HCPs view the cultural, emotional, systemic, and relational components influencing EOL care for men with mPCA?
2. How do HCPs navigate the complexity of EOL care in culturally diverse environments?
3. In what ways might systemic factors impact the EOL care this patient population receives?
4. What are the acknowledged gaps and areas for development in EOL approaches?

Summary

This chapter introduces the context and rationale for this study. It identifies the study's purpose, highlighting the clinical, relational, cultural, emotional and structural complexities involved in providing EOL care to men with mPCA in NZ. The study is guided by the principles of manaakitanga, whanaungatanga, and rangatiratanga, and by the intention to understand how HCPs navigate and experience these complexities when providing culturally responsive and equitable care. This chapter outlined the research objectives, research questions, and methodological approach used in this study. It also identified the need to understand HCPs' experiences and provide insights into the NZ context, thereby laying the foundation for the literature review presented in Chapter 2.

Chapter 2: Literature Review

Clinical, Psychosocial, and Holistic Context of Metastatic Prostate Cancer

Prostate cancer is among the most frequently diagnosed malignancies among men worldwide (Sung et al., 2021). When prostate cancer metastasises before or at the time of diagnosis, it is not a chronic medical illness but a life-threatening disease. This diagnosis disrupts a person's sense of identity, hope and relationships and affects how men and their whānau understand and interpret the future (Ferrell et al., 2017; Sanford et al., 2013b).

Prostate cancer begins in the prostate gland and is frequently slow to grow in early stages (Sanford et al., 2013b). When cancer cells move beyond the prostate, though, to bones, lymph nodes, the liver, or the lungs, the condition is called metastatic prostate cancer (mPCA) (Sanford et al., 2013b). Prostate cancer leads to more than 1.4 million new cases and over 375,000 deaths every year around the world (Sung et al., 2021). In Aotearoa New Zealand (NZ), prostate cancer is the most frequently diagnosed cancer in men and continues to be one of the leading causes of cancer-related death (Ministry of Health, 2017a). Early-stage disease is generally treatable; however, mPCA is not curable and is instead treated as a chronic, life-limiting illness (Sanford et al., 2013b).

In most cases, mPCA develops as a localised disease and subsequently spreads through molecular changes that enable cancer cells to leave their origin and spread (James et al., 2015). Bone is the most common site for metastasis, leading to numerous health issues due to complications such as pain, non-healing fractures, and spinal cord compression. The course of the illness can be highly variable depending on the tumour biology, other health conditions, and the person's treatment history (Collins et al., 2018). Diagnosis typically involves prostate-specific antigen (PSA) testing, imaging, and biopsy; molecular diagnostics will also play an increasing role in treatment selection (Pritchard et al., 2016). Standard treatment typically begins with androgen deprivation therapy (ADT) (Cornford et al., 2021). Treatment options available to patients include new-generation hormonal therapies, chemotherapy, bone-targeted agents, immunotherapy agents and radiopharmaceuticals, which have improved survival and QoL throughout their course of advanced disease (Alshehri, 2024; Franzese & Graziani, 2022; Pritchard et al., 2016; Quinn et al., 2020). A new approach to precision medicine is theranostics, which combines diagnostic imaging with targeted radionuclide therapy to identify and treat specific cancer types (Hofman, 2021; Sartor, 2021). Despite these advances, most men eventually develop castration-resistant prostate cancer, where the disease continues to progress

despite androgen deprivation therapy (Chowdhury et al., 2024; Gillessen et al., 2025; Sanford et al., 2013b). An example of theranostics in mPCA is Lutetium-177 prostate-specific membrane antigen (Lu-177 PSMA), which has been shown in clinical studies to provide excellent outcomes (Hofman, 2021; Rahbar, 2023; Sartor, 2021). mPCA continues to be an incurable disease that requires ongoing supportive and palliative care to manage symptoms, optimise QoL and support treatment decision-making (Agarwal & Epstein, 2017; Basch et al., 2017; Temel et al., 2010). Beyond physical progression and treatment, mPCA has profound psychosocial consequences that shape how patients and their whānau experience advanced illness.

A diagnosis of mPCA carries a significant emotional and existential burden. Men often experience anxiety, depression, uncertainty, and fear of death, especially when disease progression disrupts previously stable identities (Chambers et al., 2012; Scandurra et al., 2022). Treatments such as ADT can lead to hot flashes, weight gain, fatigue, and sexual dysfunction, deeply affecting body image and masculine identity (Chowdhury et al., 2024; Rindhagen, 2024; Seidler et al., 2016). For many, these changes challenge their roles as partners, providers, or independent individuals. The burden of mPCA extends beyond the individual to partners, spouses, and family members who often take on caregiving roles. Caregivers experience anticipatory grief, burnout, and emotional exhaustion, often while navigating complex health systems with limited support (Bateman et al., 2023; Skalla et al., 2013). Cultural expectations and family dynamics influence how care is provided and received, particularly in Māori whānau contexts where collective responsibility and relationality are central (Simpson et al., 2022).

Māori men experience disproportionately worse outcomes with prostate cancer. They are more likely to be diagnosed at advanced stages, less likely to receive timely diagnosis and treatment, and have higher mortality rates than non-Māori men (Egan et al., 2020; Gurney et al., 2020; Obertová et al., 2015). These disparities are rooted in structural racism, historical trauma, and the marginalisation of Māori models of health and healing (Came et al., 2018; Durie, 2004; Reid et al., 2017; Reid et al., 2019).

Mainstream health services often fail to reflect Māori values, which emphasise wairuatanga (spirituality), whanaungatanga and manaakitanga (Durie, 2004; Mason & Moeke-Maxwell, 2018). The disconnect between dominant biomedical paradigms and Māori worldviews can result in disengagement, mistrust, and spiritual distress (Moeke-Maxwell et al., 2018). Efforts to provide culturally safe care must therefore move beyond surface-level interventions to address institutional bias and embed Māori frameworks such as Te Whare Tapa Whā (Durie, 2004) and the Meihana Model (Pitama et al., 2007), both

of which emphasise holistic and relational approaches to health (Pitama et al., 2007; Schill & Caxaj, 2019). These inequities reinforce the importance of holistic and integrated models of care that address not only disease management but also the relational, cultural, emotional, and spiritual dimensions of advanced illness.

Advances in treatment have prolonged survival for many men with mPCA; maintaining QoL remains a primary goal of care. The physical, emotional and financial costs of therapy need to be weighed against the potential benefits of aggressive treatment by HCPs, while preserving patient independence, dignity and overall well-being (Agarwal & Epstein, 2017). Balancing these competing priorities will require collaborative input from the multidisciplinary team, including medical oncologists, urologists, palliative care specialists, nurses, mental health professionals, and social workers (Gillessen et al., 2025). Holistic care extends beyond illness management; it encompasses physical, emotional, spiritual, and social aspects of an individual's health and wellbeing (Lambert & Girgis, 2017). Evidence indicates that early psychosocial interventions, such as counselling and peer support, alleviate psychological distress among patients and improve their overall outcomes, thereby supporting the need for integrated models of care throughout the illness trajectory (Bateman et al., 2023; Temel et al., 2010).

Including patients and their whānau in the decision-making process promotes agency, strengthens resilience, and ensures that care is person-centred. This remains particularly significant in NZ, with whānau-based approaches considered central to the health and wellbeing of Māori (Ministry of Health, 2020). Advocacy groups, community support agencies, and whānau networks are also valuable sources of support and education and provide opportunities for shared experiences (Schill & Caxaj, 2019; Simpson et al., 2022; Te ORA, 2020).

The management of mPCA requires a holistic continuity-of-care model that acknowledges the dynamic interplay among biological, psychosocial, relational, and structural factors. Given the disproportionate burden of mPCA experienced by Māori men, culturally safe, equity-focused approaches are vital to improving outcomes and supporting quality EOL care (Curtis et al., 2019; Durie, 2004; Pitama et al., 2007).

Understanding End-of-Life Care

EOL care in oncology encompasses a range of clinical, psychosocial, and cultural practices that support patients with advanced or terminal cancer and their whānau through the final stages of life (National Institute for Health and Care Excellence [NICE], 2021; World Health Organization [WHO], 2018, 2020). Defining EOL care for mPCA can be

challenging since the disease often progresses slowly and symptoms might change over time. It involves both clinical accuracy and an appreciation for the deeply subjective and existential dimensions of dying (Cassell et al., 2019; Collins et al., 2019). The goal is not only to cope with symptoms and improve QoL, but also to maintain dignity, honour personal and cultural values, and make the transition to death as meaningful as possible (Hudson et al., 2015; Sleeman et al., 2021).

The Ministry of Health (2014b, 2017b) defines EOL care in NZ as care that respects and responds to the needs, choices, and values of patients and their whānau during the last year of their lives. In a clinical setting, EOL care is commonly understood as care provided in the last 6 to 12 months of life. However, this period can be challenging to predict accurately in oncology, especially in mPCA, where survival times can vary widely (Duhoux et al., 2024; Hoare et al., 2024). Palliative care and EOL care are closely related but distinct concepts. Palliative care may be introduced earlier in a life-limiting illness, including alongside disease-directed treatment, to address physical, psychological, social, and spiritual needs (Ferrell et al., 2017; WHO, 2020). EOL care focuses more specifically on care and decision-making as death approaches, while terminal care refers to care provided during the final days or weeks of life (Ministry of Health, 2017b; NICE, 2021). Palliative and EOL care may overlap, with care needs and service provision varying across illness trajectories and healthcare settings (Duhoux et al., 2024; Hoare et al., 2024). This study focuses on EOL care. Palliative care is discussed, where its principles, services, and practices inform care for men with metastatic prostate cancer and their whānau towards the end of life.

According to the Australian and New Zealand Society for Palliative Medicine (ANZSPM), a person with an incurable or serious illness should discuss palliation and be referred to a palliative care service without delay, even if the individual is currently receiving curative-oriented treatment (Fischberg et al., 2013). NZ national guidance for palliative care also promotes early integration of palliative care, recognising the significance of timely discussions, advance care planning and holistic support for people with terminal illness (Ferrell et al., 2017; Korfage et al., 2020; Ministry of Health, 2017b). Evidence supports integrating palliative care early alongside oncology treatment to address patients' supportive care needs, improve quality of life, and support informed decision-making (Bakitas et al., 2015; Ferrell et al., 2017; Korfage et al., 2020; Temel et al., 2010). Timely EOL planning is a related but distinct need, particularly where prognostic uncertainty complicates discussions about future care preferences and treatment decisions (Gupta et al., 2024; Moroni et al., 2014). However, opportunities for advance

care planning and shared decision-making may still be delayed until the final stages of life (Young et al., 2025). Although EOL care can be described clinically, its boundaries are often less distinct in practice, particularly for men living with mPCA, where illness progression is unpredictable.

All cancer care strives to extend life and lessen pain, but EOL care focuses more on comfort, preparation, and support (NICE, 2021; WHO, 2020). The distinction is often unclear, especially in mPCA, where patients may continue to receive systemic treatments such as chemotherapy or hormone therapy despite advanced illness (Cassell et al., 2019; Gupta et al., 2024). This can make it difficult for both HCPs and patients to recognise when the EOL phase has begun (Collins et al., 2019).

One framework that can help shed light on this transition is the “Surprise Question”: “Would I be surprised if this patient died in the next year?” (Moroni et al., 2014). If the clinician’s answer is “no”, proactive EOL planning is indicated (Gupta et al., 2024; Hudson et al., 2018; Moroni et al., 2014). While not an ideal predictor, this approach provides an opportunity for earlier conversations regarding preferences for care, resuscitation decisions, and preferred place of death (Gupta et al., 2024). Once the transition to EOL care has been recognised, attention turns to identifying how best to deliver care to meet patients’ changing needs and preferences.

Care towards the EOL may be supported through a range of healthcare services and palliative care models, including generalist and specialist palliative care, hospice services, and integrated oncology–palliative care approaches (Quill & Abernethy, 2013; Sheikh et al., 2022). Common models include hospital-based palliative care teams, such as interdisciplinary teams, that provide symptom management, psychosocial support, and care coordination in the hospital (Haroen et al., 2025). Hospice care is a specialised service that focuses on comfort and QoL, usually provided in the home or a hospice setting (Sheikh et al., 2022). Primary palliative care is provided by oncologists, general practitioners, and nurses trained in basic palliative care skills, who refer patients to specialists when necessary (Quill & Abernethy, 2013; Sheikh et al., 2022). Integrated oncology–palliative care models are coordinated approaches to providing early palliative care and continuing it as the person receives aggressive cancer therapy (Bakitas et al., 2015).

The evidence consistently demonstrates that integrated models can improve quality of life, reduce symptom burden, support earlier advance care planning, reduce carer fatigue and decrease overall healthcare costs compared with late-stage or crisis-driven palliative interventions (Bakitas et al., 2015; Haroen et al., 2025; Korfage et al.,

2020). However, equitable access to integrated models of palliative care is not available in NZ (Young et al., 2025). Barriers to timely, culturally safe, and coordinated palliative care continue to be experienced by rural communities, Māori and Pacific peoples (Foliaki et al., 2020; Jones et al., 2023; Ministry of Health, 2017a, 2017b). Regardless of the model of care, the provision of high-quality EOL care should ultimately reflect what matters most to patients and their whānau in the final stages of life.

Patients and their whānau may prioritise different aspects of EOL care than HCPs (Ekberg et al., 2021; Paladino et al., 2019). In EOL care, individuals typically prioritise symptom management, particularly relief from pain, breathlessness, fatigue, and other symptoms (Ferrell et al., 2017; WHO, 2020). Emotional and spiritual support are also significant, as they allow patients and whānau to address concerns, strengthen their relationships, and create a sense of purpose and meaning in their final moments (Haroen et al., 2025; Hudson et al., 2015). Culturally attuned support is also essential and includes respect for language and cultural identity, spiritual beliefs, and preferred means of receiving care (Foliaki et al., 2020; Mason & Moeke-Maxwell, 2018; Ministry of Health, 2014).

Many people associate dignity, comfort, and familiarity with their preferred place of care and death (Hoare et al., 2024; Ministry of Health, 2017b). Continuity and coordination of care are also important; patients and whānau appreciate access to familiar HCPs, trusted services, and effective communication throughout the EOL journey (Bakitas et al., 2015; Quill & Abernethy, 2013). Together, these priorities highlight the multidimensional nature of EOL care and reinforce the need to move beyond traditional models that focus exclusively on its biomedical aspects (Jones et al., 2023; Sleeman et al., 2021). These priorities are shaped not only by individual preferences but also by the cultural values, beliefs, and traditions that influence how people understand illness, dying, and bereavement.

In Māori culture, death is not viewed solely as a medical event; it is also a significant spiritual and social event (Mason & Moeke-Maxwell, 2018; Ministry of Health, 2014). Elements associated with a good death may include karakia (prayer), the presence of whānau, and dying on ancestral whenua (Edge & Nikora, 2010; Jones et al., 2023; Mason & Moeke-Maxwell, 2018). Healthcare models that focus on efficiency and privacy may unintentionally conflict with Māori preferences by limiting the number of visitors or placing greater emphasis on individual decision-making than on group involvement (Foliaki et al., 2020; Ministry of Health, 2017a).

When caring for Māori patients and their whānau, HCPs should openly and respectfully discuss cultural values, use Māori models of health, such as Te Whare Tapa Whā, where appropriate, and involve whānau in the care planning process (Mason & Moeke-Maxwell, 2018; Ministry of Health, 2014). Pacific peoples may also hold cultural values that influence EOL care preferences, including the importance of family in decision-making, social norms, and spirituality (Foliaki et al., 2020; Jones et al., 2023). Providing culturally responsive EOL care relies on effective communication that enables HCPs to understand and respond to patients' values, preferences, and goals of care. Communication includes establishing and maintaining conversations about prognosis, treatment options, and the implications of continuing or withdrawing from treatment (Ferrell et al., 2017; Smith et al., 2022). The uncertainty surrounding the prognosis, as well as emotional challenges when discussing death, increases the complexity of communication (Gupta et al., 2024; Moroni et al., 2014).

Best-practice recommendations suggest EOL discussions should be viewed as ongoing conversations rather than one-time events. HCPs should use simple, jargon-free language and provide patients with the opportunity to ask questions and reflect on what they have heard (Ekberg et al., 2021; Paladino et al., 2019; Smith et al., 2022). Using the hui (meeting) approach and engaging extended whānau may assist individuals with understanding and decision-making in Māori settings (Mason & Moeke-Maxwell, 2018; Ministry of Health, 2014). Despite increasing recognition of these principles, translating them consistently into clinical practice remains challenging because of prognostic uncertainty, organisational pressures, and inequities in access to care.

While there is increasing recognition of the importance of early palliative care integration and timely EOL planning (Ferrell et al., 2017), several enduring challenges continue to affect the delivery of appropriate care (Young et al., 2025). One of the most notable barriers is prognostic uncertainty, as it can be challenging for HCPs to assess the trajectory of mPCA, which contributes to delays in EOL discussions and planning for EOL care (Gupta et al., 2024; Moroni et al., 2014). The predominant medical culture also tends to favour active treatment, which may prompt oncologists to prolong disease-directed therapy even when it no longer provides meaningful benefit, thereby prolonging suffering and diminishing opportunities for comprehensive support (Ferrell et al., 2017). Fragmentation of the healthcare system also complicates effective coordination of care, as collaborative efforts between oncology, primary care, and palliative services are often inconsistent or poorly organised (Ministry of Health, 2017a; Quill & Abernethy, 2013). Systemic barriers are compounded by workforce shortages, particularly in rural areas,

where trained palliative care specialists may not be available (Jones et al., 2023; Ministry of Health, 2017a). Lastly, cultural dissonance can arise when services do not reflect patients' values, beliefs and customs, potentially leading to mistrust and disengagement with care (Foliaki et al., 2020; Mason & Moeke-Maxwell, 2018).

Addressing these challenges will require changes at both organisational and systems levels. This involves redesigning service delivery to facilitate earlier integration of palliative care, strengthening multidisciplinary collaboration among oncology, primary care, and specialist palliative care services, and ensuring that HCPs receive ongoing education in communication, cultural safety, and advance care planning (Bakitas et al., 2015; NICE, 2021; WHO, 2020). Flexible and inclusive care models that meet the cultural, relational, and psychosocial needs of patients and their whānau are essential to reducing inequities and improving the quality and coordination of EOL care (Foliaki et al., 2020; Gott et al., 2023; WHO, 2020).

Overall, the literature demonstrates that EOL care for mPCA extends beyond establishing a clinical timeframe to encompass the medical, psychosocial, cultural, and relational dimensions of care (Ferrell et al., 2017; WHO, 2020). For patients living with mPCA, where disease progression is often uncertain, proactive and culturally safe EOL planning is essential to ensure care aligns with the values, preferences, and goals of the dying patient and their whānau (Collins et al., 2019; Jones et al., 2023; Mason & Moeke-Maxwell, 2018). The delivery of quality EOL care depends on integrating palliative principles, effective communication, and culturally responsive practice to support patients and their whānau throughout the dying process (Bakitas et al., 2015; Ekberg et al., 2021; Foliaki et al., 2020).

Culturally Responsive End-of-Life Care

Culturally responsive EOL care involves healthcare systems, organisations, and HCPs acknowledging, respecting and integrating the cultural values, beliefs and practices of patients and their whānau (Curtis et al., 2019; Ministry of Health, 2014; Schill & Caxaj, 2019). This approach is foundational to addressing the inequities in EOL care experienced by Māori and Pacific peoples in NZ. In NZ, culturally responsive care also requires healthcare organisations and professionals to give effect to the principles of Te Tiriti o Waitangi by addressing inequities and ensuring that Māori, Pacific peoples, and other cultural communities receive equitable and culturally responsive EOL care (Jones et al., 2023; Sheridan et al., 2024; Waitangi Tribunal, 2023).

Culturally responsive care goes beyond cultural competence, and this distinction shapes how Māori, Pacific, and other cultural approaches to EOL care are understood throughout this review. Culturally responsive care means partnering with individuals, whānau, and communities, engaging in critical self-reflective practice, and adjusting one's approach based on the diverse cultural values, beliefs, and preferences present in each situation (Burke et al., 2023; Foliaki et al., 2020; Gott et al., 2023; Schill & Caxaj, 2019). Within NZ, these principles are particularly important for Māori, whose understandings of health, dying and bereavement are based on relational, spiritual and collective worldviews.

For Māori, EOL care is closely linked to whakapapa, whānau relationships, wairua, and whenua, meaning culturally responsive care must be shaped by these values to be meaningful (Mason & Moeke-Maxwell, 2018; Ministry of Health, 2014; Moeke-Maxwell et al., 2014). Death is understood not only as a biological event but also as a significant spiritual and collective transition shaped by tikanga and the involvement of whānau (Carey et al., 2026; Manson, 2021; Simpson et al., 2022).

A "good death" may include karakia (prayer), the presence of extended whānau, and dying on ancestral whenua (Carey et al., 2026; Manson, 2021; Nikora et al., 2012). The Te Whare Tapa Whā conceptualises health as comprising taha tinana (physical wellbeing), taha hinengaro (mental and emotional wellbeing), taha wairua (spiritual wellbeing), taha whānau (family and relational wellbeing) and a connection to whenua (land and place) (Durie, 2004; Ministry of Health, 2020). When EOL care does not take account of these interconnected dimensions of wellbeing, patients and their whānau may experience unmet physical, emotional, spiritual, cultural, and relational needs. The application of Te Whare Tapa Whā to EOL care therefore highlights the significance of identity, relationships, spirituality, and connectedness throughout the dying journey. For example, when EOL care restricts whānau presence or favours individual decision-making over collective participation, Māori patients and their whānau may experience the care as culturally unsafe (Gott et al., 2023; Ministry of Health, 2017b).

While there are many common principles of culturally responsive care across communities, Pacific peoples have their own unique cultural values and practices that influence their preferences for EOL care. Culturally responsive EOL care for Pacific peoples requires recognition of the importance of family, faith, and community in health decision-making and care preferences (Foliaki et al., 2020; Schill & Caxaj, 2019). Central to Pacific worldviews is a focus on community orientation, spiritual connection, and respect for elders, which influence how patients and families understand, experience, and respond to illness, dying, and bereavement.

Using interpreters and involving spiritual and community leaders can strengthen trust between HCPs and Pacific peoples while helping to ensure that EOL care aligns with their priorities (Foliaki et al., 2022). Across these contexts, culturally responsive communication is a core competency that oncology HCPs need to develop, specifically to communicate clearly, show emotional sensitivity, and enable group decision-making in ways that connect cultural practices to clinical care. This is essential when dealing with uncertainty regarding prognosis, discussing care goals, and managing emotional aspects of EOL care in culturally diverse populations (Bernacki & Block, 2014; Ferrell et al., 2017; Onishi, 2021). There is increasing recognition of culturally responsive practice, but a range of organisational and structural barriers hinder its consistent implementation in healthcare settings.

Like Te Whare Tapa Whā, the Fonofale model takes a holistic view of health, but places family at its foundation and centres spirituality, culture, and environment as distinctly Pacific dimensions of wellbeing (Kitione et al., 2025; Tu'akoi et al., 2025). When receiving cancer care, Pacific patients may choose to remain at home and involve extended family, community, and religious leaders in decision-making (Foliaki et al., 2020; Schill & Caxaj, 2019). When these priorities are not recognised, patients may disengage from services or report lower satisfaction, reducing the effectiveness of their care (Jones et al., 2023; Schill & Caxaj, 2019).

Effective cross-cultural communication between HCPs, patients, and whānau is essential to delivering care that reflects diverse cultural perspectives. It requires an awareness of language barriers, differing beliefs about health, and culturally specific expressions of distress, as these factors influence whether patients engage with services, feel heard in decision-making, and receive care that aligns with their values and priorities (Abdul-Razzak et al., 2014; Ekberg et al., 2021; Smith et al., 2022). In te ao Māori (the Māori worldview), the use of hui processes, whakawhanaungatanga (establishing, maintaining, and nurturing relationships), and the involvement of extended whānau can facilitate shared understanding and support collective decision-making (Komene et al., 2023; Mason & Moeke-Maxwell, 2018; Ministry of Health, 2014).

Systemic barriers, such as policies that prioritise efficiency over culturally responsive practice (Slater et al., 2013), a lack of diversity in the workforce (Czuba et al., 2023), and inadequate education and training in cultural safety (Mason & Moeke-Maxwell, 2018; Schill & Caxaj, 2019), still hinder culturally responsive EOL care. In total, these barriers create further challenges for HCPs to deliver holistic, culturally responsive care. Structural disparities further complicate access to culturally appropriate care, including

service gaps in rural areas (Ministry of Health, 2017a; Sheridan et al., 2024) and inadequate funding for Māori and Pacific health services (Came et al., 2018; Ministry of Health, 2017a; Newsroom, 2021).

Conversely, facilitators of culturally responsive EOL care include intentional incorporation of cultural paradigms into service design, formation of sustainable partnerships with iwi (tribe), hapū (subtribe) and Pacific community organisations, early integration of palliative care principles alongside culturally responsive conversations about future EOL preferences, and adherence to nationally recognised standards such as the Aotearoa Specialist Adult Palliative Care Guidelines (Foliaki et al., 2020; Hospice New Zealand, 2026; Suurmond et al., 2020). These approaches support more equitable, culturally responsive, person-centred care by strengthening relationships with communities, improving access to services, and ensuring care is better aligned with the cultural values, preferences, and needs of patients and their whānau.

Overall, the literature shows that incorporating culturally responsive principles into oncology and EOL care can improve patient satisfaction, assist with symptom management, and increase whānau coping during the EOL journey (Egan et al., 2020; Foliaki et al., 2020; WHO, 2018, 2020).

Communication between Healthcare Professionals, Patients, and Whānau

High-quality EOL care for men living with mPCA relies on effective communication, enabling patients and whānau to build trusting relationships with HCPs, participate in shared decision-making, and make informed decisions based on their values, beliefs, and preferences (Ekberg et al., 2021; Ferrell et al., 2018; Onishi, 2021). As the course of illness progression is unpredictable, communication must be open, respectful, and culturally responsive to ensure that care is consistent with patients' personal, cultural, and spiritual goals. Māori health frameworks such as the Hui Process, the Meihana Model, and Te Whare Tapa Whā highlight holistic engagement, trust, and whānau involvement, and underpin culturally safe communication between HCPs, patients, and whānau (Durie, 2004; Pitama et al., 2007; Pitama et al., 2014). Te Tiriti o Waitangi provides further guidance for healthcare delivery through the principles of partnership, participation, protection, and equity (Komene et al., 2023; Ministry of Health, 2020; Pitama et al., 2014).

For Māori and Pacific peoples, health and wellbeing decision-making often involves whānau and kaumātua (tribal elder). Therefore, HCPs should direct information and consent conversations to the wider group, not just the individual, as this reflects how decisions are collectively held and reached within these communities (Czuba et al., 2023).

Including whānau and kaumātua in the decision-making process may reinforce the patient's sense of support and belonging. However, this may also require additional time, flexibility, and cultural competence from HCPs (Komene et al., 2023).

Several barriers to effective communication have been identified: uncertainty around prognosis (Gonçalves et al., 2025; Meador et al., 2025), tensions between individual and collective decision-making (Thomas, 2019; Tipene-Leach et al., 2024), and varied experiences in learning and applying culturally safe practices (Semlali et al., 2020; Suurmond et al., 2020).

Strategies to improve communication include whānau hui, interpreters, culturally appropriate meeting protocols, teach-back methods, written summaries, and collaboration with cultural advisors (Gott et al., 2023; Nelson-Becker & Moeke-Maxwell, 2020; Talevski et al., 2020; Walczak et al., 2016). These strategies help reduce power imbalances, enhance understanding, and align care with the patient's cultural values and preferences (Komene et al., 2023; Nelson-Becker & Moeke-Maxwell, 2020). The literature consistently demonstrates that effective communication extends beyond the exchange of clinical information to encompass trust, cultural safety, shared understanding, and partnership with patients and whānau throughout the EOL process.

Emotional, Spiritual, and Healthcare Professional Dimensions of Care

Men living with mPCA often experience uncertainty, changing identities, increasing symptom burden, and progressive losses that affect their emotional and spiritual wellbeing. These experiences influence how patients and whānau understand illness, engage with healthcare services, make decisions, and prepare for the future (Chowdhury et al., 2024; Czuba et al., 2023; Rindhagen, 2024). In NZ, emotional and spiritual wellbeing are understood within holistic models of health that recognise the interconnectedness of hinengaro, wairua, tinana, and whānau (Durie, 2004; Nelson-Becker & Moeke-Maxwell, 2020).

The Te Whare Tapa Whā and Meihana models promote a holistic, whānau-centred approach to care by recognising the interdependence of physical, emotional, spiritual, and social dimensions of wellbeing (Pitama et al., 2007; Pitama et al., 2014). Within oncology and palliative care, emotional and spiritual support are increasingly recognised as essential components of high-quality care, helping patients and whānau navigate the complexities of advanced illness and EOL care (Ferrell et al., 2017; Hudson et al., 2015). The emotional impact of mPCA extends beyond the physical consequences of disease,

affecting psychological wellbeing, identity, relationships, and patients' capacity to adapt to progressive illness.

Emotional distress associated with mPCA is often related to worries about cancer progression, effects of treatment, financial concerns, or changing family roles. Emotional distress frequently co-occurs with symptoms of depression, difficulty with decision-making, and challenges related to intimacy and sexuality (Chowdhury et al., 2024; Rindhagen, 2024; Seidler et al., 2016). The levels of distress experienced will likely increase during important transitions, such as diagnosis of metastatic disease, starting or changing systemic therapy, and developing castration-resistant disease, especially in men who have been diagnosed and are receiving androgen deprivation therapy (ADT) (Chambers et al., 2012; Hofman et al., 2021; Quinn et al., 2020).

Evidence supports the importance of identifying and addressing emotional distress throughout the illness trajectory. Interventions to help patients manage emotional distress may include counselling, psychoeducation, psychological therapies, medication if indicated, and referral to appropriate specialist psycho-oncology services (Ferrell et al., 2017; Hudson et al., 2015; Onishi, 2021). Access to psycho-oncology services may assist patients and their families in managing uncertainty, maintaining QoL, and managing the complexities of advanced illness and EOL care (Basch et al., 2017; Ferrell et al., 2017; Paladino et al., 2019).

A loss of meaning and purpose, and a lack of hope, characterise demoralisation. Although it may resemble depression, it often responds to interventions that promote meaning-making, legacy-building, clarifying values, and managing symptoms (Ferrell et al., 2017; Nelson-Becker & Moeke-Maxwell, 2020). Men with mPCA may also have psychosexual issues, body image issues, and issues related to the perception of their masculinity, affecting their ability to disclose emotions and seek help (Chambers et al., 2012; Felber et al., 2024; Onishi, 2021). Furthermore, the treatment-related side effects, including ADT, chemotherapy, and other types of systemic treatments, will impact the person's mood, cognitive processes, energy levels, and their overall wellbeing; this reinforces the need for ongoing emotional support through the illness trajectory (Alshehri, 2024; Gillessen et al., 2025; Hofman et al., 2021; James et al., 2015; Quinn et al., 2020; Rahbar et al., 2023). Alongside emotional wellbeing, spirituality and meaning-making become increasingly important as patients and whānau seek to understand and cope with advanced illness and approaching death.

Spirituality encompasses an individual's search for meaning, purpose, connection and transcendence. While spirituality can be expressed through religious beliefs and

practices, it extends beyond religion to include broader questions of identity, belonging, relationships, and meaning (Nelson-Becker & Moeke-Maxwell, 2020; Schill & Caxaj, 2019). People diagnosed with advanced cancer may experience spiritual distress because of concerns about dignity, legacy, forgiveness, reconciliation, uncertainty and fear of dying (Cullen, 2021; Ferrell et al., 2017; Paal, 2024).

Spirituality is closely linked to meaning-making, through which individuals make sense of loss, reconstruct identity, and maintain a sense of purpose during advanced illness. In making meaning, the individual is influenced by their culture, family relationships, spiritual beliefs, and personal narrative (Durie, 2004; Moeke-Maxwell et al., 2014; Simpson et al., 2022; Warner & Groarke, 2022). Research indicates that spiritual need often manifests as concern about one's relationship with oneself and others, meaning, purpose, and connection, rather than being expressed in explicitly religious terms (Nelson-Becker & Moeke-Maxwell, 2020; Paal, 2024; Schill & Caxaj, 2019). Therefore, when exploring emotional, relational, and existential dimensions of distress, HCPs should provide opportunities for patients and whānau to identify what is significant to them.

Wairua, the spiritual dimension, forms part of the overall framework of Te Whare Tapa Whā and the Meihana Model and is interconnected with the other three dimensions of Hauora: physical, emotional, and whānau (Durie, 2004; Pitama et al., 2014). Patients living with advanced illness may benefit from culturally appropriate spiritual support from kaumātua and whānau-centred approaches. Access to these supports can assist the patient and whānau in navigating advanced illness and EOL care while maintaining a sense of identity, belonging, and connection (Manson, 2021; Moeke-Maxwell et al., 2014). Interventions that enhance dignity, meaning, and spiritual wellbeing have been linked with improved hope, emotional wellbeing, and QoL for individuals living with advanced illness (Ferrell et al., 2017; Hudson et al., 2015; Onishi, 2021; Warner & Groarke, 2022). Supporting these emotional and spiritual dimensions also requires healthcare professionals who are equipped to engage compassionately with patients and whānau while sustaining their own wellbeing.

HCPs involved in providing EOL care must engage emotionally, spiritually, relationally, and culturally with patients and their whānau in relation to advanced illness, dying, and the grieving process. Providing EOL care presents emotional, cultural, ethical, and relational challenges that can affect HCPs' wellbeing both professionally and in their personal perspectives (Nia et al., 2016; Oelke et al., 2013; Tipene-Leach et al., 2024). Establishing a trusting relationship with whānau requires investment from HCPs and

greater responsiveness to patients' cultural needs; however, these factors are often overlooked in the measures of productivity, workload, and performance used by many healthcare organisations (Moeke-Maxwell et al., 2019; Sheridan et al., 2011).

When HCPs are unable to adequately respond to patients' emotional, spiritual, and cultural needs, they may experience moral distress, compassion fatigue, and burnout. For this reason, reflective practice, cultural supervision, peer support, and a psychologically safe workplace are critical components of promoting HCP resilience and providing culturally safe care (Health & Disability Commissioner, 2023; Nia et al., 2016; Nursing Council of New Zealand, 2011; Oelke et al., 2013; Tipene-Leach et al., 2024).

Cultural values, beliefs, and experiences of HCPs will shape how they recognise and respond to distress, spirituality, and cultural needs. Models such as Te Whare Tapa Whā, the Meihana Model, and the Hui Process provide shared frameworks for supporting culturally responsive communication, enhancing multidisciplinary collaboration, and promoting reflective practice (Hudson et al., 2010; Pitama et al., 2014; Tipene-Leach et al., 2024). The wellbeing of the HCP workforce and cultural safety are closely interrelated; HCPs who are emotionally supported, culturally safe, and valued by their organisation are better positioned to provide compassionate, relationally grounded, and culturally responsive care. The literature demonstrates that workforce wellbeing, reflective practice, and cultural safety are essential to delivering high-quality EOL care, enabling HCPs to provide compassionate, relationship-grounded, and culturally responsive care to patients and their whānau throughout their illness trajectory.

Structural Influences on End-of-Life Care

EOL care for men with mPCA in NZ is delivered within a health system shaped by ongoing structural inequity. The literature demonstrates that systemic conditions, including under-resourcing, fragmented service pathways, and culturally incongruent protocols, limit HCPs' ability to provide relational, goal-concordant, and culturally safe EOL care. These barriers are not isolated or incidental; they are situated within institutional logics, resource allocation, and historical legacies that shape clinical practice and relational trust (Curtis et al., 2019; Medical Council of New Zealand, 2021; Ministry of Health, 2020b, 2024).

Coloniality, Te Tiriti Obligations, and Cultural Safety

NZ's health system continues to exhibit a colonial legacy, in which Pākehā worldviews, institutional norms, and service models are systematically privileged over Māori and Pacific ways of knowing, being, and healing (Reid et al., 2017; Reid et al., 2019; Smith,

2012). In clinical contexts, structural inequities manifest through policies, funding priorities, and service designs that overlook the relational, collective, and spiritual aspects of care. The principles of Te Tiriti o Waitangi clearly outline the responsibilities that health services and practitioners must uphold to protect Māori rights and achieve equitable outcomes (Jansen et al., 2009; Ministry of Health, 2020a, 2020b, 2024). However, many health services struggle to implement these principles because they retain organisational logics that prioritise efficiency, standardisation, and throughput over cultural responsiveness.

Cultural safety requires HCPs to engage in ongoing reflexivity around their positionality, power, and biases, and should be measured by service users rather than service providers (Curtis et al., 2019; Medical Council of New Zealand, 2021). The literature describes an ongoing tension between HCPs' ethical obligation to culturally safe practice and the structural barriers that constrain its implementation (Jones et al., 2019). Clinical pathways, time-bound consultations, and siloed service structures severely limit opportunities for whānau engagement, spiritual enquiry, and incorporation of tikanga. Those limitations erode relational trust and compromise HCPs' ethical capacity to provide care that reflects patients' cultural identity, particularly at EOL (Curtis et al., 2019; Jansen et al., 2009; Tipene-Leach et al., 2024). In the end, the disparity between policy rhetoric and the reality of practice suggests there is a need to transform structures, not just individuals. Without organisational accountability and appropriate resourcing, cultural safety remains an aspirational goal rather than a consistently enacted standard of care.

System Context, Geographic and Socioeconomic Access

In NZ, hospice care is experiencing ongoing and intensifying financial pressure. For example, in 2024, the total cost of providing hospice services nationally was approximately $226 million, while government funding covered only $114 million, resulting in a $112 million gap that hospices bridged through donations, retail, and philanthropy (Jenkins, 2024; Nelson Tasman Hospice, 2025). Sector leaders have raised concerns regarding the unsustainability of providing services in this way. An independent analysis commissioned by a group of hospices indicated that total expenditure would soon exceed income, placing services at serious risk after 12 months, at a time of increasing need for hospice care, which is projected to double by 2045 (Jenkins, 2024; Nelson Tasman Hospice, 2025). Recent reports demonstrate these warnings are being realised: Totara Hospice has already restricted patient numbers owing to budget constraints and apologised for any "unavoidable suffering" this causes (Radio New Zealand, 2025). Hospice New Zealand (2025) and Totara Hospice (2025) call for urgent government investment and argue that

current funding levels are inequitable and unsustainable. Some hospices may not be able to sustain their current level of services without continued investment (NZ Herald, 2025; Stuff, 2025). This could impair the sector's ability to meet the increasing demand for hospice and EOL care.

Despite these pressures, hospices provide considerable benefits for every $1 of government investment; for example, they yield at least $1.59 in direct and broader health-system benefits, including day-care services and reduced hospital admissions and emergency department visits (Hospice New Zealand, 2025; Radio New Zealand, 2025). The literature suggests that funding constraints may limit whānau engagement, cultural supervision, and care coordination. In some areas where cost-cutting has occurred, patient numbers have further reduced, limiting access (Irurzun-Lopez et al., 2025; Khullar & Chokshi, 2018; Tipene-Leach et al., 2024). This represents a compounded disadvantage when combined with the geographic and socioeconomic disadvantages experienced by rural and low-income whānau, delaying referrals, limiting access to specialist palliative care, and increasing distances with associated cost and time obligations (Ministry of Health, 2017a; Pomeroy, 2022; Sheridan et al., 2024). Consequently, later referrals leave less time for meaningful conversation about palliative and EOL care, limit preferences and options for receiving care and for place of choice and create barriers to providing culturally safe and goal-concordant care. Structural reforms and secure funding are critical, as many equity commitments are aspirational rather than actionable.

Language, Interpreters, and Health Literacy

Communication is vital to providing culturally safe and goal-concordant EOL care. Unfortunately, patients and whānau continue to experience language challenges and limited access to interpreter services and trained interpreters, which often impede informed decision-making (Enríquez Raído et al., 2020; Hilder et al., 2019; Silva et al., 2016). It is not uncommon for HCPs to report relying on family members to translate clinical information, either because some facilities lack access to interpreters or because HCPs cannot promptly book one while providing care. Reliance on family members raises issues of trust, confidentiality, meaning, and shifting the balance of power between the whānau and the HCPs. These issues can be especially acute in emotionally charged situations such as discussing prognosis, seeking informed consent for procedures, and advance care planning (Korfage et al., 2020; Semlali et al., 2020; Silva et al., 2016).

Beyond spoken language translation, the literature recognises additional challenges posed by technical terms, such as medical terms and clinical jargon. Evidence

indicates that medical terminology and clinical jargon may exceed the health literacy levels of patients and whānau, leaving them confused, disengaged, or passively consenting to care, because insufficient time is available for explanation (Ekberg et al., 2021). While plain-language materials, visual supports, and teach-back methods are useful (Brach, 2024, pp. 12–13, 15–18, 41–44; Suurmond et al., 2020), there are larger systemic influences, such as not providing institutional support for interpreter services, having no established system to employ interpreters, and not having access to culturally safe resources tailored for their patients' experience in healthcare.

Intervention evidence also shows that structured communication support programmes improve prognostic discussions and advance care planning in advanced cancer (Korfage et al., 2020; Walczak et al., 2017). These challenges represent more than individual communication failures; they also represent broader structural inequities inherent in how services are designed and how resources are accessed and distributed. The potential for miscommunication and marginalisation will persist without investment in robust communication systems that build capacity, are affordable, and provide multilingual, culturally specific, and publicly accessible support. These inequities are disproportionately affecting Māori, Pacific, and migrant communities, but also some other patient groups requiring culturally responsive communication support.

Fragmentation and Coordination

EOL care typically includes several different service interfaces: primary care, oncology, radiology, hospice, and community support, often each operating in silos. The literature describes how patients and whānau navigate fragmented services characterised by variable communication, inconsistent documentation, and unclear boundaries of responsibility. This fragmentation undermines relational safety, disrupts continuity of care, and fails to provide care that aligns with cultural values and the patient's goals.

Another recurrent challenge identified in the literature is the lack of systematic collection and transmission of cultural preferences, including tikanga, spiritual care needs, and preferences for whānau involvement. These preferences were often recorded informally or in inconsistent detail and did not travel with the patient across these settings. In the absence of shared care plans and interoperable documentation, clinicians may not recognise or understand relational or cultural signals and cues, leading the patient to feel that care was impersonal or irrelevant to what they valued or preferred. A continuous exchange of information between the hospital and community teams is limited. The literature describes how referrals are delayed, communication is intermittent, and

uncertainty regarding care responsibilities arises as patients transition between acute and palliative services. This can lead to missed opportunities for whānau participation in care and confusion over who is leading the care.

The literature highlights several enablers for aligned, culturally safe care, including routine whānau hui, shared care plans, and recorded tikanga or preferences. Implementing these components into system design, with institutional infrastructure supporting them, will foster trust and lay the foundation for a feedback loop of effective communication and the traditions or lived values of patients and their whānau (Pitama et al., 2014; Royal New Zealand College of General Practitioners [RNZCGP], n. d.). Nonetheless, the uptake of these enablers is often varied and dependent on ad hoc clinician action rather than organisational systems and prompts. Addressing fragmentation in palliative care requires more than improved workflows; it involves a deep relational understanding of coordination that places whānau at the centre, recognises and respects cultural identity, and ensures continuity of information is not only clinical but also social and spiritual. Interventions at the system level that have been demonstrated to alleviate burnout and improve co-operation between care settings or transitions in other clinical contexts may provide direction for re-designing palliative care (Panagioti et al., 2017).

Relational Labour, Bereavement, and Professional Sustainability

Culturally safe end-of-life care involves more than clinical competence; it requires relational engagement, emotional presence, and responsiveness to spiritual and whānau-centred needs. Unfortunately, HCPs frequently cite time constraints, staffing shortages, and productivity-oriented metrics that impact capacity to deliver this kind of care. The relational labour of establishing trust, practising tikanga, and guiding whānau through grief is typically deprioritised in favour of institutional goals prioritising throughput and standardisation over cultural responsiveness.

Tension exists in bereavement care, where post-death procedures often demonstrate a modern emphasis on individualised grief, rapid procedural processes, and a limited relational approach to extended whānau. The literature describes how the rigidity of the systems, in terms of tangihanga (funeral rites and ceremonies) timeframes, church-based practices, collective grief, and the quick release of the body, can undermine trust and subsequently harm. Relationship-building and collective grieving practices are not peripheral; they are integral to healing, honouring the person who has died, and respecting spiritual and relational continuity (AlAli, 2025; Silverman et al., 2020). Further, HCPs may experience the burden of this emotional load. HCPs may experience moral distress when

they are unable to support whānau preferences or fulfil commitments to equity because of systemic inefficiencies. The dissonance between what they want to do and what they feel they can do leads to compassion fatigue, burnout, and disengagement. Evidence-based interventions exist to support HCP wellbeing for organisations and individuals, but implementation is inconsistent.

Psychologically safe teams, cultural supervision, and creating protected time for relational work, including whānau hui and bereavement follow-up care, are one mechanism for mitigating burnout and enhancing resilience; organisation-level interventions are even more potent than those for individuals only, in reducing clinician burnout (Brook et al., 2021; Panagioti et al., 2017; Varela-Agra et al., 2025). However, sustainable change requires more than individual coping practices. Sustainable change involves creating organisational frameworks that value emotional and spiritual labour as a condition for working together and providing opportunities for reflective practice to shape team routines and to measure performance based on the realities of culturally safe care, as expressed by team members.

Taken together, the literature demonstrates that structural barriers continue to constrain equitable, culturally safe, and coordinated EOL care for men living with mPCA and their whānau in NZ. These ongoing gaps highlight the need for further qualitative research to explore how HCPs navigate these structural influences in everyday clinical practice, particularly when providing mPCA EOL care to Māori and Pacific families in NZ.

Meaning-Making, Identity, and Cultural Understandings of Dying

Patients and whānau living with advanced cancer often reflect on the meaning of their lives, the importance of their relationships, and how they wish to be remembered after death. As illness progresses, many seek to strengthen significant relationships, create a sense of legacy and find meaning in their illness experience. These reflections can help maintain dignity, strengthen whānau connections, and support emotional wellbeing throughout the illness trajectory.

Cultural, spiritual, and relational contexts influence how meaning is constructed in NZ. Māori customs, beliefs, and practices relating to wairuatanga, whakapapa, and whanaungatanga shape their understanding of dying as spiritual and interconnected with the past, present, and future (Nikora et al., 2012). Practices such as karakia, tangihanga, storytelling, and communal mourning are culturally relevant ways for patients and whānau to understand, express and cope with death and dying within their own beliefs and traditions (McManus & Du Plessis, 2023; Moeke-Maxwell et al., 2019; Nikora et al., 2012).

Culturally, meaning for non-Māori people is often shaped by spirituality and by strong social connections to whānau and friends (Ministry of Health, 2017b; Moeke-Maxwell et al., 2017; Perry, 2024).

For men living with mPCA, the process of making meaning will often be influenced by how they understand their identity as men, the difficulties they face in relation to their masculinity and autonomy, and how their relationships with significant others will change. Advanced illness may challenge previously held beliefs about independence, strength, and responsibility, requiring men to reconstruct aspects of their identity as relationships and care needs evolve (Te Aho o Te Kahu, 2024). HCPs can support this redefinition by creating a safe space for open communication, developing and maintaining meaningful connections, and providing culturally responsive care that encompasses the emotional, spiritual, and relational needs of advanced progressive illness (Jones et al., 2023).

Understanding how patients and their whānau create meaning throughout advanced illness may facilitate the delivery of high-quality EOL care (Holm et al., 2018). Meaning-making shapes how patients and whānau communicate, make decisions, maintain relationships and navigate emotional and spiritual challenges. Collectively, the literature indicates that recognising the relational, cultural and spiritual aspects of meaning-making enables HCPs to provide more compassionate, person-centred and culturally responsive EOL care.

Integrated Theoretical Framing

Māori models of health, together with principles of equity and cultural safety, form part of the conceptual framework for understanding HCPs' views on EOL care for Māori men living with mPCA. This conceptual framework provides a lens for understanding the lived experiences of patients, whānau, and HCPs, for interpreting clinical narratives, and for connecting these lived experiences with broader systemic and institutional influences (Whautere, 2022, p. 43). It also provides both an epistemological and ethical rationale for using reflexive thematic analysis (RTA), as discussed in chapter three.

Integrating Indigenous knowledge with critical equity theory provides a framework for understanding care as relational, culturally informed, and shaped by broader social, political, and institutional contexts (Whautere, 2022, p. 44). The concept of ōritetanga (equity) aligns with the perspective that equitable EOL care is achieved by considering interpersonal relationships as well as the structural conditions that affect access, participation, and health outcomes (Ministry of Health, 2020a; Moeke-Maxwell et al., 2014; RNZCGP, 2025). This framework situates HCPs' practice within clinical, cultural, and

institutional contexts, supporting the examination of both interpersonal relationships and systemic conditions that shape the quality of EOL care (Curtis et al., 2019; Waitangi Tribunal, 2023).

Māori Models of Health and Care

Māori models are central to this conceptual framework, which conceptualises health and wellbeing as holistic and interconnected. Te Whare Tapa Whā depicts a whare with four interdependent walls. The four walls of the whare are taha wairua, taha hinengaro, taha tinana and taha whānau (Mason & Moeke-Maxwell, 2018; Ministry of Health, 2014). Collectively, these models move beyond individualistic and biomedical models of healthcare by emphasising spiritual, emotional, physical and whānau as interconnected dimensions of care.

The Meihana Model builds on these principles by positioning the patient and whānau within cultural, historical, and systemic currents. The Meihana Model also acknowledges taiao (environment) and iwi-katoa (social structures) to convey health determinants external to the individual, reflecting the influence of ongoing colonialism, structural inequities and migration on health and wellbeing (Pitama et al., 2007; Pitama et al., 2014; Schill & Caxaj, 2019; Whautere, 2022, p. 22).

Mauri Mate, a development specifically for palliative and hospice situations, puts these principles into practice through a model that establishes the baseline for expectations of service delivery under mana (dignity and authority), whanaungatanga, and tikanga, and defines action in relation to the types and levels of service provided. Mauri Mate also establishes actions to ensure effective governance and workforce development, to ensure appropriate communication with patients and whānau, and to provide support for whānau at EOL (Hospice New Zealand, 2020, 2023; Te ORA, 2020). Together, these models position EOL care as a relational, culturally grounded practice, with whānau engagement, spiritual integrity, and cultural identity prioritised above clinical decision-making and service delivery, rather than relegated to an auxiliary status (Edge & Nikora, 2010; Whautere, 2022, p. 47).

Te Tiriti o Waitangi, Equity, and Cultural Safety

Te Tiriti o Waitangi provides the constitutional and ethical foundation for equality in healthcare. The principle of ōritetanga is expressed in Article III by recognising the right of Māori peoples to achieve the same health outcomes as other groups in society, including through an equitable involvement in the delivery of health services to achieve good health.

Māori should be treated as equal partners in providing and receiving care, especially in relation to cancer and palliative care services, which encompasses their rights to participate and have their rights protected, and to be involved in all aspects of their continuum of care throughout their lifetime (Jones et al., 2023; Ministry of Health, 2020a; RNZCGP, 2025; Sheridan et al., 2024; Waitangi Tribunal, 2023, pp. 27–33). The Whakamaua: Māori Health Action Plan (Ministry of Health, 2020b) provides an operational framework for Te Tiriti by identifying key areas of action for the health sector to remedy the persistent inequity faced by Māori and to fulfil their obligation under Te Tiriti to ensure equity in health outcomes.

NZ's definition of cultural safety is reflective, relational, and determined by patients and their families. HCPs must continuously reflect on their cultural position, assumptions, and power, and ensure that the care environment recognises patients' cultural identity and needs (Curtis et al., 2019; Nursing Council of New Zealand, 2011). Cultural safety does not solely rest on the actions of individual HCPs. Rather, the healthcare organisation must demonstrate systemic accountability, holding collective responsibility for addressing the structural barriers to equitable access to care. This includes addressing institutional racism, a key social determinant of health inequity and an affront to the Crown's full obligation under Te Tiriti o Waitangi (Came, 2014; Came et al., 2019b).

Sector health guidance indicates a need to navigate systems for cultural safety. To this end, healthcare organisations have developed guidance on leadership, measurement, and redesigned practice to disrupt inequitable access and communication processes (Hayward et al., 2024). Collectively, these commitments provide an analytical framework for examining barriers and enablers to culturally safe EOL care, including fragmented referral pathways, limited access to interpreters, time-constrained service delivery, tikanga-consistent policies, and meaningful whānau engagement.

Relational communication is a key mechanism for operationalising culturally responsive care. Evidence cited from NZ indicates that when communication demonstrates respect for others, empathy towards the other person's experience, and the recognition of diverse cultural perspectives, there is a positive impact on shared decision-making, reduction in harm due to miscommunication, and alignment between clinical decisions and the values and preferences of patient and whānau (Hayward et al., 2024; Ministry of Health, 2020; Health & Disability Commissioner, 2023).

Within this context, communication is viewed not simply as a neutral means of relaying information but rather as an ethical practice through which manaakitanga and rangatiratanga are enacted. This perspective aligns with Māori models of health and care

that focus on the relational aspects of supporting dignity and trust at the end of life in a culturally congruent manner (Whautere, 2022, p. 47). Beyond interpersonal relationships, Māori frameworks and the principle of ōritetanga highlight the structural conditions that shape equitable care delivery.

Engaging with iwi-katoa and systemic determinants through the Meihana Model allows exploration of how funding, services, and institutional systems (such as policies) interact to shape the context of care (Pitama et al., 2007; RNZCGP, n. d.; Whautere, 2022, p. 52). Using this structural, systems-oriented approach enables literature on both equity and cultural safety to interrogate how colonial histories, entrenched policy frameworks and practice manifest as institutional practices that privilege certain modes of communication, cultural values, and health priorities over others (Curtis et al., 2019; Harris et al., 2018; Ministry of Health, 2020b).

By contextualising HCPs' narratives within broader institutional contexts, the literature review supports consideration of three interrelated dimensions of clinical ethics and quality of care: institutional culture (e.g., resourcing), referral pathways, and HCPs' capability to provide culturally responsive and equitable EOL care (Whautere, 2022, p. 48).

Integrative Summary

Collectively, these theoretical frameworks position EOL care as a relational, culturally mediated, and structurally mediated practice. Māori models provide a holistic understanding of wellbeing and care; Te Tiriti o Waitangi and cultural safety establish the ethical foundations for equitable care; and reflexive thematic analysis offers a methodology for critically interpreting HCP narratives within these broader contexts (Ministry of Health, 2020a; Whautere, 2022, p. 48; Schill & Caxaj, 2019). Together, these frameworks constitute the conceptual foundation for the methodology described in Chapter 3.

Gaps in Literature

Although existing literature addresses palliative care service delivery and culturally responsive care in Aotearoa New Zealand (Mason & Moeke-Maxwell, 2018; Young et al., 2025), less is known about healthcare professionals' perspectives on EOL care specifically for men living with mPCA. This study addresses this gap by exploring the relational, cultural, emotional, and structural complexities healthcare professionals experience when providing EOL care within the NZ healthcare context.

While QoL and psychosocial outcomes continue to gain recognition in prostate cancer research, EOL experiences have yet to be adequately researched, particularly in

culturally diverse settings and among Indigenous populations. Additionally, there is limited literature available to provide insight into how HCPs manage the relational, cultural, emotional and structural complexities associated with EOL care for men living with mPCA. As such, there is a need for research examining HCPs' experiences of providing EOL care for men living with mPCA in NZ.

Gaps in Prostate-Specific End-of-Life Care

Although psychosocial factors related to prostate cancer have received more attention over time, limited research has explored how men with prostate cancer experience these factors during their final months of life. There have been numerous studies exploring the impact of masculinity, gender identity and psychological adjustment on men who have been diagnosed with prostate cancer (Lebel et al., 2020; Occhipinti et al., 2019; Spendelow et al., 2018). The evidence from these studies suggests that masculinity, perceived stress and identity can considerably affect a man's QoL and emotional health. However, little research exists to understand the impact of these factors on men who have advanced prostate cancer and are living with it while dying.

Cornford et al. (2021) support greater specificity in the prostate cancer care pathway, while Gillessen et al. (2025) promote a multidisciplinary, patient-centred approach to addressing the psychosocial and clinical complexity associated with mPCA. However, existing frameworks do not adequately explore the identity disruptions, relational changes and existential issues associated with having advanced disease and EOL care. Holm et al. (2018) found that men with mPCA experience considerable declines in QoL during their last few years; however, very little research has been undertaken to examine the relational, emotional and existential experience of living with mPCA and dying with mPCA.

Moeke-Maxwell et al. (2018) provided evidence from NZ that demonstrated the impact of tangihanga and tikanga disruptions on whānau life, causing existential distress. More recently, Towers (2025) reported a similar experience among whānau who experienced tangihanga disruptions due to the COVID-19 pandemic restrictions. Together, these reports demonstrate that culturally responsive EOL care for men living with mPCA can only occur when care providers integrate the relational, emotional, spiritual and cultural aspects of the dying process into their clinical practice.

Fragmented Integration of Holistic Care

Although widely recognised as integral parts of palliative care, the emotional, spiritual, relational and cultural dimensions of care are not routinely incorporated into practice in

most of the world. According to Yanez et al. (2025), who conducted a scoping review of dignity therapy, holistic and culturally informed approaches are needed, and dignity therapy may alleviate psychosocial and existential distress. Both Bergerot et al. (2024) and Feldstain (2024) indicated that dignity therapy is an effective intervention for promoting both psychological and spiritual wellbeing; however, implementation would require overcoming numerous barriers. In NZ, the Ministry of Health (2017a) identified the need for a strategic direction to enhance person-centred palliative care by more effectively integrating the emotional, spiritual and relational aspects of wellbeing. Taken together, the above studies indicate that existing models of care do not provide a consistent framework for including these types of care; therefore, additional culturally responsive approaches to providing end-of-life (EOL) care must be developed.

System-level factors could also contribute to this fragmentation. Most health institutions prioritise throughput and operational efficiency, thereby limiting opportunities for relationship-building and the provision of holistic care. The Health and Disability System Review (2020) and Waitangi Tribunal (2023) have identified fragmentation and inequity as ongoing issues within NZ's health system. Similarly, Gómez-Vírseda et al. (2020) and Hardy et al. (2023) reported that HCPs are frequently not given sufficient support in terms of time, training, and resources to provide holistic care for their patients. In settings with cultural diversity within the patient population, the limitations listed above may limit HCPs' ability to provide spiritual care, support traditional cultural practices, or foster relational closure to achieve a good death, based on Indigenous worldviews.

Whānau and Caregiver Involvement

Caregiving and shared decision-making have been discussed in similar terms throughout palliative care research; however, the experiences of whānau supporting men living with mPCA have been largely overlooked until now (Holm et al., 2018; Moeke-Maxwell et al., 2018). In NZ, the role of whānau in caring for someone who is ill, dying or experiencing grief is often significant. Whānau members may perform many roles beyond providing physical care to their loved one, including advocacy for cultural values; emotional support; continuity of care; and care that is consistent with their family's beliefs regarding tikanga (Moeke-Maxwell et al., 2018). Unfortunately, the way that many healthcare systems are set up can fail to acknowledge the interconnected and shared nature of whānau involvement in the care of their loved one.

A review of the current literature demonstrates a lack of distinction in the caregiving experiences associated with various types of cancer. As a result, there is minimal

understanding about some of the unique caregiving challenges that are specific to men diagnosed with mPCA. Some of these challenges may include a prolonged illness trajectory; changes in caregiving responsibilities as adult children take over from their parents; providing supportive care for incontinence; and the emotional impacts experienced by male caregivers due to changes in their loved one's masculine identity, independence, and autonomy. Holm et al. (2018) found that caregivers generally do not receive support in their pursuit of psychological and emotional wellbeing while supporting a loved one through the challenges of caregiving. Spendelow et al. (2018) and Groarke et al (2020) found that identity threats, perceived stress, and emotional adjustment all impacted the QoL of male patients diagnosed with prostate cancer. Taken together, researchers have found that whānau and caregivers typically provide support for their loved one's physical care needs, as well as providing support for many of the social and emotional effects of dealing with an advanced illness. Unfortunately, this complexity has not been adequately incorporated into most of the current EOL care frameworks.

Increasingly, research demonstrates that Māori and Pacific whānau face systemic barriers in accessing EOL health services. For example, many Māori and Pacific families lack access to culturally safe hospice or palliative services; do not receive assistance navigating decision-making processes; and do not have their social, cultural and spiritual needs addressed adequately (Huggard et al., 2024; Foliaki et al., 2020). Researchers also found that systemic barriers affected access to specialist palliative services, and the dispersed geographic locations of service delivery hindered equitable access to services (Egan et al., 2020; Hospice New Zealand, 2025). These challenges exacerbate the difficulties faced by whānau members who are responsible for providing culturally safe and supportive care, while receiving inadequate support from the healthcare system to be able to do this.

The COVID-19 pandemic highlighted existing friction between institutional demands and indigenous ways of understanding dying, grief, and cultural practices. For example, Towers (2020) found that restrictions on tangihanga ceremonies increased distress in Māori communities, while Moeke-Maxwell et al. (2018) demonstrated that disruptions to tikanga and the grieving process negatively affected the wellbeing of whānau members. Despite an increased acknowledgement of the value of whānau-centred care by policymakers, there has been limited empirical research on how front-line HCPs navigate cultural tensions when providing care. Collectively, these studies suggest that culturally informed, gender-sensitive, and disease-specific approaches to care for

patients with mPCA at EOL are required to enhance the experience of both patients and whānau.

Cultural Responsiveness and Equity in Practice

Te Tiriti-aligned policy frameworks are part of NZ's health system; however, inequities in prostate cancer indications, access to treatment and treatment outcomes, particularly for Māori and Pacific men, continue to be an issue (Egan et al., 2020; Gillessen et al., 2025). Cultural safety is regarded as an essential professional standard in the health profession (Curtis et al., 2019; Hardy et al., 2023; Medical Council of New Zealand, 2019, 2020). Nonetheless, there is a lack of evidence showing how Māori-based frameworks, Te Whare Tapa Whā and the Meihana Model or Pacific values, are implemented in both oncology and EOL care settings.

The practical aspects of delivering culturally responsive care, such as access to language support, the application of tikanga, and reliable whānau involvement in care and decision making, remain inconsistently implemented in the healthcare sector; therefore, it is still reliant on the skill and knowledge of individual HCPs rather than being established as an inherent component within services (Hardy et al., 2023; Hayward et al., 2024; Ministry of Health, 2020; Health & Disability Commissioner, 2023). Te Aho o Te Kahu (2023) suggests that whānau-centred approaches are most effective when Indigenous leadership is involved in the design and delivery of services.

Indigenous-led service models remain the exception rather than the rule, particularly in cancer care services in NZ. The use of cultural taboos, religious beliefs, and a lack of communication can adversely affect the ability to engage in meaningful EOL conversations with individuals from culturally diverse backgrounds, as outlined by Cáceres-Titos et al. (2025). The findings from their study highlight the need to develop sensitive and culturally responsive approaches to caring for culturally diverse populations. These findings also support the claim made by Curtis et al (2019), Hayward et al (2024), and the Ministry of Health (2020) regarding the need for HCPs to adjust their behaviours, interactions and methods of providing care to meet the values, beliefs, and preferences of both patients and whānau when providing culturally responsive care. There remains limited evidence regarding how HCPs implement cultural responsiveness in their daily practice (Curtis et al., 2019; Hayward et al., 2024; Kidd et al., 2018). Without evidence demonstrating how culturally responsive care is operationalised in clinical settings, commitments to cultural safety will likely remain aspirational rather than transformational

(Curtis et al., 2019; Medical Council of New Zealand, 2019, 2020; Health & Disability Commissioner, 2023).

Healthcare Professionals' Experiences and Wellbeing

Research has shown that the voices of HCPs are underrepresented in the literature, which has concentrated primarily on system-level barriers, such as delayed referrals, resource limitations, and time constraints, rather than the relational, cultural, emotional, and existential work of providing EOL care (McCracken et al., 2021; Rosenwohl-Mack et al., 2021). Existing research has also focused on general palliative populations, with little attention to the specific challenges of caring for men living with mPCA (Holm et al., 2018; Lebel et al., 2020; Spendelow et al., 2018). While frameworks for reflective practice and culturally appropriate care are available (Nursing Council of New Zealand, 2011), there is limited evidence of how these frameworks support HCPs to respond to the emotional, relational, cultural and existential complexities they face in everyday practice (Hardy et al., 2023; McCracken et al., 2021; Rosenwohl-Mack et al., 2021). This gap is especially significant given the longitudinal nature of mPCA, in which HCPs often form long-standing relationships with patients and whānau and repeatedly witness disease progression, disruption to identity, existential distress, and the challenges of providing EOL care over time (Holm et al., 2018; Moeke-Maxwell et al., 2018).

Linking System Structures to Bedside Practice

The NZ health system is often regarded as having structural difficulties, including resource constraints, fragmented service delivery systems, and staff shortages (Gillessen et al., 2025; Ministry of Health, 2017a). Less is known about how these broader system-level issues affect communication, relationship-building, and care delivery at the bedside (Gómez-Vírseda et al., 2020; McCracken et al., 2021; Rosenwohl-Mack et al., 2021). Simpson et al. (2020) and the Waitangi Tribunal (2023) argue that many of these inequities are systemic and connected to breaches of the obligations under Te Tiriti o Waitangi. However, very little research has specifically investigated how institutional priorities, such as efficiency-based models of care, dominance of biomedical models, and funding constraints, influence the provision of culturally safe and whānau-centred EOL care for Māori men living with mPCA (Curtis et al., 2019; Hayward et al., 2024; Ministry of Health, 2020).

According to Gómez-Vírseda et al. (2020), traditional approaches to EOL care often fail to capture the relational and cultural context of patient autonomy, underscoring

the need for more context-sensitive care. Similarly, there is limited understanding of how HCPs enact culturally responsive practice in everyday clinical settings while managing organisational expectations and service pressures (Curtis et al., 2019; Hayward et al., 2024; Ministry of Health, 2020). This gap between system-level structures and the relational realities of care is an important area for future research, especially regarding reform, inequities, and culturally responsive EOL care (Curtis et al., 2019; Simpson et al., 2020; Waitangi Tribunal, 2023).

The body of literature indicates that significant gaps remain in our understanding of how HCPs experience and navigate the relational, cultural, emotional, and structural complexities involved in providing EOL care to men living with mPCA (Curtis et al., 2019; Holm et al., 2018; McCracken et al., 2021). A limitation of existing research is that it has not adequately addressed HCPs' perspectives, how they enact cultural safety in their daily practice, and how the systemic barriers they face can hinder the delivery of relational care. These gaps are particularly apparent within the context of NZ and were the motivation for the present study.

Conclusion

The literature reviewed demonstrates that living with mPCA extends beyond disease progression and symptom burden, encompassing the emotional, relational, spiritual, and cultural dimensions of care. Men living with mPCA may experience changes in identity, challenges to autonomy, and disruption to established whānau and social roles, while whānau often provide significant emotional, practical, and cultural support throughout the course of illness (Bateman et al., 2023; Chambers et al., 2012).

The review emphasised the need to provide access to culturally appropriate and whānau-centred EOL services. Māori and Pacific worldviews conceptualise wellbeing as comprising physical, emotional, spiritual, relational, and whānau dimensions of life. These cultures provide valuable frameworks and models for understanding the experiences of ill health, dying, and grief among patients and their whānau (Durie, 2004; Foliaki et al., 2020; Pitama et al., 2007; Schill & Caxaj, 2019). Despite recognising these connections, Māori and Pacific peoples continue to experience significant inequities in access to, and delivery of, services as well as health outcomes. The model of service delivery is also a contributing factor, with service fragmentation, workforce pressures, and resource constraints potentially limiting access to holistic and culturally appropriate EOL services (Curtis et al., 2019; Egan et al., 2020; Gurney et al., 2020; Ministry of Health, 2017a).

The review identified significant gaps in understanding these issues. There is limited research examining how HCPs, patients, and their whānau experience and navigate the emotional, relational, spiritual, and cultural dimensions of EOL care (Holm et al., 2018; Lebel et al., 2020; Spendelow et al., 2018). There is often limited representation of whānau voices in research, particularly within the Māori and Pacific contexts (Foliaki et al., 2020; Huggard et al., 2024; Moeke-Maxwell et al., 2018), and there is limited evidence in current literature of how HCPs practice cultural safety, provide relational care, or identify and navigate structural barriers in their daily practice (Gómez-Vírseda et al., 2020; Hardy et al., 2023; McCracken et al., 2021; Rosenwohl-Mack et al., 2021). There is emerging interest in Te Tiriti o Waitangi obligations and culturally safe care; however, research is lacking on how these obligations are realised in the context of oncology and EOL services (Curtis et al., 2019; Hayward et al., 2024; Te Aho o Te Kahu, 2023).

Together, these studies suggest that the EOL care provided to men living with mPCA is guided by the intersection of relational, cultural, emotional and structural components (Curtis et al., 2019; Durie, 2004; Pitama et al., 2007; Schill & Caxaj, 2019). Despite increasing awareness of these factors, there are many gaps in knowledge about how HCPs experience and navigate them in practice. Understanding HCPs' perspectives will provide important insights into how relational, cultural, and structural factors influence the delivery of EOL care. It will also facilitate the development of culturally responsive, equitable, and patient-focused practices. The next chapter will describe the research methodology used to explore HCPs' perspectives on providing EOL care to men living with mPCA in NZ.

Chapter 3: Methodology and Method

This research uses qualitative methods to investigate the experiences and perspectives of healthcare professionals (HCPs) who deliver end-of-life (EOL) care to men diagnosed with metastatic prostate cancer (mPCA) in Aotearoa New Zealand (NZ). This chapter outlines the research design, guiding methodology, participant recruitment, data collection, analytical approach, ethical considerations, strategies used to ensure rigour, and the researcher's reflexive positioning.

The objective is to determine how interpersonal relationships, cultural beliefs, emotional labour, and health-system structures influence HCPs' experiences of EOL care. Māori principles and relational approaches are therefore used throughout this study to explore how HCPs negotiate ethical and cultural responsibilities at individual and system levels when providing care for Māori and non-Māori patients and whānau during EOL. This approach allows the researcher to obtain a holistic view of how HCPs operate at a personal level while also accounting for the influence of relationships, culture, and systems on the delivery of EOL care.

Research Design

The research used interpretive description, informed by Māori research principles such as relationality, whanaungatanga, manaakitanga, and ōritetanga. Semi-structured interviews were used to support culturally grounded data collection and directly address the research question regarding EOL experiences. A qualitative methodology is well-suited to examining human experiences in the context of mPCA in NZ (Komene et al., 2023; Thompson, Thorne, & Sandhu, 2016). The research study explored how HCPs understand and implement EOL care, as well as how cultural, social, and structural factors influence these discussions. Gaining an understanding of how cultural, social, and structural factors affect EOL conversations contributed significantly to the study's findings and to future approaches to patient care.

The research was informed by a Māori worldview, including respect for tapu surrounding EOL discussions, which shaped the interview protocol and consent process to support cultural safety (Hudson et al., 2010; Te ORA, 2020; Whautere, 2022). Although Māori leaders were not involved in all stages of the study, the overall methodological design was guided by Māori principles of manaakitanga, whanaungatanga, and rangatiratanga, alongside considerations of ōritetanga. These principles supported a culturally relevant and contextualised understanding of HCPs' experiences. Data analysis

was conducted using reflexive thematic analysis (RTA) (Braun & Clarke, 2022), with coding in three iterative rounds and adjustments made every 2 weeks during reflexive supervisory meetings, which included reinterpreting provisional themes through a cultural lens.

The research was based on a constructivist perspective, recognising that knowledge and reality are co-constructed through social and cultural interactions rather than being objective and fixed entities (Eberle, 2023; William, 2024). Healthcare professionals' (HCPs) perspectives, shaped by their cultural identities, interactions with patients and whānau, and clinical obligations, contributed to addressing the study objectives. From a constructivist perspective, EOL care is understood as contextual and shaped by multiple realities.

Data were collected through semi-structured interviews, which allowed participants to describe their experiences in their own words and enabled follow-up questions to clarify responses (DeJonckheere & Vaughn, 2019; Jamshed, 2014; McGrath et al., 2019). This approach was particularly useful when discussing the sensitive and often emotionally charged aspects of EOL care. The interview guide was designed to foster open conversation, honouring the cultural significance and emotional depth of the subject matter discussed.

Methodological Framework

This study used a qualitative research design based on an interpretive descriptive methodology and a constructivist–interpretivist framework. This view holds that reality cannot be fixed or objective, but is instead shaped by people's interactions, cultural environment, and lived experience (Abdul-Razzak et al., 2014; Tanlaka & Aryal, 2025; Turin et al., 2024). A constructivist view suggests that there are numerous realities; the researcher and participants co-constructed meaning to make sense of them. This was especially useful for a study examining EOL care for men with mPCA, in which emotional, cultural, and relational meanings are deeply rooted in clinical practice.

The methodological approach was based on interpretive description, which is well suited to health research that links qualitative investigation with clinical application (Abdul-Razzak et al., 2014; Kilgour et al., 2025; Thompson Burdine et al., 2020). Interpretive description is a method that strikes a balance between flexibility and structure, enabling an in-depth understanding of practice while acknowledging the complexity of human experience.

Although phenomenology focuses on understanding the essence of lived experience and grounded theory on theory generation, the primary aim of interpretive description is to generate clinically relevant knowledge to inform healthcare practice. This aligns with the study aim to understand HCPs' perspectives of EOL care to inform future service delivery and clinical practice (Thorne, 2025).

The purpose of this research was to examine HCPs' perceptions of and engagement with values-based care in EOL contexts, avoiding theoretical overgeneralisations and instead centring on lived, relational experiences. The research was informed by a relational epistemology (Burns et al., 2022; Junjie & Yingxin, 2022), recognising that knowledge is co-created through relationships, discourse, and collective reflection. This perspective is informed by constructivist and interpretivist paradigms and highlights the importance of relationships grounded in connection, empathy, and trust, which are central to EOL care. While the researcher is not Māori, this research was guided by Māori principles of manaakitanga, whanaungatanga, rangatiratanga, and considerations of ōritetanga. These principles informed the ethical, relational, and interpretive conduct of the research.

Manaakitanga framed a sense of welcome and emotional safety, ensuring that participants felt heard and valued (Hudson et al., 2010; Pitama et al., 2007; Te ORA, 2020). Whanaungatanga is central to establishing rapport and relational trust, recognising that a genuine relationship can enhance authenticity in sharing experiences (Hudson et al., 2010; Rolleston et al., 2022). Finally, rangatiratanga ensured that participants remained in control of how their contributions would be represented, interpreted, and shared (Hudson et al., 2010; Ministry of Health, 2020b; Reid et al., 2017). Collectively, these principles provided an ethical and culturally responsive foundation that honoured participants' expertise and upheld the integrity of the research process.

These values complemented formal ethical protocols, adding a layer of consideration for emotional safety, cultural responsiveness, and relational accountability in the research process; for example, decisions about Karakia, koha (gift), and transcript handling were discussed with the supervisors and documented in a protocol shared with participants. Their inclusion reflects a deliberate and respectful attempt to engage with Māori worldviews and uphold culturally appropriate research practice, even as a non-Māori researcher.

Research has shown that HCPs bring a wealth of experience and education to their profession. For Māori participants, this included knowledge grounded in te ao Māori; a Māori worldview shaped by cultural identity, intergenerational learning, and the legacy of

colonisation and systemic inequity (Reid et al., 2017; Sheridan et al., 2024). For non-Māori participants, care approaches were influenced by clinical training, institutional frameworks, and individual cultural background. Interpretive description supported examination of how these cultural systems and worldviews interact in practice (Junjie & Yingxin, 2022).

As a non-Māori researcher with experience in postcolonial healthcare contexts (including South Africa and New Zealand), she acknowledges the historical and ongoing effects of colonialism. The experiences in these healthcare systems have given her insight into the dynamics of power, cultural clashes, and the impact of systemic injustices on healthcare delivery. This understanding has shaped the researcher's approach to this study, with a commitment to cultural humility, self-awareness, and critical reflection. The constructivist lens, combined with interpretive description and Māori principles, provided a methodological and moral foundation that supported this reflexivity while centring participants' voices and lived realities.

Collectively, this framework guided data collection and interpretation, facilitating the co-construction of meaning between the researcher and participants. The outcome was a collection of deep, situational insights on how care is perceived and given at the crossroads of clinical practice, cultural identity, and relational ethics. Therefore, the approach was not only methodologically useful but also ethically and culturally sound, as it was grounded in principles that support both high-quality care and research informed by Māori principles.

Participant Recruitment

Principles of autonomy, accessibility and cultural safety guided the recruitment of participants. HCPs in NZ who had direct experience providing EOL care planning for patients living with mPCA were purposively sampled.

Participants were recruited via targeted invitations distributed through cancer, palliative care, and primary care networks, including hospitals, hospices, professional healthcare associations, and Māori HCPs. Recruitment materials were sent by email and consisted of the Participant Information Sheet (PIS) (Appendix B) and recruitment advertisement (Appendix B). Snowball sampling was also used to enable participants to identify other eligible HCPs who might have been interested in participating (Martinez-Mesa et al., 2016; Negrin et al., 2022).

Interested HCPs contacted the researcher directly by email. An initial eligibility screen was done, and eligible participants were given the Participant Information Sheet (PIS) and permitted at least 48 hours to consider participation. Participants were given the

choice of a face-to-face interview or an interview via Microsoft Teams, and all chose the latter. Verbal informed consent was obtained immediately before the commencement of each interview and before audio recording. Participants signed and emailed the consent form after the interview. Participants were informed of their rights, including the right to withdraw from the study at any time and assured that their data would be kept confidential.

Eligible participants were practising HCPs actively involved in the care of patients living with metastatic prostate cancer, especially those involved in EOL care planning, and willing and able to provide informed consent. HCPs who were not actively involved in the care of patients with mPCA, particularly in EOL care planning, were excluded from the study.

Seven participants were recruited. The sample size was appropriate for the qualitative descriptive design, providing adequate depth and richness to explore HCPs' experiences and allowing for detailed reflexive analysis. The following section presents the participants' professional characteristics and relevant experience.

Participant Characteristics and Professional Backgrounds

Seven healthcare professionals participated in this study, representing medical oncology, health psychology, specialist palliative care, nuclear medicine, hospice care, general practice, and district nursing. Their professional experience spanned specialist cancer services, primary care, hospice, and community settings. Participants brought varied perspectives on clinical treatment, psychosocial support, symptom management, care coordination, and EOL care. Table 3.1 summarises their professional characteristics and relevant experience.

Table 3.1

Participant Characteristics and Professional Backgrounds

Participant	Gender	Professional role	Professional experience
P01	Female	Medical oncologist	Extensive oncology experience; over 20 years of medical practice
P02	Female	Health psychologist	Approximately 7 years with the organisation; psycho-oncology experience since 2017
P03	Female	Palliative care clinical nurse specialist	13 years in palliative care
P04	Male	Principal nuclear medicine scientist	23 years of professional experience, including approximately 7–8 years working with prostate cancer

P05	Female	Hospice clinical nurse specialist	Approximately 12 years working with metastatic prostate cancer
P06	Male	General practitioner	Approximately 20 years working with older adults, including patients with cancer
P07	Male	District/community nurse Manager	Nursing since 2007; district nursing since 2018

Data Collection Methods

Data collection was primarily through semi-structured interviews. Participants were given the option of face-to-face or Microsoft Teams interviews, but all chose to participate through Microsoft Teams. This approach was well-suited to the qualitative design (DeJonckheere & Vaughn, 2019; Jamshed, 2014; McGrath et al., 2019) and accommodated participants' preferences. Semi-structured interviews gave participants the freedom to share their stories, leading to the discovery of new themes and prompting reflection on emotionally and culturally sensitive aspects of EOL care.

The researcher prepared an interview guide (Appendix F) based on the study's qualitative methodology to understand how HCPs interpret and provide EOL care. The guide covered eight primary areas:

1. Definitions and understandings of EOL care.
2. Professional experiences with mPCA patients.
3. Integration of cultural beliefs in clinical practice.
4. Communication with patients and whānau.
5. Emotional and spiritual support.
6. Challenges in delivering high-quality EOL care.
7. Recommendations for service improvement
8. Final reflections on practice and experience.

Open-ended questions facilitated participant-led discussion, enabling them to prioritise issues most relevant to their clinical and cultural contexts. The focus was on culturally safe communication and the role of whānau, which aligns with the bicultural principles that underpin NZ's healthcare system (Hudson et al., 2010).

Each interview took around 60 minutes; however, the time varied depending on the participant's schedule. The interviews were conducted in a controlled manner that aimed to strike a balance between being honest about the process and respecting different cultures. When culturally appropriate and with the participants' consent, a karakia (prayer) was offered at the beginning or the end of the session. This was an expression of respect

for Māori traditions and cultural protocols. Some participants preferred to start and end without a karakia.

After the karakia or greeting, a brief introduction was provided to explain the purpose of the study, ensuring that participants were fully informed and allowing them to ask questions. At the end of each session, there was a summary, a call for final thoughts, and a closing karakia if participants wanted one. Reflective notes were written immediately after each interview to document nonverbal indicators, including tone, pauses, and emotional inflections. These observations added complexity to the background, especially when cultural norms may have affected how vulnerability or distress were shown (Saldaña, 2021).

With the participants' consent, all interviews were recorded and transcribed using Microsoft Teams transcription. Transcripts were manually checked for accuracy by the researcher, with an additional focus on all te reo Māori and culturally specific wording to verify accurate meaning, pronunciation, and intention.

Data Analysis: Reflexive Thematic Analysis

Reflexive thematic analysis (RTA) was utilised for data analysis, adhering to the technique developed by Braun and Clarke (2006, 2019, 2022). RTA was selected for its congruence with Māori research principles and its methodological flexibility, which aligns effectively with the study's constructivist paradigm (Byrne, 2021; Warner & Groarke, 2022). It acknowledged the researcher's active role in co-constructing meaning, therefore facilitating an iterative, interpretive, and reflective engagement with the data.

RTA is suitable for qualitative research examining the intricate social and cultural dimensions of EOL care among healthcare professionals. Recognising the researcher's subjectivity as an analytical benefit rather than a constraint facilitates the identification of themes within the dataset and enhances the uncovering of meaningful patterns (Braun & Clarke, 2019, 2022; Byrne, 2021; Warner & Groarke, 2022). This was essential for comprehending the intricate, emotionally laden, and culturally embedded dimensions of the participants' narratives.

The six-phase reflexive thematic analysis was implemented: familiarisation, initial coding and clustering development, theme development, reviewing and refining themes, defining and naming themes, and producing the report; each phase contributing to progressively reducing and clarifying thematic clusters (Braun & Clarke, 2006, 2019, 2022).

Phase 1: Familiarisation

Becoming intimately acquainted with the dataset involved repeatedly listening to and reading all transcripts. This active and interpretive engagement aligns with Braun and Clarke's (2019, 2022) recommendations for the early identification of patterns, points of emphasis, and areas of tension, which the researcher recorded in reflexive notes and in an analytic memo. Throughout phase 1, the researcher paid particular attention to how participants constructed their professional identities, engaged with culturally and spiritually relevant issues, represented their relational dynamics with patients and their whānau, and provided insight into the systemic factors contributing to those experiences. The researcher also reflected on how her clinical background, cultural standpoint, and research intent influenced her interpretation of the data. Familiarisation allowed for the development of conceptual frameworks for coding.

Phase 2: Initial Coding and Code Development

In Phase 2a, the researcher conducted initial line-by-line coding to identify recurring patterns of meaning that would guide the development of themes aligned with the research aim. Manual coding was performed in Microsoft Word and Microsoft Excel to enable close engagement with the data. The researcher maintained a version-controlled codebook, time-stamped coding logs, and performed regular cross-checks to enhance transparency and auditability throughout the coding process.

Participant responses were coded for semantic (explicit) and latent (interpretive) meanings based on Braun and Clarke's (2006, 2019, 2022) Reflexive Thematic Analysis. Qualitative coding, Byrne (2021) notes, not only describes the accounts of research participants but requires the researcher to reflexively engage with the data to interpret how meaning is made through experiences.

In coding, the researcher coded for patterns relating to cultural values, professional identities, systemic barriers, emotional labour and engagement with whānau. Reflexive analytic notes were written throughout the coding process to document emerging interpretations, methodological decisions, questions, and areas of analytic interest. Detailed exploration of each participant's transcript led to the production of data extracts, initial codes and associated Reflexive Analytic Notes. Examples of Phase 2a coding are provided in Appendix G.

In Phase 2b, the researcher clustered the initial codes into broader clusters of shared meaning. This involved clustering conceptually related codes, seeking relationships

across participants' accounts and developing candidate clusters based on patterns identified across the data set. Microsoft Excel was used to compare the codes systematically but was kept sufficiently flexible to identify convergence and divergence across participants' experiences.

Throughout this process, the researcher was involved reflexively, moving back and forth between the coded extracts and the whole data set to ensure that the developing clusters accurately reflected the participants' accounts, while also acknowledging the researcher's interpretive role. Key analytical decisions and the rationale for cluster development were documented in reflexive analytic notes.

The iterative, interpretive and reflexive process yielded 18 clusters of shared meaning across the dataset. These clusters provided the analytical basis for the subsequent development of candidate themes (Appendix H).

Phase 3: Theme Development

In this study, the iterative process of comparing and reviewing the clusters generated in Phase 2b supported theme development. The process allowed the researcher to identify conceptually related patterns of shared meaning across participants' accounts. The researcher examined relationships within and between clusters to generate candidate themes that reflected wider patterns within the dataset and addressed the research aim.

The researcher was reflexively involved throughout the process, constantly moving among the coded data, the full data set, and the emerging thematic framework. Ongoing comparison, critical reflection, and consideration of alternative interpretations refined the candidate themes, recognising that themes are actively developed through the researcher's interpretive engagement with the data rather than discovered within it (Braun & Clarke, 2019, 2022; Byrne, 2021; Warner & Groarke, 2022). Reflexive analytic memos identified key analytical decisions, emergent interpretations, and rationale for theme development.

The researcher also drew on Māori principles in interpreting shared meaning patterns. Interpretations of participants' accounts were framed using concepts such as whanaungatanga, manaakitanga, wairuatanga, rangatiratanga, and ōritetanga to comprehend the relational, cultural and systemic contexts (Durie, 2004; Moeke-Maxwell et al., 2019). The researcher used these concepts as interpretive lenses rather than imposing them on the data, thereby guiding the interpretation of how relationships, cultural identity, collective decision-making, spirituality, and equity informed HCPs' understanding of EOL care for men living with mPCA.

This iterative, reflexive process showed that many candidate patterns were related rather than distinct. Relationship-based care was closely related to communication, whānau involvement, emotional labour and structural barriers to care. Similarly, relational and psychosocial inequities were closely interconnected with broader systemic barriers that shaped the delivery and experience of EOL care. This iterative process reduced the original 18 clusters of shared meaning to a smaller number of candidate themes. The themes were provisional and were reviewed and refined during Phase 4 to ensure coherence, distinction, and alignment with the dataset.

Phase 4: Reviewing and Refining Themes

The fourth phase of reviewing the themes provided an opportunity to refine and group them (Braun & Clarke, 2006, 2019, 2022; Byrne, 2021; Warner & Groarke, 2022). Supporting data on the significance of themes informed the decision to combine, modify, or delete themes. The review process included consideration of cross-cultural dimensions to ensure that the representation of Māori and non-Māori was evidenced honourably and respectfully.

In accordance with the principles of reflexive thematic analysis, two levels of thematic analysis were employed in this phase of data analysis. The first part involved reviewing the level of coherence among data extracts within each theme and determining whether coherent patterns emerged across the entire set of extracts. Data extracts that did not align with the central organising concept of a particular theme were redistributed or removed. Additionally, subthemes were reviewed at this point to ensure they aligned appropriately with their respective overarching themes, avoiding unnecessary disaggregation of the analytic narrative.

Secondly, an overall review of the themes was conducted to ensure they reflected the full scope of participants' experiences. Part of this review involved revisiting transcripts and earlier codes to confirm that all data relevant to this analysis were represented and that the thematic structures were consistent with participants' experiences. A key element of the analysis was ensuring that appropriate conceptual boundaries existed between themes, so that each theme satisfactorily represented a single coherent pattern of shared meaning.

Using an iterative and recursive analysis technique, the dataset was categorised into coherent patterns of meaning. To establish conceptual soundness, themes were revised through ongoing and reflexive communication and dialogue with supervisors, along with continual re-examination of the data. Detailed analysis of each theme is presented

and discussed in Chapter 4. The results from this phase produced reliable, consistent themes, clear distinctions between them, and associations with the research question. These developed themes became the basis for Phase 5, in which they were defined and titled in greater depth.

Phase 5: Defining and Naming Themes

The fifth phase involved defining and naming the themes identified during phase 4, following Braun and Clarke's (2006, 2019, 2022) framework, as further described in the RTA analysis literature (Byrne, 2021; Warner & Groarke, 2022). This phase examined how each identified theme related to cultural safety in EOL care and to the relationship-based provision of EOL care across the healthcare system, with respect to the research objectives.

This phase represented a deeper level of interpretation than the previous four phases, as it not only examined patterns of shared meaning in the data but also provided a coherent organisational structure for the named themes. In this respect, the researcher examined each developing theme to determine the data captured by each, how the themes assisted the researcher's understanding of HCPs' perspectives, and how each related to the other named themes within the overall analytic framework. This process ensured that the themes represented a meaningful coalescence of patterns to answer the research question, rather than merely descriptive representations.

The theme definitions were refined through a cyclical process of re-examining the coded data extracts, re-evaluating the boundaries of the themes, and ensuring clarity of thought regarding the concepts and the themes' intended meanings. Where required, the names of the themes were altered to reflect their intended meaning better and to provide a concise, easily understood description of the analytical significance of the theme.

During this phase, subthemes were also identified to describe different but related patterns within each overarching theme. The subthemes provided a coherent structure for organising the findings presented in Chapter 4, while retaining the complexity and depth of the participants' accounts.

As in previous phases, this phase of analysis was informed by a Māori analytical lens. The researcher used the concepts of whanaungatanga, manaakitanga, wairuatanga, rangatiratanga, and ōritetanga to inform the interpretation and naming of themes. These concepts were not themes per se but rather served as interpretive lenses for understanding the relational, cultural, spiritual, and ethical aspects of the participants' experiences.

The outcome of Phase 5 was a set of clearly defined and coherently named themes, each supported by a concise analytical description. These descriptions form the basis for presenting the findings in Chapter 4 and for explaining the meanings of the various themes and sub-themes, with detailed illustrative data extracts.

Phase 6: Producing the Report

The final report describes the themes identified in the research and illustrates them by presenting participants' quotations. The credibility of the study, in conjunction with how it will be used to assess transferability, is supported by the methodological approaches used in conducting the semi-structured interviews; the cultural framing of the research design and methodology and that the limitations of this study have been acknowledged in the final report (Braun & Clarke, 2006, 2019, 2022; Byrne, 2021; Warner & Groarke, 2022). The researcher acknowledged that her positionality would influence how she interpreted the meaning in the data gathered from research participants, and that this potential influence could be addressed by being reflexively aware of it.

The field notes comprised data obtained by observing the non-verbal communication participants demonstrated during the interviews, such as tone of voice, pauses, and gestures. The use of non-verbal communication to obtain additional data for analysing and interpreting themes demonstrates the cultural impact of emotions, which at times assists participants in understanding and identifying the meanings associated with the cultural expressions observed during the interview process.

Ethical considerations

EOL care is an emotionally sensitive and culturally significant issue for the people of NZ (Cargo et al., 2016; Chamberlain, 2016; The New Zealand Psychological Society, 2002). Ethical integrity was of paramount importance to the study's design and implementation. Ethics Committee approval was integral to the design and conduct of this research project (AUTEC) [AUTEC Reference Number 25/38, see Appendix A for additional information].

A significant aspect of the ethical integrity of this research is participants' ability to give fully informed consent (Cargo et al., 2016). All participants received a Participant Information Sheet (PIS) [see Appendix B] that articulated the aim of the research, the intended methodology, the potential risks and benefits of their participation, and their rights as participants. Recruitment was open for four weeks, during which HCPs could read the PIS, ask questions, and decide whether to participate in the research project. After the first

48 hours, when the PIS was distributed, some prospective participants indicated that they would have liked to participate.

Interviews were held via Microsoft Teams, and participants' needs determined scheduling. At the start of each interview, the participant was asked to acknowledge their consent to participate verbally. After the interview, the participants were asked to email their signed consent forms to the research team. The copies of the consent forms are provided in Appendices C and D.

The data gathered in this research project were treated confidentially in accordance with the principles of confidentiality and anonymity (Taylor et al., 2016; The New Zealand Psychological Society, 2002). Due to the nature of purposive sampling, it was not possible to ensure complete anonymity for participants in this project. However, efforts were made to protect the identity of all participants. Each participant was assigned a pseudonym, and the written transcripts and final report did not include identifying information, such as names, places of employment, or geographic locations, of any participants. The interviews conducted on Microsoft Teams were transcribed using the Microsoft Teams transcription feature, and the research team manually corrected the transcripts to ensure accuracy and remove any information that could identify participants.

Cultural safety was of utmost importance to the researcher, particularly when dealing with participants who identified as Māori. The researcher adhered to tikanga Māori customs during the interviews, including allowing the participant to choose whether they would commence or conclude the interview with a karakia (prayer). The researcher provided each participant with a koha (gift) to acknowledge the time and effort they expended in supporting this research (Hudson et al., 2010).

The researcher recognised that talking about EOL care had the potential to cause emotional distress to the participants. The participants were advised that they could discontinue the interview at any time or choose not to answer any question. All participants received information about support services (including the AUT counselling program, their employee assistance programme and the Cancer Society) in case they experienced discomfort during or after the interview (Khankeh et al., 2015; Westland et al., 2025).

Rigour

Rigour in qualitative research is defined as an open, trustworthy, and methodologically sound study that provides reliable, credible, transferable, and confirmable results (Cypress, 2017; Nowell et al., 2017). Rigour becomes particularly important when researching sensitive topics such as EOL care, as it is essential to ensure that any

interpretation is both culturally and ethically appropriate (Cypress, 2017; DeJonckheere & Vaughn, 2019). To ensure rigour in this study, well-established qualitative criteria credibility, transferability, dependability, and confirmability were applied in accordance with informed Māori research principles and relational ethics (Hudson et al., 2010; Reid et al., 2017).

The prolonged analysis and repeated interpretation of the data made the data more credible. The researcher read each transcript multiple times and compared the newly identified codes and themes with the complete dataset to ensure they accurately reflected the participants' intended meanings (Cypress, 2017; Nowell et al., 2017). Throughout the research, direct quotes from participants were used to support interpretations. The researcher used reflexive journaling to increase credibility by prompting her to consider her own beliefs, cultural background critically, and how those beliefs influenced her interpretive decisions during data coding and analysis (Berger, 2015; DeJonckheere & Vaughn, 2019).

Transferability was guided by explicit contextual descriptions that outlined the research environment, participants' demographic characteristics, and the sociocultural context of EOL care. The results provide insights for utilisation in various healthcare service contexts, particularly bicultural or indigenous-responsive services (Cypress, 2017; Huygens & Nairn, 2016; New Zealand Psychologists Board, 2011). This is important, as it provides participant narratives that add context to participants' work and cultural setting.

To maximise dependability, the researcher was transparent about her methodology and consistent throughout the research process. This required the researcher to document each of the steps involved in recruiting participants; obtaining consent from participants, conducting interviews with participants; managing the data collected during the interviews; and creating themes from the data and developing an audit trail throughout the study so that others would be able to evaluate the research and increase their confidence in the results obtained from the research (Cypress, 2017; Nowell et al., 2017). The researcher used Microsoft Excel to coordinate and compare the participants' codes, further improving both the consistency of the analytic processes and the transparency of the process.

Confirmability was demonstrated by evidence that the results were derived from participants' statements rather than from researcher bias (Cypress, 2017; Nowell et al., 2017). The researcher was able to provide this evidence through supervision, reflective writing and by maintaining a clear distinction between the original data and the interpretative layers. Adding other cultural perspectives, especially those influenced by Māori worldviews, provided the interpretation with balance and realism (Hudson et al., 2010; Reid et al., 2017; Sheridan et al., 2024).

Throughout the study, the researcher maintained a high level of qualitative rigour by using these methods. Furthermore, the researcher produced methodologically sound and culturally relevant results that contribute to the body of knowledge in the developing field of EOL care in NZ.

Reflexivity and limitations

Although Māori concepts guided this research, it did not involve Māori advisors throughout the research process; therefore, these concepts were applied with caution and solely within the scope of this study. The scope of the research plan and timeline left very limited opportunities for co-design. To maintain all aspects of cultural integrity and interpretive trustworthiness while conducting this research, the researcher relied on the process and guidance provided by the supervisory team; used koha and karakia as part of the research; integrated other Māori health frameworks into the analysis; and had an appropriate amount of contact with the supervisors (Hudson et al., 2010; Cunningham & Mercury, 2023).

Reflexivity is an important part of the researcher's ethical framework; as the researcher wrote in journals throughout and following the interviews to record reflections on thoughts, assumptions, and how they responded during data collection and analysis, this reflexive approach confirmed that the participants' perspectives were meaningfully communicated and clearly articulated according to both cultural and social moral standards (Berger, 2015; Holm et al., 2018; Olmos-Vega et al., 2022). Reflexivity also served to challenge conventional beliefs and to monitor the power imbalance between researcher and participants, especially when participants narrated their stories through a culturally different lens (Ide & Beddoe, 2023).

Chapter 4: Findings

The results of Reflexive Thematic Analysis (RTA) are presented and discussed in this chapter, including healthcare professionals' (HCPs) views on EOL care for men living with metastatic prostate cancer (mPCA) in Aotearoa New Zealand (NZ). Analysis identified four overarching themes reflecting the concepts of whanaungatanga, wairuatanga, manaakitanga, rangatiratanga, and ōritetanga. These are presented in Table 4.2.

Each theme is a unique but interconnected pattern of shared meaning across the dataset. Together, these themes articulate how EOL care is perceived, experienced, and facilitated through relational, cultural, ethical, and systemic contexts. To convey the findings clearly and in sufficient detail, each theme is presented with its associated subthemes, which help demonstrate the nuances of these accounts.

The interpretation was informed by Māori principles of whanaungatanga, manaakitanga, wairuatanga, rangatiratanga, and ōritetanga, and through these lenses the researcher comprehended the integral cultural, spiritual, ethical, and structural aspects of the participants' experiences. To support each theme, data extracts from the analysis will be included, with a participant identifier accompanying each data extract to maintain participant confidentiality, while allowing for analytic transparency. The table provides a summarised list of themes and subthemes derived from the RTA, illustrating the patterns of shared meaning found across the dataset. Table 4.2 outlines the themes and their respective subthemes.

Table 4.1

Overview of Themes and Subthemes Identified Through Reflexive Thematic Analysis

Theme	Subthemes
Theme 1: Whanaungatanga – Relational Care and Whānau Involvement at End-of-Life	Whānau Central to the Decision-Making. Continuity of Relationships and Physical Presence at End-of-Life. Emotional Investment and Labour in Relationship-Based Care.
Theme 2: Wairuatanga and Manaakitanga – Cultural Responsiveness and Making Meaning of End-of-Life	Spiritual Dimensions of End-of-Life Care Experience. Culturally Responsive Care in Practice. Finding Meaning at the End-of-Life.
Theme 3: Rangatiratanga – Autonomy, Identity, and Ethical Care	Autonomy Within Relationships at End-of-Life. Maintaining Dignity and Identity at End-of-Life. Ethical Tensions in End-of-Life.
Theme 4: Ōritetanga – Structural Inequities and Access to End-of-Life Care	System Constraints impacting Delivery. Limited access to services in different parts of the service delivery system. Communication and coordination breakdowns between services.

Theme 1: Whanaungatanga – Relational Care and Whānau Involvement at End-of-Life

This theme demonstrates that EOL care is understood as collective and relational, rather than as an individualised clinical experience. HCPs described EOL care as occurring within and through relationships among patients, whānau, and HCPs. Ongoing relationships between patients and their whānau across all aspects of the patient experience continue to shape how EOL care is provided and interpreted. This is also reflected in how continuing relationships between professionals, patients and their whānau shape how patients receive, support and provide EOL care.

The understanding of whanaungatanga is not based solely on the physical presence of whānau. Rather, it represents a way of being and providing care, in which relationships are the focus of how EOL care is experienced, facilitated and interpreted. EOL care does not occur as an isolated individual experience. Rather, it occurs within a broader network of relationships through which meaning, communication, and support are negotiated.

This relational understanding reflects the broader cultural understanding of health and wellbeing in NZ, as people are situated within their whānau and communities. Therefore, EOL care cannot simply be reduced to clinical management; it is considered (and experienced) as being a shared experience through a network of relational obligations and cultural value systems. As such, HCPs must navigate complex interpersonal dynamics that affect how patients receive, interpret, and enact EOL care.

Subtheme 1: Whānau Central to the Decision-Making

Findings from participants across psychology, hospice, and primary care indicated that decision-making regarding EOL care is a collective effort between the patient and their whānau, rather than an individual activity. Participants indicated that when a person receives a diagnosis of mPCA, it affects not only the patient but also the larger whānau system, thereby influencing how decisions regarding EOL care are negotiated, understood, and communicated.

Participant 02, a health psychologist in psycho-oncology, described the mPCA diagnosis as belonging to the community and therefore as a community experience. Therefore, care decisions will reflect the community's decision-making.

> "A diagnosis does not stand alone…it has different meanings and impacts across the whānau unit…support not just the patient but the whānau around them.

According to this account, a relationship is at the centre of decisions; because both the emotional, psychological, and social impacts of mPCA are experienced within a community, the meaning of mPCA is created by the community rather than by individuals. Consequently, one cannot consider the care provided as separate from the dynamics of the community.

A collaborative, relational model characterised EOL care; HCPs worked in tandem with the patient and their whānau throughout the evaluation and care-planning processes. Palliative care Clinical Nurse Specialist Participant 03 described the model as fundamentally centred on supporting the patient(s) and their whānau to work together.

> "…nursing team that goes and meets the patients and their whānau… does a holistic assessment…"

This shows how decisions relate to the broader relational network in which medical decision-making becomes a continuous, collective decision-making process among the patient and whānau.

In the same way, Participant 05 has illustrated through their experience with hospice agency care that many times, if a patient is unable or unwilling to express their wishes, the family will decide for them.

> "I do find it happens often [with] Polynesian cultures and with Samoan men who can be very stoic…in my experience, [they] have nominated a family member, often a daughter or a son, to speak on their behalf… sometimes [it's] hard to get to know what that person really wants because they've made a decision to defer to somebody else…it can be an interesting space."

This is indicative of the underlying tensions present in this type of relationally driven care. Whānau support is integral to this type of care but can sometimes inhibit or mediate the patient's voice. Therefore, HCPs need to negotiate and interpret these complex relational environments, in which autonomy may be expressed in different ways and is not always clear or direct.

Participant 06, an experienced general practitioner with a long career in aged care, discussed how EOL care is a relational process and explained how important it is to have relational closure:

> "A real need to feel that you've connected with your family…that you've left on a good note."

His comments illustrate that EOL decision-making is more than just clinical care, as emotional, relational, and whānau values will influence how a person experiences death. Decisions made at EOL are not just about care options but also about achieving or restoring relational harmony at the end of a patient's life.

The narratives demonstrate that whānau is the basis for EOL decision-making. This includes relational, emotional, and cultural factors that shape decision-making. All participants' accounts suggest that autonomy is not solely an individualised construct but rather a means of expressing oneself through the family network, shaped by whānau, cultural requirements, and interpersonal relationships. Within this relational context, HCPs must learn to balance the tension between respecting the patient's wishes and working with the whānau as an integral part of care, thereby providing ongoing ethical and practical challenges for practitioners.

Subtheme 2: Continuity of Relationships and Physical Presence at End-of-Life

Participants consistently indicated that relational continuity is essential for appropriate EOL care. In each clinical context, participants described being familiar with a patient, rather than engaging in fragmented or episodic interactions, as a prerequisite for understanding the patient's individual needs, values, and preferences.

Participant 05 emphasised that the continuity of the relationship allows care to reflect what is important to the individual involved:

> "I think that the base on which you build everything else…knowing a person as an individual, having had a relationship and some continuity of care to know that person. To know what is spiritually and culturally meaningful to them, and to be able to explore it. It is often not a one-session conversation; it is something you build on and…need a small quantity of trust for. It's a sharing of information sometimes, but that enables you to tailor care to what is truly important to that person… different things are important to different people. Moreover, if you do not have that base to work on, it can be a bit of a challenge in my experience."

Participant 05 explained relational support relies on sustained engagement rather than isolated interactions; through continuity, HCPs can gain an in-depth, contextually rich understanding of the patient.

From the perspective of a specialist practising within their field of expertise in a palliative care setting, Participant 03 describes relational care as both active and holistic. It involves both the patient and whānau.

> "…we go and meet the patients and their whānau…[and] do a holistic assessment…to see what any of the issues are."

This account supports the assertion that relational presence necessitates conscious, continuous interaction with the patient and acknowledgement of their position within broader relational and social networks. Therefore, caregiving is not limited to managing physical distress but also encompasses emotional, social, and cultural aspects. As such, the relational foundation of care at the end of life is supported by work performed in relational presence.

Participant 01, who has worked in all three areas of oncology (public, private and governance), stated that continuity of care is broader than the clinician-patient interaction.

> "I work both in the public sector…and then in private…[and] also have governance responsibility…to support the care of patients."

This illustrates that relational continuity also encompasses structural continuity, whereby services work cohesively so that patients experience their care as integrated (i.e., not disjointed). If this alignment is missing, continuity of care is at risk of disruption, particularly in situations where geographic or organisational barriers to accessing EOL-coordinated care exist.

Multiple participants emphasise the continuity of relationships as a key component of good-quality EOL care and an essential prerequisite for facilitating appropriate communication, building trust, and creating an environment that enables collaborative decision-making with patients and their families during their end-of-life journey. Fragmented care disrupts the continuity of the relationship between patients and their family or whānau (therefore providing fewer opportunities for ongoing relational interactions).

Subtheme 3: Emotional Investment and Labour in Relationship-Based Care

When describing the realities of providing EOL care across disciplines, participants shared that considerable emotional labour is involved in working closely with patients and their whānau during a time of great uncertainty, distress, and anticipated loss. Further to this,

participants noted that this type of emotional labour was viewed as a natural aspect of providing relational care to patients and whānau, rather than as incidental to clinical care.

Participant 02 has shared a detailed account of her experience providing emotional support to both patients and their whānau:

> "A broad range of challenges…psychosocial, spiritual, distress…from a psychological point of view, hope and despair…When a family member is affected, it has a ripple effect, and a diagnosis does not stand alone…it has different meanings and impacts across the whānau unit…My role is to assess how we can best support not just the patient but the whānau around them, and to help people reconnect to a sense of meaning through end-of-life or their diagnosis."

The experiences described show how complex the emotional landscape can be in EOL care, as it is constantly changing and often contains elements that contradict one another. HCPs need to find a balance between the hope that is offered and the acceptance of death. As everyone within a whānau has an emotional reaction to the caring process, HCPs will need to manage the broad range of emotions that can conflict among the patient, the whānau, and themselves.

Participant 04, a professional in the theranostics context, shared their experience of the emotional burden both HCPs and whānau share.

> "I found one of my colleagues very stressed after becoming emotionally attached to a patient who was dying…another staff member did not even want to see the pictures. We are human, we get attached, but if you feel you are not coping, you should take support."

> "Whānau also worry about what will happen…the male is seen as the breadwinner…that worry is always there."

> "They have very high hope…this is the last ray of hope…it puts pressure on us…"

The duality of emotional labour within EOL care is expressed in this experience. HCPs support not only the emotional experience of the whānau and the emotional experience of HCPs, but they are also required to manage their emotional response internally by doing both outward-facing empathy and inwardly recovering their emotional state; therefore, showing that HCPs must be able to maintain their professionalism when dealing with emotions at EOL care.

Participant 06 articulated how emotional labour provided by HCPs assists with relational closure during the EOL process:

> "Knowing that it is gonna be OK…that the family will be alright…and that they have left on a good note."

The above demonstrates that emotional labour is about more than distress management; it is also about creating opportunities for resolution, connection, and peace. Therefore, in this instance, emotional labour is directed at assisting patients and whānau with achieving a sense of relational completeness at the end of their life.

In the analysis, these accounts articulate that emotional labour is a fundamental component of relational care. Emotional labour involves HCPs balancing empathetic communication with professional boundaries when caring for patients and whānau. Participants explained that their emotional involvement is a key part of their role at the EOL, as they provide emotional support to others while also managing their own internal responses within the same scenarios. The complexity of relational work in EOL can be understood as the need for HCPs to remain attuned to their emotions while continuing to fulfil their professional responsibilities.

Theme 2: Wairuatanga and Manaakitanga – Cultural Responsiveness and Meaning-Making in End-of-Life Care

Participants outlined how cultural traditions, spirituality, and ways of creating meaning in life have influenced their experience of dying and their care at the EOL. As such, participants described care at EOL to include more than just the aspects of care provided for physical illness and symptoms, but also the spiritual, emotional, and cultural frameworks they use to understand and experience dying.

Both wairuatanga and manaakitanga (care, respect for others, and our responsibility for one another) are seen as interconnected frameworks that work together, within which HCPs can, and do, engage with patients and whānau to provide EOL care. These two cultural practices were not described as simply additional or supporting types of care but felt to be foundational to the provision of culturally appropriate, meaningful, and safe EOL care.

Within the cultural framework of wairuatanga, participants indicated that it is important to know and understand the spiritual beliefs and existential concerns of their patients, and to promote a search for meaning at the EOL; within the framework of

manaakitanga, they indicated that a demonstration of respect, compassion, and relational responsibility must accompany the act of providing care at EOL.

While participants identified the importance of clinical management of illnesses related to EOL care, they also noted the limitations of a strict biomedical approach to EOL care. Participants believed that clinical management alone is insufficient to meet patients' needs; therefore, providing meaningful EOL care requires a holistic approach that incorporates spiritual, cultural, and relational aspects of health and wellness.

Recognising how patients and their families create meaning in their lives because of their illness, the care they will receive at EOL, and the connection they feel to others is an important component in successfully providing culturally appropriate EOL care.

This finding suggests that, to provide culturally appropriate EOL care, providers must approach it differently from simply adding discrete cultural practices or items; rather, it requires a fundamental shift in how they define, conceptualise, and provide EOL care. Participants explained that wairuatanga and manaakitanga were core values underpinning their practice of EOL care and defined how they tended to the physical, emotional, spiritual, and relational needs of patients and their whānau. The data demonstrate that holistic care is perceived as an interconnected, relational process, and that spirituality and culture are integral to supporting patients and their families as they approach the end of life.

Subtheme 1: Spiritual Dimensions of End-of-Life Care Experience

The participants noted that spirituality plays an important role in care for those nearing the EOL, yet many did not explicitly mention their spirituality. Nevertheless, the participants had identified ways in which their connection to spirituality profoundly influenced their understanding of illness and dying, as well as how they viewed their identity and how they interact with other people they have relationships with.

Participant 02 described spirituality as a component of overall wellbeing, and noted spiritual distress is often also associated with psychological and social distress:

> "From a spiritual dimension…is the disconnection that people feel in terms of purpose and meaning…helping people to reconnect to that sense of meaning."

Thus, this account suggests that Participant 02 experienced spirituality as part of a broader framework of identity and meaning, rather than as a separate area of care or

concern. Therefore, for this participant, their spiritual concerns were integral to their emotional and social experiences and influenced their understanding of their illness.

Participant 06 indicated that spiritual distress is manifested in subtle or indirect ways:

> "What I did see…distress. Moreover, I wondered if there was something spiritual going on because some people passed away so peacefully, and other people were just tossing and turning right at the last minute…we weren't able to communicate with them; we didn't know what was going on. They had medication for pain and things, but I wondered if maybe there was a spiritual distress going on…I didn't know what was the outcome out of those situations."

This explains how spiritual distress could manifest through indirect means, because not all people express their feelings of distress verbally; sometimes it is possible to see someone's changes or behaviour as indicators of spiritual distress. In this case, interpreting spiritual distress is uncertain because it depends on personal intuition rather than on a clear verbal expression of the distress.

Participant 03 shared how HCPs included spirituality in the overall care given to patients with physical and psychological care:

> "…physical, spiritual, psychosocial needs…requiring specialist palliative care input…"

The above shows that spirituality is seen as part of holistic care, not as a separate or optional component, with HCPs addressing the spiritual needs of patients who are dying, along with all other needs, as part of their overall assessment.

Across all these accounts, spirituality was an important yet often hidden part of EOL care. Participants indicated that spiritual needs were diverse and could be expressed in different ways. Participant 02 expressed a spiritual need for meaning and purpose, while Participant 06 reported feeling restlessness that manifested as disruptive behaviour. Still, Participant 03 demonstrated spirituality through a holistic approach to wellbeing. These examples illustrate the many ways spiritual needs are expressed and the importance of cultural diversity in shaping how people express them. The implicit aspects of spirituality also presented both benefits and barriers for HCPs, as they relied on subtle signs or intuition to determine whether a person might require spiritual support.

Subtheme 2: Culturally Responsive Care in Practice

Participants expressed that culturally responsive care requires more than simply understanding or affirming cultural differences; it also requires active engagement with patients' values, beliefs, and practices, which shape how we provide care and communicate with patients. Instead of relying on pre-established cultural frameworks, participants characterised responsiveness as relationally created through engaging in curious, open, and ongoing dialogue with patients and whānau.

Participant 02 highlighted how cultural values were included in the conversation with the healthcare provider in the following way:

> "Practices inherent in different cultures… [we need] to be curious and bring it into conversation…so we can learn together."

Participant 02 demonstrated an interactive process for engaging with culture by collaborating with the patient to identify the aspects of their cultural context that were most significant to them. Rather than applying pre-existing assumptions about the patient's needs, the participant indicated that they continued to modify the care delivered to accommodate the patient's needs in response to the ongoing back-and-forth around established expectations.

According to Participant 03, patients and whānau should always be the focus of care, not HCPs' perspectives.

> "I am hugely aware of the need to make the focus the person, the patient and their whānau…and to make sure that my cultural and spiritual beliefs are not at the fore of that."

HCPs who consciously evaluate themselves in relation to their own culture and practice reflexivity as HCPs must step back from their own cultural framework and allow the patient's beliefs and values to guide the care process. This approach will form the basis for meaningful collaboration between the HCPS and the patient, with the patient's culture central to future interactions.

Participant 05 identified the connection between culturally responsive care and relational continuity, including establishing trust:

> "Knowing a person…what spiritually and culturally is meaningful to them…it's not a one-session conversation…You need a small quantity of trust."

It reinforces the idea that the development of culturally responsive support is a product of relationships that foster meaningful exchange and understanding. For this participant, a major factor in establishing access to and thus a patient being willing to share about their cultural or spiritual lives included establishing trust.

The experience of Participant 05 also shows that language differences and varying levels of familiarity with the healthcare system can influence the decision-making process:

> "It's often not fully understood…particularly when there are language barriers…and that window has been missed."

This illustrates that communication difficulties can create uncertainty about whether the recipient fully understands the message, leading to important decisions being made with some ambiguity about the shared understanding of that information. For this participant, culture and language affect the ease with which both patients and whānau can access and engage with information and make decisions about their care.

Participant 01 noted there are often discrepancies between what is expected culturally when someone passes away and what is expected through institutional processes:

> "Family may want the body to always be with the whānau…if the person has to go to the morgue…distressing…if they cannot be released… trauma…"

This demonstrates how bureaucratic delays can have a detrimental effect on culture, showing that the timeframes of institutions and those of cultural practices do not align. For some whānau, the separation of the deceased from the family represents a break in important relationships and spiritual processes. It demonstrates that structural aspects of an institution's systems may unintentionally work against culturally appropriate EOL care.

Participants shared their experiences with providing culturally appropriate care across multicultural and multilingual patients. They shared how differences in communication (language skills) affected interpretations of health literacy, communication styles, and expectations for clients and families. Participants suggested that culturally appropriate care was influenced by both direct communication between HCPs and patients and the external environment surrounding those communications. All participants expressed that culturally appropriate care was a process that required time, trust, and continual development of relationships.

Subtheme 3: Finding Meaning at End of Life

According to participants, the way in which people create meaning at the EOL will differ from person to person.

Participant 05 describes how creating meaning from a situation can help patients come to terms with their emotional and spiritual needs as they approach the end of their lives.

> "People who have meaning tend to cope a little bit better…if there is a belief…it seems to bring people peace…they can almost look forward to leaving this world…"

The account presented the view that belief systems provide patients with a sense of grounding and acceptance, regardless of their content. Furthermore, Participant 05 views the process of creating meaning not just as an individual psychological quality, but also as a relational and existential process, influenced by the cultural, spiritual, and interpersonal contexts in which one lives.

Creating meaning may involve reconnecting with aspects of one's identity, and culture, relationships, and situations also influence it. In these various accounts, meaning was not viewed as a concrete endpoint or a linear process, but rather as fluid and dependent on an individual's situation, relationships, and values.

Participant 02 indicated that helping patients come to terms with their experiences was important to providing care for patients who were approaching the EOL:

> "…helping people to reconnect to that sense of meaning through end-of-life or through their diagnosis."

This statement indicates that meaning-making for patients supports their understanding of their situation and helps them maintain an identity throughout the process as they progress toward the end of their life. For Participant 02, her support for her patient included providing emotional and spiritual support as they navigated the uncertainty of the EOL process.

Participant 06 reflected that, as some patients age and approach the end of their lives, they will begin to reconnect with their cultural identity:

> "I think that people, if they come from a different culture, then obviously the original culture is important to them. Sometimes people have let go of their cultural values, but often in their final years, they do go back to those

> cultural values…appreciate where they came from… it's like they return to their culture. So, we rely on family to bring those cultural needs to the patient. And I think that as health practitioners, we're not expected to know a lot about their culture but be respectful and understanding. I think everyone just wants to be respected at the end of the day."

This participant's account shows that as one nears the end of their life, their sense of cultural identity may develop. Therefore, it may shape an individual's perception of their life situation and influence what they find meaningful at that time.

From a relational perspective, Participant 07 explained how a patient's role within their whānau influenced the comprehension of their experience at the EOL:

> "Some of the patients are the patriarch of the family…having this terminal illness is quite daunting for them. It's really hard for them to accept that this is it…especially when you are a man. It's like, 'I shouldn't have this, I should be leading my family, I should be on top of everything, I should be making sure my kids are OK before I go."

This illustrated the relationship between meaning-making and whānau; humour, for example, was a way for whānau members to come together to support those who were terminally ill by giving them a sense of connectedness. Similarly, whānau members used humour to create meaning for themselves through their connection to the terminally ill whānau member.

Across participants' accounts, several factors influenced how whānau and patients interpreted their experiences at EOL in terms of creating meaning. In participants' reports, these included culture, relationships within the patient's whānau, and the patient's personal meaning of their illness. The data suggest that creating meaning was a highly individualised process shaped by an individual's environment, relationships, and values.

Theme 3: Rangatiratanga – Autonomy, Identity, and Ethical Care

The focus of this theme is the complexity and intersectionality of care at the EOL, specifically in the navigation and negotiation of autonomy (as it relates to self-determination), identity, and ethics. The decision-making process is described as complex and multi-layered across all jurisdictions. Every participant articulated that the process is extremely ambiguous, requiring HCPs to balance multiple competing priorities. That decision-making must consider the patient's wishes, clinical reality, the relational influence of family, and ethical dilemmas.

Rangatiratanga, which represents a person's self-determination, was articulated as an integral yet often controversial aspect of care at EOL. Most participants discussed that

the practice of autonomy is not undertaken in a vacuum or independently; rather, it is relationally influenced and shaped by whānau, cultural expectations, and the extent to which the HCPS is constrained in their clinical practice. Therefore, it must be recognised that decision-making is not a single act but a continual negotiation within relational and systemic contexts.

In general, the participants understood rangatiratanga as a more complex form of autonomy that has a relational aspect, is culturally situated, yet remains subject to external influences. Supporting a patient's autonomy requires HCPs to engage with complexity and effectively navigate the increased tension among honouring the patient's wishes, being responsive to whānau, and the impact of healthcare system limitations.

These findings oppose the biomedical constructs of autonomy as self-contained individualism. Autonomy is redefined as a relational entity and as the ethical negotiation that supports it. This lends to the need for EOL practices that explicitly acknowledge the philosophically intertwined characteristics of identity, responsibility, and decision-making. Rangatiratanga thus builds upon the relational or culturally grounded characteristics introduced in the prior themes, while also identifying the ethical complexities associated with supporting patients at EOL.

Subtheme 1: Autonomy Within Relationships at End-of-Life

Throughout the findings, participants described autonomy as negotiated with others in their lives, not as something that belongs solely to individuals. Decision-making about EOL involved complex interactions among patient choice, whānau input, cultural expectations, and clinical advice, underscoring the complexity of exercising autonomy at EOL.

Participant 05 describes some of the difficulties of ensuring that the decisions reached reflected a genuine understanding by all parties involved in making those decisions:

> "It brings up the question of informed consent…how informed is consent, when there are long-term implications for people in extending life?"

This highlights how the difficulties encountered with emotional distress, communication barriers and relational dynamics can hinder patients' ability to ascertain whether they understand information provided to them. The way the patient experiences informed decision-making will depend on the complexity of the situation and the interplay among the patient, their whānau, and the HCPs, rather than following a linear or predictable path.

Regarding autonomy, Participant 05 explained that decisions made by extended family members involved in the decision-making process may influence another person's decision. Some people want to decide after hearing from a family member.

> "They will nominate a daughter or a son…and sometimes [it's] hard to get to know what that person really wants."

This information suggests that, for many people, autonomy also depended on others' decisions, and that the decision-making process is influenced by family roles, expectations, and relationships rather than solely by the individual's choice.

Participant 01 indicated that clinical ambiguity adds layers of difficulty to clinical decision-making.

> "…identifying when they're entering the end-of-life phase…has become more difficult…and making decisions around that."

As a result, making decisions for patients often involved uncertainty about their current clinical status, which made it very difficult for patients to understand their choices and to know when they would have an opportunity to make specific decisions.

Also illustrated that clinical uncertainty influenced patients as they tried to determine their future:

> "Helping them come to terms with what everything meant…what to expect."

This suggests that patients' definitions of their situations and the types of advice they sought from HCPs were impacted by uncertainty. For this participant, decision-making involved responding to changing situations, rather than occurring in discrete events.

All the accounts provided by the participants suggested that their experience of autonomy regarding EOL was influenced by the surrounding context and the relationships within which they made decisions. They indicated that cultural values, whānau involvement, and uncertainty about clinical factors influenced how patients expressed preferences and the course of decision-making. The different narratives suggest that autonomy was not experienced as a discrete, singular concept; instead, it was a negotiated process shaped by the patient's culture or by the relational circumstances surrounding each patient.

Subtheme 2: Preserving Identity and Dignity at End-of-Life

The participants highlighted preserving identity and dignity in EOL care, especially since people lose their ability to function and to be independent when their illnesses worsen, and their social roles begin to diminish. Participants also highlighted that feeling like oneself is a key component of an individual's experience of EOL care, and that relational, existential, and physical factors shape this experience.

Participant 07 gave an example of how a person may lose some of their identity because of an illness, and he mentioned that some men viewed themselves in a role as the provider and leader for their family:

> "Especially if some of these men are really young as well…around 50s to 60s. It's harder for them, especially when they've got young kids."

This example indicates that the progression of illness may cause an individual to lose their central roles. Thus, they may interpret their situations differently at the end of their lives because they no longer hold these important roles.

Participant 02 agrees, expressing that many people feel life has no significance or valuable function during their illness:

> "…the disconnection that people feel in terms of purpose and meaning…"

This indicates how disease affects how people see themselves; it brings emotional and spiritual issues to the forefront as they near death.

In the opinion of Participant 03, providing person-centred care requires caring for a person beyond simply caring for a diagnosis:

> "… people come in …. [with] issues like spinal cord compression, it's about helping them navigate treatments…but alongside that, trying to figure out what is important to this person. What other services could support that, being at home with supports…needing age-residential care…[or] inpatient hospice care to manage symptoms."

This statement implies that dignity is closely connected to acknowledging a person as more than their diagnosis, as well as to honouring the values and preferences that shape how they see themselves in relation to dying.

According to the participants, how a patient preserves their identity and dignity at the end of their life depends on their relationships with others, their cultural values, and the

understanding they have developed of their experiences. The roles a patient plays within the whānau, their connections with others, and having a reason or purpose to live have all been expressed as ways in which a person will come to understand themselves as they go through their disease process. The narratives provided by the participants suggest that dignity is supported when people feel they are being recognised in ways that reflect their relationships, cultural values, and a sense of who they are; rather than through physical comfort alone.

Subtheme 3: *Ethical Tensions in End-of-Life*

Each participant delineated several ethical dilemmas related to EOL care, specifically regarding how to determine what is hopeful while realistically assessing the patient's EOL experience in decision-making. Ethical dilemmas arise in relational, communicative, and clinical contexts and require HCPs to navigate difficult, sometimes very emotional situations.

Participant 04 explained that when there is no or little chance for further successful treatment options, managing the expectations of patients and their whānau can be a significant challenge:

> "They have a very high hope…this is the last hope…we have to be very clear… don't keep too high hope on it."

This demonstrates the difficulties HCPs face in balancing patients' hopes with the need to communicate clearly about the unlikelihood of future treatment success.

Participant 5 noted that, despite someone being able to communicate, there may still be a miscommunication; this creates uncertainty about whether the information has been accurately understood:

> "It's documented that [it was] fully understood… and then finding out months later that actually it wasn't fully understood."

This account describes some of the difficulties experienced when attempting to ensure that both parties share a common understanding of an idea, under circumstances such as emotional stress, barriers to effective communication, or simply making assumptions.

Participant 01 recognised how challenging it can be to identify someone's impending death as well as initiate planning of care before it's too late.

> "…having appropriate advance care planning…so that it can go well for them."

The above illustrates the uncertainty clinical professionals experience when attempting to identify appropriate times to begin planning for a patient, given the varying nature of each illness trajectory and how rapidly patients' needs can change.

According to these participants, ethical dilemmas in EOL care delivery arise when HCPs must make multifaceted decisions that balance honesty, compassion, and respect for a patient's autonomy amid the complexity of their relational and clinical settings. Participants commented on how clinical uncertainty, communication difficulties, and patients' and whānau expectations will affect decision-making during this time of need, and how HCPs will experience ethical dilemmas arising from the practice itself. The experience of ethical dilemmas appeared to stem from the HCPs' ability to collaborate with those affected by events surrounding the patient, given the ever-changing nature of care delivery and the unique, varying needs of all parties involved.

Theme 4: Ōritetanga – Structural Inequities and Access to End-of-Life Care

The theme reflects the concept of ōritetanga, in which systemic and structural factors affect equitable access to EOL care. The participants described how fragmented services, workforce shortages, unfair funding distributions, communication breakdowns, and geographic variations in service availability adversely affected the quality and coordination of care for men with mPCA. These barriers are multidimensional; examples include limited-service availability, inequitable access to services across geographic and socioeconomic contexts, and fragmented communication and coordination among services. It is important to note that participants indicated they experience these barriers in different ways; Māori and other historically underserved populations were identified as having greater difficulty accessing EOL care, further entrenching their inequity in healthcare access and outcomes.

These structural barriers affect both the accessibility of EOL care and the care experience. Fragmentation of services disrupts continuity, limits the potential for relational connections to form, and limits the ability to deliver culturally responsive, person-centred care to individuals. Consequently, structural and systemic factors will affect the quality and meaning of an individual's EOL experience.

Central to these findings is the argument that structural inequities should be treated as an essential component of EOL care. The previous themes explore relational, cultural, and ethical considerations in caring for individuals at EOL; this theme describes how these

dimensions are facilitated or blocked by the healthcare delivery system. Achieving ōritetanga in EOL care requires change at both the HCP and health system levels. Participants' experiences show that providing equitable care depends not only on culturally responsive and relationship-centred practice but also on a culturally safe, integrated, coordinated, and accessible health system that responds to the diversity of patient and whānau needs and enables timely access to appropriate services.

Subtheme 1: System Constraints Impacting Delivery

The participants highlighted limitations in the healthcare system that hinder access to timely, coordinated, and effective EOL care. Limitations included workforce shortages, gaps in service delivery, and limited capacity in primary and community care, all of which affect care delivery in practice.

Participant 01 highlighted how the clinical and administrative roles both had identified deficits in support for patients as they entered the end stages of their life through the transition of care between primary services and hospice practices located in rural areas:

> "Primary care access is now insufficient…particularly [in] Northland… there can be gaps in access to primary care support and Hospice support for end-of-life."

This account exemplifies how system-level limits affected continuity of care, as limited access to both primary care and hospice care creates fewer opportunities to provide ongoing, responsive support for patients transitioning from specialist care back into the community.

Participant 03 shared their experience of navigating the intersection of clinical complexity and resource constraints and how that impacted the pathways available to a patient:

> "…trying to figure out what it is that's important… [while] needing other services…inpatient Hospice…or age residential care."

This participant's experiences illustrate how HCPs are forced to navigate competing demands when resources or services are insufficient to provide an appropriate level of support to their patients.

Participants noted that delays, a lack of coordination among providers, and limited availability of services contributed to the identification and support of patients not occurring

promptly. These system-wide constraints affected access to appropriate services and shaped the timing and coordination of care.

Throughout the various reports, end-of-life care was viewed as dependent not only on clinical decisions but also on the broader environment in which care is delivered. Participants outlined how structural factors, including resource availability and service capacity, affect the options available to patients and their families. This creates an imbalance between what clinicians would consider ideal care versus what is practically possible.

Subtheme 2: Limited access to services in different parts of the service delivery system

According to some participants, barriers prevent people from developing independent living skills (EOL), including distance from support services, limited funds, and broader system-wide barriers; therefore, these factors affect how and when individuals can access support services and how effectively their care meets their unique needs.

Participant 01 demonstrated that limited resources available in the rural communities make it difficult for people to gain access to needed medical services:

> "One of the patients…had lain in the back of the Ute…for three hours… because he was living extremely rurally."

According to this, geographic separation also creates difficulties in accessing timely medical care, since travelling long distances and the limited availability of local services can disrupt continuity of care for those with chronic illness.

Financial access was cited as a major factor in whether an individual could obtain a specific type of treatment (particularly when the treatment is privately funded). Participant 04 provided an example of the financial burdens faced by patients and their families:

> "This treatment comes with a cost and is not publicly funded…it brings a burden on the family. Some of them sell their house or extra land… they always feel guilty for doing this. If something doesn't work, they say, 'I sold that part.' I remember one patient who sold his car just before coming for the treatment and paid."

Overall, this demonstrates how treatment costs can limit patients' treatment choices, with the level of financial stress influencing patients' care decisions and contributing to inequitable access.

Participant 04 emphasised the disparity in access to treatment between Māori and other cultural groups. Financial obstacles were identified as impediments to Māori patients' sustained care:

> "Ethnicity-wise, 99. 9% of the patients were European, New Zealand European. I got only two Māori patients. One died after the first treatment, and one didn't come back for the second because of financial issues…"

This description shows how the structural environment has created financial barriers to obtaining necessary medical care (which has affected Māori's ability to receive ongoing care in NZ).

According to participants, structural barriers to accessing services undermined ōritetanga by restricting timely and equitable access to EOL care due to delays, limited availability, and inconsistent delivery. Consequently, these structural barriers also affected the quality of EOL care received by both patients and whānau, as well as the choices available to them.

Subtheme 3: Communication and Coordination Breakdown between Services

The participants pointed out that the widespread fragmentation of healthcare services creates a barrier to the development of coordinated and effective EOL care. In addition, the failure of healthcare service providers or HCPs to communicate clearly with one another was cited as a contributing factor to poor communication, ultimately leading to discontinuity in EOL care and suboptimal patient outcomes.

Participant 05 discussed how assumptions regarding patients' understanding could lead to miscommunications and hinder informed decision-making about the patient's care:

> "It's documented that [it was] fully understood…and then finding out months later that actually it wasn't fully understood."

Because of this, communicating at the EOL requires more than simply conveying information; it requires building a shared understanding that can be affected by emotional distress, communication barriers, or unexamined assumptions. Additionally, Participant 05 mentioned that language will frequently be another complicating factor in building that mutual understanding:

> "Particularly when there are language barriers… [things are] not fully understood."

These examples demonstrate how communication gaps will limit a patient's ability to be involved in decision-making about their care, and how language and culture intersect with broader structural factors that shape how information is interpreted and acted upon.

Participant 01 remarked on the fragmentation of care delivery when specialist services stop, and community services begin:

> "…the interface between the specialist care and then the caring for patients in the community…can be an issue."

This sheds light on how poor coordination across services may create gaps in care for patients and their whānau at the end of life. Poor coordination may delay the transfer of information; lead to inconsistent or incorrect information being provided to the patient and their whānau; and disrupt continuity of care for the patient and whānau.

A review of the participant accounts revealed that a lack of coordination and poor communication affected the delivery of coordinated care and could contribute to unequal EOL care experiences. Additionally, the fragmented nature of service delivery impacted not only the clinical pathway of patients receiving care but also the relational and cultural elements of care that patients and whānau found important.

A theme across all narratives on successful EOL communication was the degree of service integration. When limited in their ability to identify and connect with other services, patients or whānau were required to navigate between multiple independent systems, resulting in inconsistent information, delayed access to care, and reduced opportunity for person-centred or culturally appropriate care or communication.

Contextual consideration: COVID-19 amplified existing structural barriers

While only two participants mentioned COVID-19, it's not a distinct subtheme. Instead, it is presented here as a contextual consideration because the pandemic merely amplified the structural barriers outlined above. The pandemic added pressure to already-strained systems and exposed how fragile the structures that typically define EOL care for men living with mPCA were.

During COVID-19, normal care pathways broke down, particularly in coordination, staffing, and service capacity, exposing how fragile these structures already were. Participant 06 pointed to the failure of multidisciplinary collaboration:

> “Well, that really failed through COVID. That was a dreadful, dreadful time to be palliative… I don’t want to even talk about that because it was awful.”

COVID-19 disrupted cross-disciplinary working relationships, revealing the vulnerability of care pathways. For this participant, COVID-19 did not just put the system under stress; it also showed how quickly team coordination could break down under added pressure on the system itself, leaving HCPs with little or no consistency.

Similarly, Participant 07 described the long-term consequences of COVID-19 on workforce capacity and service funding, noting that:

> “…after COVID, everything has been tightened…we don’t hire nurses anymore…it takes more than three months to get approval.”

Delays in service delivery and reduced access to community support increased stress on teams, affecting the quality and timeliness of EOL care. According to the participant, they experienced increased stress and pressure from these demands, which directly affected the quality and timeliness of EOL care provided to patients with life-limiting illnesses who required considerable in-home assistance.

These narratives suggest that COVID-19 worsened long-standing inequities in access to coordinated, culturally responsive EOL care. The pandemic heightened fragmentation, delays in referrals and discharge planning, and strain on the workforce delivering community-based palliative care. COVID-19 functioned as a structural magnifier, elevating systemic vulnerabilities that shape the EOL experiences of men living with mPCA.

Chapter 5: Discussion and Conclusion

The focus of this chapter is on research findings from a study examining how healthcare professionals (HCPs) in Aotearoa New Zealand (NZ) understand and navigate the relational, cultural, ethical, and structural aspects of providing good EOL care for men living with mPCA. The findings indicate that the relationships between HCPs and patients, the cultural beliefs and values of both groups, ethical considerations, and the structures within the healthcare system all impact EOL care delivery and experiences for HCPs, patients, and whānau.

HCPs viewed the provision of EOL care as extending beyond treatment of physical symptoms and biomedical support before and during dying. Rather, EOL care was seen as an emotionally grounded, relational, and culturally situated experience in which the input of whānau, relationship continuity, communication, spirituality, and shared decision-making were important. HCPs spoke about workforce challenges, fragmented services and resource limitations as environmental factors that could support or inhibit the delivery of culturally appropriate and whānau-centred EOL care.

Although the broader palliative care literature provides an important foundation for interpreting these findings, the present study specifically examines HCPs perspectives on EOL care for men living with mPCA. This literature is therefore drawn upon to inform understanding of care as patients approach the EOL.The findings in this chapter were identified according to the four areas of focus as follows: (1) relationality as the foundation of EOL care; (2) autonomy and shared decision-making in relational care; (3) Spirituality, Meaning-Making, and Culturally Responsive Care; and (4) Structural Conditions Shaping End-of-Life Care. In addition to the existing literature, findings are viewed through the lens of Māori health models: Te Whare Tapa Whā, the Meihana Model, and Mauri Mate. This chapter concludes with an overall synthesis of findings, implications for practice and policy, limitations, and directions for future research.

Relationality as the Foundation of End-of-Life Care

A significant finding of the study was that HCPs believe EOL care is fundamentally about relationships. Participants described EOL care as involving not only managing physical symptoms and treatment decisions but also a continual process grounded in the relationships that develop between the patient and their whānau. The relationships between HCPs and their patients and whānau help enhance the quality of communication, trust, emotional support, decision-making, and the provision of culturally responsive care.

There is growing evidence that high-quality palliative care is fundamentally relational and that establishing and sustaining meaningful HCP-whānau relationships is crucial to achieving this (Ferrell et al., 2017; Hudson et al., 2015; Quinn et al., 2020).

While the literature addressing relational approaches to care has been well documented in the palliative care literature, the study's findings suggest that whanaungatanga offers a broader understanding of relationality than is typically expressed in biomedical relationship-centred models. Relationship-centred care primarily focuses on the quality of interactions between HCPs, patients, and whānau. In contrast, whanaungatanga seeks to place individuals within a network of whānau and community, link them to their ancestry, and encourage a shared responsibility for wellbeing, in which wellbeing is experienced relationally rather than individually (Durie, 2004; Pitama et al., 2007; Slater et al., 2013). Accordingly, relationships are not merely used as an avenue to improve communication or adherence to treatment; they provide the basis for understanding how an individual experiences care, identity, autonomy and wellbeing. This distinction has significant practice implications. Therefore, EOL care is informed by whanaungatanga and requires proactive HCP engagement with whānau, consideration of collective decision-making, and the implementation of service delivery models that foster ongoing relational connections over time (Mason & Moeke-Maxwell, 2014, 2018; Slater et al., 2013). This does not necessarily mean relationally centred approaches are unique to a Māori viewpoint; however, the results of this study have shown that whanaungatanga extends existing definitions of relational care by explicitly proposing that individuals exist within broader networks of reciprocity and collective responsibility. The findings indicate that EOL care interventions need to broaden their focus to include whānau engagement and opportunities for collective discussion, maintain continuity across services, and support ongoing relationships. In that way, whanaungatanga contributes to a culture-based framework that enhances the conceptualisation and operationalisation of relational care in EOL care.

Continuity was particularly evident in participants' descriptions of relationality and their experiences of how ongoing relationships supported HCPs in establishing trust, appreciating cultural values, acknowledging evolving needs, and having sensitive conversations about prognosis and future care planning. These findings are consistent with the existing literature, which highlights that continuity of care enhances trust, promotes shared decision-making, and facilitates patient and whānau satisfaction with EOL care (Bakitas et al., 2015; Quill & Abernethy, 2013). However, there was also evidence of an important inconsistency regarding continuity. Participants viewed relational

continuity as an ideal; however, maintaining uninterrupted continuity was often difficult due to the current fragmentation of the healthcare system, including workforce shortages, service boundaries, and inconsistent access to care. Therefore, it should be viewed as a system-level goal requiring organisational and public policy support, rather than something that depends on a single HCP. Thus, maximising opportunities for continuity through coordinated communication, care planning, and the delivery of integrated services is likely to be more realistic than expecting continuous relationships with individual HCPs throughout the EOL journey (Hospice NZ, 2025; Ministry of Health, 2017a).

Relational care required a significant amount of emotional labour. Participants explained the emotional labour required to support patients and whānau during times of uncertainty and deterioration, and through grief and loss, while simultaneously managing their own emotional responses. Participants consistently reported that emotional labour was both rewarding and burdensome (Bateman et al., 2023; Dijxhoorn et al., 2021; Koh et al., 2020). However, this study extends what is currently known about emotional labour by demonstrating that it is not only related to professional responsibilities as a caregiver but also shaped by expectations regarding relational responsibility, collective care, and emotional presence (as culturally related). For many participants, emotional availability was an essential element of culturally responsive practice, rather than an optional component of care.

The findings raise significant concerns about training and the organisation's role in this area. Many of the participants expressed feeling emotionally drained, alone and without support for managing difficult conversations about prognosis and witnessing whānau distress, and the growing emotional strain related to EOL care. The evidence suggests that the relational and emotional components of providing care could be considered essential professional competencies that require ongoing development and support, rather than something that HCPs would naturally evolve as they practice. Studies indicate reflective practice, supervision, debriefing opportunities and a supportive cultural environment for staff can provide significant benefits for HCPs (Dijxhoorn et al., 2021; Ferrell et al., 2017; Koh et al., 2020). The current findings further demonstrate the need for structured professional development in communication, cultural responsiveness, grief and bereavement support, and the management of emotional conversations. Participants' experiences highlight the need for culturally responsive supervision, regular opportunities for reflective practice, peer support, and clarity regarding expectations for emotional and cultural labour. In the absence of this support, there is a potential burden on individual HCPs in maintaining relationally and culturally responsive care, which could lead to HCP

burnout and, ultimately, diminish HCPs' ability to remain emotionally present for their patients and whānau.

All these findings can contribute to the concept of relationality as not simply one component of the overall care provided at EOL, but rather as the basis on which culturally competent, ethical, and person-centred care is provided. Trust, enhanced communication, cultural understanding, and an environment for effective decision-making and emotional support are all fostered through relationships. Therefore, relationality provides the context through which cultural, ethical, and clinical aspects of care can be understood and enacted and thus is an essential dimension of high-quality EOL care.

Autonomy and Shared Decision-Making in Relational Care

A key finding of this study was that autonomy at EOL was understood in terms of relationships, cultural expectations, shared responsibility, and emotional readiness, rather than as an individualised expression of choice. Current biomedical models of care emphasise autonomy as the individual's right to make independent decisions; all participants emphasised that decision-making was part of relationships with whānau and with respect for the wider cultural and social contexts that influence them. These findings add to the existing literature on relational autonomy, which suggests that an individual's preferences and decisions are developed and expressed within networks of relationships rather than in isolation (Gómez-Vírseda et al., 2020; Schill & Caxaj, 2019). Furthermore, these findings align with Māori perspectives on rangatiratanga, which view self-determination as an integral component of broader whānau relationships, collective responsibility, and cultural identity (Durie, 2004; Pitama et al., 2007). Given that the experience of progressive illness, uncertainty and increasing reliance upon others may heighten the importance of family relationships, cultural identity and shared decision-making during the care of men with mPCA, relational autonomy may be of relevance within this setting.

Whānau-centred decision-making was identified as a primary example of relational autonomy. In accordance with research in both Māori and Pacific cultures, decision-making regarding treatment, future planning and EOL preferences was often collaborative rather than individual. Decisions regarding care and planning for future EOL options were found to be regularly reviewed together as whānau. There were also various levels of obligation, consideration of individual needs, and cultural appropriateness (Foliaki et al., 2020; Mason & Moeke-Maxwell, 2018) that were identified as influencing how decisions were made together as whānau. However, the findings also went beyond merely showing

that whānau were involved in decision-making. Participants indicated that they had engaged in lengthy conversations during which they needed to consider how to balance the differing preferences of all involved, with the need to protect the patient from experiencing excessive grief, the need to maintain cohesiveness as a whānau unit, and the need to fulfil all of the whānau members' culturally defined obligations. These combined findings illustrate how, as whānau and patients face uncertainty about the future, worsening health, and the need to make emotionally charged decisions, collective decision-making is becoming increasingly important. The involvement of whānau in decision-making does not imply reduced autonomy for the patient; rather, it provides the patient with emotional, cultural, and practical support to enable them to participate in making difficult or future decisions. The findings also align with previous literature on relational autonomy and how one's ability to make their own choices is negotiated and maintained in the process of living with an advanced chronic illness, in their relationships with others, providing protection from emotional pain, and sharing responsibility with others during the process of dying (Carey et al., 2026; Gómez-Vírseda et al., 2020; Moeke-Maxwell et al., 2014).

Additionally, the finding highlights the interconnectedness between autonomy, identity, and dignity. Participants noted that these patients with mPCA spoke extensively about how changes to their bodily function due to progressive illness and their increasing reliance on whānau impacted their identity in relation to their social and whānau lives. Previous literature indicates that when this happens to men through discovered disruptions, they experience a loss of their sense of autonomy, masculinity, dignity, and psychosocial wellbeing (Chambers et al., 2012; Ferrell et al., 2017). However, the current findings suggest that dignity does not depend solely on an individual's independence or ability to function. For many men living with mPCA, dignity was closely linked to their relationships with others, their whānau and cultural identity, and developing a sense of belonging through community connection. Therefore, autonomy needs to be understood relationally. Care decisions are made based not only on the patient's clinical condition but also on their understanding of themselves, their whānau, their community, and their cultural framework. HCPs need to consider their patients' relationships, including their identity and value systems, and the impact that whānau and other relationships have on their patients' ability to exercise autonomy when supporting them, rather than viewing the patient as a single entity making decisions for themselves.

Participants noted experiencing ethical tension while reconciling cultural and relational definitions of autonomy with biomedical definitions of informed consent,

providing information to patients, and supporting patients' decisions alone. The current healthcare system is based largely on principles of individual autonomy and procedural consent (Curtis et al., 2019; Ministry of Health, 2017a). Participants highlighted several examples in which patients indicated and expected to delegate their decision to whānau. However, patients frequently avoid discussing their prognosis and prioritise the collective wellbeing over their individual will, which conflicts with their expressed preference to delegate decision-making to whānau. These tensions reflect broader issues in the Māori palliative care literature regarding how collective decision-making, relational obligations, and whānau-centred care cannot be aligned with the individualised biomedical model of consent (Carey et al., 2026; Moeke-Maxwell et al., 2014). Findings indicate that, rather than being viewed as a manifestation of multiple ethical paradigms, the relationship between HCPs and patients is often shaped by ongoing trust, communication, and mutual understanding. Because of this ongoing interaction and ethical tension, ethical practice obligates HCPs to go beyond compliance with established procedures, to practice cultural humility, to adhere to relational obligations, and to address the individual needs of both patients and whānau (Ferrell et al., 2017; Ramsden, 2002).

Findings indicated that relational autonomy continued to develop throughout the course of illness. As function declined, care options changed, and reliance on whānau increased, the complexity of decision-making grew and became increasingly embedded within relationships (Gómez-Vírseda et al., 2020; Schill & Caxaj, 2019). Because of this, relational autonomy appeared to develop over time rather than be a static characteristic of decision-making (Durie, 2004; Pitama et al., 2007).

The findings imply that autonomy at the EOL can be considered a negotiated relational process, shaped by how relationships are formed and maintained, rather than a simple exercise of individual choice. When we use rangatiratanga to consider autonomy, we do not see it as an independent concept from others, but as shaped by patients' relationships, connections to their culture, shared decision-making, and their ability to maintain identity and dignity in the event of progressive illness. This broader understanding of autonomy also expands the dominant biomedical definitions of autonomy. These findings emphasise the importance of delivering EOL care that recognises the interconnected roles of relationships, culture, identity, and whānau support in making meaningful decisions.

Spirituality, Meaning-Making, and Culturally Responsive Care

A key finding was that spirituality, meaning-making, and culturally responsive care were clearly interconnected components of the EOL care experience. Participants highlighted the roles of these processes in helping whānau and patients make sense of their illness, maintain identity, and prepare for dying. Participants explained that patients and whānau sought to make sense of illness, suffering, and dying by using spiritual, cultural, and relational methods. Spirituality and meaning-making were found to be part of one's relationships with whānau and friends, one's sense of cultural identity, connection to whānau, and one's personal beliefs. Other studies show that spirituality is central to palliative care and an important factor in QoL, coping, and emotional wellbeing for those at the EOL (Ferrell et al., 2017; Newsroom, 2021; Paal, 2024). Furthermore, the findings indicate that spiritual care in EOL care is about more than just meeting a person's religious requirements; it is about how whānau and patients create meaning and identity and prepare for dying within their cultural and relational context.

The participants' views of spirituality were representative of a broader understanding of wairuatanga than is usually demonstrated with the biomedical model of care. Participants identified spirituality as a relational concept embedded in one's cultural identity and relationships with whānau, and as a source of meaning. Compared with the biomedical approach to understanding EOL care, spirituality is often viewed as a separate aspect of care that can be addressed independently of the physical, psychological, or social aspects. Participants reflected that spirituality is grounded in whānau relationships, cultural identity, belonging, and how everyone makes sense of their lives. In accordance with Māori concepts of health and wellbeing, participants' spirituality was defined by connection; a sense of belonging; ancestry; identity; purpose; and peace, rather than by spiritual or religious affiliation or practice (Durie, 2004; Newsroom, 2021; Pitama et al., 2007). These results imply that spiritual care does not only focus on the assessment of spiritual or religious attachments but also requires that HCPs acknowledge the relational and cultural contexts in which spiritual needs are experienced. Wairuatanga did not emerge as a standalone area of care but rather as an interrelated aspect of overall wellbeing, with implications for how patients and whānau viewed their illness; how they prepared for dying; and how they maintained continuity of identity along the EOL journey.

According to the findings, spirituality and personal meaning-making are closely linked. Participants indicated that as patients tried to make sense of their illness, they often reflected on their relationships, personal experiences, accomplishments, regrets, and values to help them understand its significance. The literature supports the idea that

meaning-making has beneficial effects on psychological adaptation, enables the retention of dignity, and helps to manage uncertainty and death (Ferrell et al., 2017; Newsroom, 2021). Based on the findings, individuals often engage in meaning-making through their relationships with whānau and cultural frameworks of identity and belonging. Meaning-making was identified as especially relevant to mPCA due to the prolonged illness trajectories, cumulative care burden, and ongoing uncertainty, which create multiple opportunities for the patient and whānau to reflect on their identity, dignity, relationships, and future priorities. Unlike traditional perspectives that view meaning-making as a purely psychological, individual process, participants demonstrated that they created meaning in their lives through collaborative communication, shared experiences, and ongoing relationships with their whānau and community members.

Occasionally, participants offered a spiritual interpretation when reflecting on distress, raising the question of whether spiritual factors had contributed to patients' experiences of fear, uncertainty, or discomfort. While these interpretations were not verified directly, they illustrate the extent to which participants regarded spiritual considerations as important alongside physical, psychological, and social factors that may also have influenced distress. These findings are also consistent with holistic models in palliative care, which view suffering as an outcome of multiple interconnected components and consider how spirituality may affect how an individual engages with their illness and dying (Ferrell et al., 2017). The findings suggest that HCPs should remain open to the possibility of spiritual components in a patient's experience and seek opportunities to discuss them appropriately.

Additionally, the findings support the importance of manaakitanga in fostering culturally responsive EOL care. Participants demonstrated Manaakitanga through establishing relationships with patients and whānau; using varied communication styles; enabling whānau to engage with or participate in the provision of care; respecting cultural practices; and being as responsive as possible to culturally and spiritually specific individual needs. Therefore, manaakitanga has not been abstractly conceptualised as a cultural value but has instead functioned as a practical method for delivering care, culturally informed clinical interactions, relationship-building, and decision-making. The results of this research support the contention in the cultural safety literature that, to provide culturally appropriate EOL care, staff must demonstrate humility; create trusting relationships; reflect on themselves; and recognise different types of illness, dying, and grieving (Curtis et al., 2019; Paal, 2024; Ramsden, 2002). These findings indicate that culturally appropriate care is not merely an added element of EOL care; rather, it provides

a framework for acknowledging and addressing the spiritual, emotional, and relational dimensions of care.

The findings also have significant implications for how we practice healthcare. Several participants described uncertainty in recognising spiritual distress, particularly through discussions about whānau, identity, relationships, or future planning. These findings suggest that spiritual care should be fully integrated into practice. While spiritual care should not be considered an optional or specialised component of care, spiritual and cultural needs should be routinely explored through conversations about identity, relationships, sources of meaning, cultural values, and whānau priorities. The major role of healthcare organisations is to ensure that staff have access to appropriate education and training, continuing professional development, opportunities for reflection, peer support, and culturally appropriate supervision. Such support may enhance providers' confidence and competence in identifying and addressing spiritual distress across diverse care contexts (Ferrell et al., 2017). These practices can help ensure that, during the provision of holistic EOL care, individuals' physical, spiritual, cultural, relational, and emotional needs are met.

The findings indicated that spirituality, meaning-making, and culturally responsive care are part of the same overall process by which patients and whānau understand their illness, maintain their identity, and prepare for dying. Applying the principles of wairuatanga and manaakitanga to establish spiritual wellbeing was found to be a relationally negotiated and culturally situated process that is interdependent with the emotional, social, and existential dimensions of wellbeing. Together, these conclusions underscore the need for a comprehensive model of holistic EOL care that considers the interplay among the spiritual, cultural, relational, and clinical dimensions.

Structural Conditions Shaping End-of-Life Care

A key finding is that the delivery of EOL care was shaped by both the clinical competence and commitment of HCPs and the conditions under which they provide that care. Consistent with the principle of ōritetanga, participants described how the fragmented nature of services, barriers to communication, workforce pressures, and inequitable access to EOL services limited their ability to provide relational, culturally responsive, and person-centred EOL care. These findings suggest that, for HCPs to be skilled and committed to providing quality EOL care, the health systems in which they provide care must facilitate continuity, coordination, and equitable access to care.

Participants identified fragmentation among healthcare services as a key barrier to the provision of EOL care. Participants reported that navigating multiple HCPs, transitioning between services and inconsistencies in communication interrupted continuity of care and added to the burden on patients, whānau and the healthcare workforce. Despite the need for formal structures, processes, and explicit role definitions in healthcare systems, the findings support the idea that fragmentation can disrupt the relational aspect of care, which the current literature identifies as essential for high-quality EOL care. Previous research indicates that a lack of service coordination results in diminished patient experience, increased caregiver burden, and limited access to timely assistance (Health and Disability System Review, 2020; Hospice New Zealand, 2025; Ministry of Health, 2017a).

The findings reveal ongoing disparities in access to EOL care. Participants noted multiple factors that affected the care options available to patients and their whānau, including variations in service provision, physical location, financial means, and access to specialist care. Disparities were particularly apparent in access to specialist palliative care services, community-based services, and new treatments. As with previous studies undertaken in NZ, these findings confirm that ongoing structural inequities continue to shape who can access suitable and timely care, resulting in differences in EOL experiences across ethnic or demographic groups (Curtis et al., 2019; Ministry of Health, 2017a; Sheridan et al., 2024).

Another major structural factor influencing how care is given is the pressure put on the workforce. Participants explained that pressure from an increasing workload, inadequate staffing, heightened service demand, and competing clinical priorities all made it difficult to deliver the care they felt was important for providing relational, culturally responsive, and patient-centred care. The findings indicate that, in addition to concerns about workforce shortages, there is a strain between the requirements for service delivery and the time needed for establishing relationships, supporting families, and having difficult discussions regarding disease progression and death. The findings show that workforce pressures affect both service capacity and the quality of care HCPs at EOL can provide.

Effective communication between HCPs, their patients and whānau is considered vital in both enhancing and reducing the negative impacts of structural factors on service delivery. Effective communication also helps coordinate services, build relationships, enable collaborative decision-making, and support a seamless continuum of care. A communication breakdown can create confusion, delays, duplication of services, and uncertainty for the patient and whānau. Overall, the results support a broader

conceptualisation of communication, viewing it not only as an interpersonal skill but also as an organisational process that supports the coordination and integration of EOL care across all healthcare systems.

The findings have significant implications for policymaking and service delivery. Improving EOL care requires going beyond individual HCPs' training to address broader structural issues that affect how patients receive services. Improving coordination between services, establishing effective communication between systems, ensuring a sustainable workforce, and reducing inequalities in access to care were among the structural issues many participants reflected as affecting their experience of providing quality EOL care. Without addressing the structural issues that affect the provision of relational, culturally appropriate, and whānau-centred care, efforts by individual HCPs to improve the quality of EOL care will likely remain limited.

Overall, these findings highlight that EOL care is shaped by the interplay between individual healthcare professionals' practices and the structural conditions of the healthcare system. Structural conditions of the healthcare system did not operate independently of the relational, cultural, spiritual and ethical dimensions of care; rather, they played an important role in determining how healthcare professionals could apply and realise those dimensions in practice. In conclusion, these findings emphasise that effective healthcare systems must actively foster continuity, equity, communication, and workforce capacity to support the provision of high-quality EOL care.

Overall Synthesis

This study explored how HCPs in NZCPs in NZ conceptualised and navigated the relational, cultural, ethical, and structural aspects of EOL care for men with mPCA. Together, these findings indicate that EOL care is best understood as a continuously developing, relationally negotiated, culturally situated, and structurally mediated process, rather than a specific biological event. Participants shared that the interconnected nature of whanaungatanga, wairuatanga, manaakitanga, rangatiratanga, and ōritetanga, within complex networks of relationships among patients, whānau, HCPs, communities, and the healthcare system, helped shape their perspectives on EOL care. This view supports the principles of the Māori health model, which sees wellbeing as relational, holistic and interrelated (Durie, 2004; Pitama et al., 2007).

A key insight from this research was that the interrelated, relational, cultural, ethical, spiritual and structural dimensions of care are not separate domains but are interdependent and continually shape one another. The relational foundations of

whanaungatanga provide the basis for trust, continuity, and participation in decision-making processes. Wairuatanga and manaakitanga show how aspects of spirituality, cultural identity, dignity, and meaning are essential to a person's experience of illness and dying. Rangatiratanga demonstrates that individual experiences of autonomy are rarely experienced in an individualistic manner. Rather, they are continually negotiated through relationships, cultural obligations, emotional readiness, and constantly changing environmental contexts. The ability for relational, cultural and ethical care to happen in practice was also influenced by structural inequities, fragmented care, workforce pressures, and institutional constraints. These findings support the growing concept of autonomy and care being based on relationships (Gómez-Vírseda et al., 2020).

The findings challenge the dominant biomedical understanding of EOL care, in which symptom management, clinical decision-making, and individual autonomy are considered the primary indicators of quality care. Clinical expertise is still vital; however, high-quality EOL care is experienced through relational presence, cultural humility, emotional attunement, ethical responsiveness and continuity of care. How health professionals relate to patients and whānau within the relational and cultural contexts that create meaning around illness, dying, and bereavement is equally as important to quality EOL care as what health professionals do clinically.

Māori concepts provided more than a cultural lens for interpreting the findings; they offered an integrated framework for understanding how care is experienced and delivered at the EOL. Whanaungatanga (relationship), wairuatanga (spirituality), manaakitanga (caring for others), and rangatiratanga (empowerment) are interconnected concepts through which Māori, whānau, and health professionals establish identity, autonomy, spirituality, belonging, and care. Together, these concepts illuminate the elements of EOL care that are typically marginalised in biomedical approaches to care, while also providing a culturally grounded understanding of ethical, compassionate, person-centred care within NZ. In doing so, the findings broaden existing understandings of Māori approaches to health, illness and care by demonstrating how they operate within the unique context of advanced cancer and EOL care (Mason & Moeke-Maxwell, 2018).

Thus, the findings demonstrate that to provide men who have a diagnosis of mPCA with high-quality, equitable EOL care, more than merely clinical skills, technical proficiency, or care availability are required. Rather, systems of health that support relational continuity, cultural safety, whānau-centred practices, spiritual care and the wellbeing of their healthcare workforce are required. In the absence of an equitable healthcare system, relationally and culturally responsive EOL care delivery remains

vulnerable to disruptions by the very institutional structures through which it is expected to occur. As such, the findings position relationality, culture, and equity not as supplementary aspects of EOL care but as the fundamental conditions that make quality care possible. Achieving equitable EOL care for men living with mPCA requires a healthcare system that promotes whānau-centred practice, cultural safety, continuity of relationships with healthcare providers, and workforce wellbeing. If a healthcare system does not offer support or equity, the relational, cultural and spiritual foundations of care are at risk of being disrupted by the systems through which care is delivered (Curtis et al., 2019).

Implications for Practice

This research is highly relevant to clinical practice in oncology, palliative care, primary care and community settings. Providing high-quality EOL care requires consideration of the relational aspects of care delivery, cultural responsiveness, spiritual support, and the wellbeing of those who provide care. Whanaungatanga, wairuatanga, manaakitanga and rangatiratanga can be used to culturally frame the ethical, relational, and spiritual aspects of care and provide a basis for developing models of practice that incorporate these principles as fundamental to EOL care.

First, this research highlights the critical role of relational continuity in providing meaningful EOL care. Without sufficient time, organisational support, and stable care pathways, HCPs face challenges in establishing and maintaining the relationships necessary to provide culturally responsive, spiritually aligned care and to engage in shared decision-making. Systems that prioritise efficiency over relational connection can compromise the quality and culturally safe delivery of EOL care (Chambers et al., 2012; Ferrell et al., 2017; Quinn et al., 2020).

Second, the findings emphasise the need for culturally responsive practice that is driven by humility, reflexivity, and relational connection. To provide culturally safe care, HCPs must move beyond their own cultural frame, listen deeply to patients and whānau, and support their whānau collective decision-making and relational autonomy. Providing cultural safety, promoting reflexive practice, and engaging in Indigenous health training will support Māori and Pacific whānau and promote equity in culturally responsive EOL care (Curtis et al., 2019; Ramsden, 2002).

Third, recognising and responding to spiritual distress at the EOL has been identified through these findings as an essential aspect of EOL care. Acknowledging that spirituality is expressed through identity, relationships, meaning, and emotion enables HCPs to identify and respond to spiritual distress appropriately. To respond appropriately

to patients' spiritual or other forms of distress, HCPs need to be relationally attuned and able to identify the distress being expressed (Ferrell et al., 2017).

In addition, the key finding indicates that organisational structures must support the emotional labour that is inherent in EOL care. Essential components for sustaining and enabling HCPs to provide compassionate, relationship-based care include reflective supervision, emotional support, and opportunities for debriefing. If these supports are not available, HCPs are more likely to become emotionally disconnected from their work, less responsive to the needs of Māori and Pacific whānau, and less involved with their patients and their whānau (Ferrell et al., 2017; Mason & Moeke-Maxwell, 2018; Ramsden, 2002).

The findings suggest a demand for practice settings that favour relational care practices over task-based models, culturally safe environments, and HCP wellbeing as features of quality EOL care. Creating equitable access to healthcare by using relational, culturally safe and spiritually informed practice approaches to care for men with mPCA and their whānau may enhance health equity, dignity, cultural safety and person-centred care in relation to EOL care provision.

Implications for Policy

These findings have important implications for cultural safety, health equity, and health system design. Structural inequities across the continuum of care continue to affect EOL care for men living with mPCA. These inequities include service fragmentation, barriers to accessing care, and workforce pressures that undermine the cultural and relational dimensions of care. Addressing these challenges requires system-level reform that strengthens culturally responsive models of care, improves service integration, supports workforce sustainability, and embeds equity and cultural safety throughout policy and service delivery (Curtis et al., 2019; Health and Disability System Review, 2020; Ministry of Health, 2017a, 2020a).

First, there should be alignment of national health policy frameworks with Māori health models such as Te Whare Tapa Whā, the Meihana Model, and Mauri Mate across palliative care guidelines, service design, and quality standards (Durie, 2004; Pitama et al., 2007). These models provide Māori-centred, culturally informed, spiritually located, and whānau-centred approaches that are consistent with Te Tiriti o Waitangi obligations of partnership, participation, and protection. Embedding these models at the policy level will help create consistent, culturally safe practices across the continuum of care, including primary care, oncology, hospice, and community services.

Second, continued investment is required for Māori and Pacific community-based service and health workforces. Māori and Pacific provider organisations are kaupapa Māori (Māori-centred research) and Pacific-led, with a workforce of navigators, kaiārahi (leaders), nurses and community health workers who deliver culturally informed care. Enhancing this workforce, supporting community partnerships, and resourcing for culturally informed service delivery will increase access, improve cultural safety, and create continuity of care (Curtis et al., 2019; Ministry of Health, 2017a). These providers are already central to providing relational support and advocacy; policy should acknowledge and fund their work as core to service delivery rather than peripheral.

Third, it is necessary to improve integration among primary care, oncology, hospice, and community services to develop relational continuity of care and reduce the burden on whānau. According to participants, care fragmentation and opportunities for relationally and culturally appropriate communication are hindered by health systems largely based on standardised biomedical models and focused on the efficient delivery of services. Therefore, system design must preserve time for relational presence and culturally informed communication, as these components are necessary for high-quality EOL care (Hospice New Zealand, 2025; Ministry of Health, 2017a).

Fourth, institutions must address issues of racism, structural violence, and ongoing colonisation (Curtis et al., 2019; Jones et al., 2019; Ramsden, 2002). Policies that limit whānau presence, restrict culturally informed practices, or privilege biomedical norms over Indigenous worldviews require review. The embedding of cultural safety, equity, and relational ethics into policy, planning, and accountability is essential to improving care for Māori, Pacific peoples, and other ethnic groups (Curtis et al., 2019; Ramsden, 2002). It is essential that strong leadership, workforce development, and system-wide equity monitoring are undertaken to achieve this.

These policy implications demonstrate that improving health systems requires relationally grounded, culturally informed, and equitable approaches to EOL care and underscore the importance of system-wide changes to address the identified structural inequities. A systems approach supports actions at the system level needed to improve individual services; these actions could include embedding cultural safety, building workforce capability, enhancing service integration, and supporting whānau-centred care models. Implementing these changes together can help build the conditions for men living with mPCA and their whānau to receive equitable, high-quality, and culturally safe EOL care.

Limitations

This qualitative research has limitations that contextualise its results and define the contributions to the overall literature. The study analysed data from HCPs rather than patients or whānau. While this provided important insights into different dimensions of EOL care, HCPs may have different perspectives on relational autonomy, cultural expectations, and the lived experiences of structural inequities than patients and whānau. Therefore, future studies should include patients' and whānau voices to help comprehensively understand EOL care of men with mPCA.

The sample size reflects the goals of the RTA, which are to prioritise depth of information about HCPs providing EOL care rather than to collect a wide variety of data across a range of HCPs (Braun & Clarke, 2022). However, the small sample size limits our ability to understand the diverse range of practice experienced by HCPs across NZ. Furthermore, although one participant mentioned a patient from rural NZ, HCPs from rural, remote, or under-resourced areas were not included in the sample. The researcher acknowledges that patients living in remote areas often must travel long distances to access healthcare, and that these distances affect their experience of EOL care in ways not captured in this research. Consequently, these findings represent a single situated account and should not be used to conclude EOL care experiences among patients living in remote areas of NZ.

Similarly, the researcher's positionality also affects the findings of this study. Reflexivity was a central part of the research process; however, as with all qualitative interpretive work, the results of this study are only one of many possible interpretations, and there are likely other interpretations that could be made of the same data or themes based upon the theoretical lenses and cultural contexts of different researchers.

Although Māori concepts and ideas informed the analytic framework, the study was not a kaupapa Māori research design. A kaupapa Māori approach could have provided a deeper understanding of the complexities of tikanga, relational processes, and whānau-focused experiences. The current study draws on Māori concepts to inform interpretation rather than a Māori-led perspective.

The research did not incorporate the perspectives of policymakers and organisational leaders, who could have added valuable insights into potential structural limitations, institutional priorities, or system-wide reform. Organisational structures, funding models, and policy development all have the potential to influence how EOL care is provided. The involvement of those in policy development, organisational leadership, and

decision-making may have provided additional insight into how these factors affect access to and the provision of EOL care.

Directions for Future Research

This research identifies several areas for future research that could enhance understanding of EOL care for men living with mPCA and inform the development of culturally appropriate and relational models of EOL care.

The first area for future research would be to include patients' and whānau voices, especially those of Māori and Pacific peoples. This study focused solely on HCPs' perspectives; however, to better understand how relational autonomy, identity, spirituality, meaning-making, and structural inequities shape dying and being cared for, it will be important to include patients' and whānau perspectives.

The second direction of research involves kaupapa Māori and Pacific-led research that focuses on culturally appropriate methods for providing EOL care, which could be another avenue for future research. Research conducted using Indigenous methodologies may provide valuable insight into factors of EOL care, a topic that is not typically addressed within conventional biomedical models of EOL care. Examples of cultural aspects of care include tikanga, wairuatanga, whānau obligations, collective decision-making, and intergenerational relationships. Such research may help advance equity and fulfil the obligations of Te Tiriti o Waitangi in oncology and palliative care.

The third area of future research should include an assessment of how culturally appropriate models of care and interventions that support both patients and whānau at EOL can be evaluated for their effectiveness, acceptability, and cultural suitability. This research will yield useful information to assist with workforce development, service delivery and policy development. In evaluating such models of care, clinical, relational, cultural, and whānau-centred outcomes should be assessed.

Finally, research should also include further evaluations of how the healthcare system can better support relationally grounded EOL care. Research involving HCPs, organisational leaders, service managers and policymakers may provide a better understanding of how integrating services, workforce, funding arrangements and institutional practice can affect EOL service delivery. Longitudinal studies may also be useful in understanding how patients, whānau and HCPs' relational, cultural, and spiritual needs change as their illness progresses, and, as such, how services can adapt to these changing needs over time.

Collectively, the outcomes may contribute to the development of more equitable, culturally safe and person-centred EOL care for men living with mPCA and their whānau.

Conclusion

The findings of this study reveal how the EOL experience of men living with mPCA in NZ is shaped by interconnected relational, cultural, ethical, and structural processes. The study used Māori concepts (whanaungatanga, wairuatanga, manaakitanga, rangatiratanga, and ōritetanga) as interpretive lenses to understand how relationships, identity, spirituality, autonomy, and the broader socio-structural environment shape EOL experiences.

The findings indicate that relational connection, shared decision-making, spiritual and cultural responsiveness, and the circumstances that enable these forms of care to be delivered in practice are fundamental components of high-quality EOL care. Participants stated that relationships are essential for building trust, creating avenues for communication, enabling autonomy, and assisting patients and whānau in navigating complex decisions throughout their illness trajectory. Spirituality, meaning-making, and culturally responsive care are likewise highlighted as ways of maintaining identity, dignity, and wellbeing while at EOL. Additionally, regarding the delivery of EOL care, participants identified broader structural conditions (for example, service fragmentation, inequitable access, workforce pressures, and communication difficulties) that affect the quality of care received.

These Māori concepts serve as a culturally based framework that provides HCPs with a way to interpret the EOL care experience, highlighting the relational, cultural, spiritual, ethical, and structural dimensions. The findings illustrated the importance of relationally grounded, culturally responsive, and integrated approaches to EOL care across oncology and palliative care settings. Further, the study demonstrated that autonomy, identity, spirituality and belonging are not only individual phenomena but are also constructed through relationships with whānau, healthcare providers, the community, and the broader health system.

In conclusion, the relational, cultural, ethical and structural factors that impact the EOL experience of men who have mPCA in NZ can be described as interconnected. Although derived from a small number of purposively selected participants, results from this study provided rich descriptions of how these factors intersect to influence experiences of EOL care. Additionally, the findings demonstrate the importance of establishing strong relational and culturally relevant communication, improving service

integration and continuity of care, and investing in organisational structures to support workforce wellbeing and the delivery of culturally safe practices.

Overall, the research demonstrates that relational, cultural, ethical, and structural processes are interconnected and collectively shape the delivery and experience of EOL care. Findings indicate that quality EOL care should be relationally grounded, culturally responsive, and structurally supported, ultimately promoting equity, dignity, and wellbeing for both men who have mPCA and their whānau.

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Appendix A – Ethical Approval 25/38

Auckland University of Technology Ethics Committee (AUTEC)

16 April 2025

Liesje Donkin
Faculty of Health and Environmental Sciences

Dear Liesje

Re Ethics Application: **25/38 The final journey of Metastatic Prostate Cancer: facilitating collaborative discussion in end-of-life care for Aotearoa, New Zealand**

Thank you for your responses to AUTEC's conditions.

Your ethics application has been **approved in stages** for three years until 16 April 2028.

This approval is for phase one only the health professionals. Subsequent phases of the project should be provided as an amendment to the study once the first phase is undertaken.

Standard Conditions of Approval

1. The research is to be undertaken in accordance with the Auckland University of Technology Code of Conduct for Research and as approved by AUTEC.
2. All public facing documents must have the AUTEC approval number and be of a high standard of spelling and grammar. Dates on the Information Sheet(s) and Consent Form(s) must be consistent.
3. Any amendments to the project must be approved by AUTEC prior to being implemented.
4. A progress report is due annually on the anniversary of the approval date.
5. A final report is due at the expiration of the approval period, or, upon completion of project.
6. Any serious or adverse events must be reported to AUTEC, this includes unforeseen issues that might affect continued ethical acceptability of the project.
7. AUTEC grants ethical approval only. You are responsible for obtaining management permission for access from any institution or organisation at which your research is being conducted and you need to meet all ethical, legal, public health, and locality obligations or requirements for the jurisdictions in which the research is being undertaken.

The application number and title need to be referenced on all correspondence related to this project.

All forms are available online http://www.aut.ac.nz/research/researchethics

For any enquiries, please contact the Secretariat at ethics@aut.ac.nz
(This is a computer-generated letter for which no signature is required)

The AUTEC Secretariat
Auckland University of Technology Ethics Committee

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Appendix B - Participant Information Sheet- Healthcare Professionals

Date that data collection will start:

20 May 2025

Project Title

The final journey of Metastatic Prostate Cancer: Facilitating collaborative discussion with Healthcare Professionals in end-of-life care for Aotearoa, New Zealand.

Kia ora,

You are invited to participate in a research study exploring end-of-life (EOL) care for men with advanced prostate cancer. This study is being conducted by Lisa Faye Maritz, a Master of Arts in Psychology student at the Auckland University of Technology (AUT). Other members of the research team include Associate Professor Liesje Donkin (Primary Applicant), Professor Jason Landon (Co-Supervisor), and Penelope (Penny) Hayward (Māori research team member).

What is the purpose of this research?

This study explores how men with metastatic prostate cancer experience end-of-life (EOL) care and healthcare professionals support them during this period. Particularly for Māori men, we aim to understand what makes EOL care meaningful, respectful, and culturally acceptable. By gathering diverse viewpoints, we seek to identify the needs of healthcare providers, patients, and whānau in EOL care. Reflexive Thematic Analysis (RTA) will be used to identify essential themes highlighting challenges, support needs, and cultural considerations in EOL care. The goal is to inform healthcare practices that are patient-centred, respectful, and culturally appropriate.

We are Healthcare professionals involved in the care of men with metastatic prostate cancer, such as doctors, nurses, and palliative care providers, to participate.

Participants will be invited to take part in an interview (either in person or online) to share their experiences, perspectives, and insights on EOL care. The interviews will help us understand key issues, support requirements, and cultural aspects of EOL care. This information will be used to improve understanding of EOL care needs and

shape future healthcare practices, ensuring care is culturally appropriate, patient-centred, and sensitive to the experiences of patients, whānau, and healthcare professionals. Participation is voluntary, and all information shared will remain confidential.

The study will involve approximately 6-8 healthcare professionals in New Zealand.

This research aims to:

1. Document the lived experiences of healthcare professionals in navigating EOL care and accepting death.
2. Identify how communication and decision-making impact culturally appropriate EOL care delivery.
3. Provide healthcare professionals and policymakers with strategies for facilitating meaningful conversations about death and dying.
4. Highlight disparities in EOL care for Māori and non-Māori men and suggest improvements in healthcare delivery.

The findings of this research may be used for academic publications and presentations. The study results will be included in a master's thesis at Auckland University of Technology (AUT), published in peer-reviewed journals, and presented at relevant conferences.

This study is funded by the Auckland University of Technology (AUT).

How was I identified, and why am I being invited to participate in this research?

You have been invited to participate in this research because you are a healthcare professional actively involved in providing care for patients diagnosed with metastatic prostate cancer, particularly in end-of-life (EOL) care planning. Your expertise and professional experiences are valuable in exploring the challenges, best practices, and culturally responsive approaches to EOL care.

Participants have been identified through:

- Healthcare facilities and community outreach.
- Online networks, professional organisations, and forums.

The recruitment process ensures that all potential participants are provided with adequate time and information to make an informed decision about their involvement. The research team is available to answer any questions and provide further details if needed.

Who is Eligible to Participate?

- Be actively involved in providing care for patients diagnosed with advanced or metastatic prostate cancer, particularly in EOL care planning.
- Be willing and able to provide informed consent and understand the study information provided.

Who is Not Eligible to Participate?

- Healthcare professionals who are not actively involved in providing care for patients diagnosed with metastatic prostate cancer, particularly in EOL care planning.

Your participation will help inform culturally appropriate and patient-centred approaches to EOL care.
contributing to improved support systems and care experiences for patients and their whānau.

How do I agree to participate in this research?

Your participation in this research is voluntary (it is your choice), and whether you choose to participate will neither advantage nor disadvantage you. You can withdraw from the study at any time by informing the Researcher. If you choose to withdraw from the study, then information collected up until your withdrawal from the study will continue to be used and included in the study to protect its quality. You can ask for information collected up until your withdrawal from the study to be deleted, unless you withdraw after the study analyses have been undertaken.

To participate in this study, you must review the Participant Information Sheet and provide informed consent. Consent forms can be signed at the time of the interview or beforehand. You can agree to participate by:

- Signing the Consent Form included at the end of the Participant Information Sheet.

- Providing oral consent during a videoconference session, which will be recorded.

Participation is entirely voluntary, and individuals can take the time they need to decide. They are encouraged to contact the research team before deciding if they have any questions.

What will my participation involve?

As a healthcare professional participating in this study, your role is to provide valuable insights into the experiences, challenges, and best practices of end-of-life (EOL) care for individuals with metastatic prostate cancer (mPCA). This study aims to explore professional perspectives on patient needs, culturally respectful care practices, and barriers to effective care.

The interview can be conducted:

- In person at AUT North Campus, Level 4, AF Building, 90 Akoranga Drive, Northcote, Auckland.
- Virtually via videoconference (Microsoft Teams or Zoom).

Each session will last approximately 60 minutes and will cover topics such as:

- Your professional experiences with end-of-life care for patients with mPCA.
- Observations of patient and whānau needs, including cultural and spiritual considerations.
- Barriers to effective end-of-life care and how they can be addressed.
- Best practices in providing culturally responsive and patient-centred care.

This is a qualitative study using semi-structured interviews to explore participants' perspectives in depth:

- Interviews will be audio-recorded to ensure accuracy in analysis.
- Transcriptions of the recordings will be created and analysed using thematic analysis.
- The study aims to identify key challenges and strategies that can improve EOL care for mPCA patients.

Ethical Considerations and Support

- Some topics may be sensitive, including discussions about illness progression and acceptance of death.
- You are free to skip any questions, take breaks, or withdraw at any time.
- Support will be available throughout your participation to ensure your comfort.

Your participation will help shape a better understanding of how healthcare professionals can support mPCA patients and their whānau in their end-of-life journey.

What are the benefits?

While there may be no direct personal benefit, your contributions will help improve culturally responsive and patient-centred EOL care practices. The findings will inform healthcare professionals and policymakers to enhance care for men with advanced prostate cancer and their whānau.

What are the costs?

The main cost to participants is their time. Each interview will take approximately 60 minutes. If an in-person session is preferred, participants may incur transportation or parking costs, which will not be reimbursed. However, as a token of appreciation, participants will receive a voucher after completing the interview.

Parking Information:

- If interviews are at AUT North Campus: There is limited, on-site paid parking, including mobility spaces, at the North Campus. Use the UbiPark app or the meter to pay.
    - Use carparks 2 and 7 for casual parking.
    - Parking rates (Monday to Friday, 6 am - 6 pm):
        - By UbiPark app: $1. 75 per hour to a maximum of $7 per day (transaction fees apply).
        - By meter: $2 per hour to a maximum of $8 per day (credit card transaction fees apply).
    - Parking is free (for AUT staff and students) at the North and South campuses outside of these hours, on weekends, and on public holidays.

- Do not park in permit areas: Permit areas are marked. Students must not park in these or any area not designated as a pay-and-display area. If you park in an unauthorised area, you may receive a breach notice from Parking Enforcement Services.

Will the results of the study be published?

The results of this research will be published in a master's thesis at the Auckland University of Technology (AUT) and available through the AUT Library. Findings may also be published in peer-reviewed academic journals and presented at conferences. Participants will not be identifiable in any publication.

What are the discomforts and risks?

This study involves minimal risk, but discussing end-of-life experiences may be emotionally challenging. Potential discomforts include:

- Emotional distress when discussing personal experiences.
- Fatigue from the length of the interview.

How will these discomforts and risks be alleviated?

AUT Student Counselling and Mental Health is able to offer three free sessions of confidential counselling support for adult participants in an AUT research project. These sessions are only available for issues that have arisen directly as a result of participation in the research and are not for other general counselling needs. To access these services, you will need to:

- drop into our centre at WB203 City Campus, email counselling@aut.ac.nz or call (09) 921 9292. or call (09) 921 9292.
- Let the receptionist know that you are a research participant and provide the title of my research, my name, and my contact details, as given in this information sheet.
- You can find out more information about AUT counsellors and counselling on https://www.aut.ac.nz/student-life/studentsupport/counselling-and-mental-health

Furthermore, if you choose not to use AUT's counselling service, several resources are available. You may have access to confidential Employee Assistance programmes (EAPs) through your workplace. Additionally, professional organisations such as the New Zealand Medical Association (NZMA), the New

Zealand Nurses Organisation (NZNO), the Australasian College of Physicians (RACP), and the Royal New Zealand College of General Practitioners (RNZCGP) offer support for the wellbeing of their members.

The Cancer Society of New Zealand offers emotional, psychological, and practical support for patients, whānau, and healthcare professionals involved in cancer care.

- Call 0800 CANCER (0800 226 237) for free support and information.
- Visit www.cancernz.org.nz for resources, local support groups, and counselling services.
- Local Support Centres: The Cancer Society has regional centres across New Zealand, offering one-on-one support, group therapy, and information sessions.

Specialised Support Services: Medical Protection Society, and your clinical supervision will provide tailored wellbeing resources and counselling for healthcare professionals experiencing stress or burnout.

What will happen to information about me?

Your information will be handled with strict confidentiality:

- Identifiable data (e. g., name, contact details) will be securely stored and accessible only to authorised research staff.
- De-identified (coded) data will be used for analysis and may be shared with ethics committees or research institutions.
- Anonymised data, where all links to personal identity are removed, cannot be withdrawn once processed.
- Data will be securely stored at AUT for at least 6 years before being permanently deleted.

This study uses Otter AI, mentioned on the AUT website as one of the software options for transcription, but it is not an AUTEC-approved transcription software for transcribing interview recordings. Participants should be aware of the following:

- Is the use of Otter AI mandatory? No; however, all interviews will be transcribed using Otter AI, followed by a review by the researcher to ensure accuracy, especially concerning the Māori words. Once transcription is completed, the audio file will be deleted.

- What identifiable information will be collected? The voice recording will be utilised for transcription purposes.
- How is information de-identified? Upon transcription, the researcher will substitute personal identifiers with pseudonyms and codes.
- Does Otter AI share data with third parties? The platform does not utilise the data for advertising or commercial objectives.

Māori data sovereignty

Māori data sovereignty is about protecting information or knowledge that is about (or comes from) Māori people. We recognise the taonga of the data collected for this study. To help protect this taonga:

- We have consulted with Mr Joseph Stafford about the collection, ownership, and use of study data.
- We allow Māori organisations to access de-identified study data for uses that may benefit Māori.

What opportunity do I have to consider this invitation?

You have up to 2 weeks to a month to decide whether to participate. The research team is available to answer any questions during this time.

Will I receive feedback on the results of this research?

Participants can request a summary of the study results. The findings will be shared in a way that maintains confidentiality.

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

Any concerns regarding the nature of this project should be notified in the first instance to the Project Supervisor, Associate Professor Liesje Donkin, at liesje.donkin@aut.ac.nz or 09 921 9999 ext. 8164. Concerns regarding the conduct of the research should be notified to the Executive Secretary of AUTEC ethics@aut.ac.nz, (+649) 921 9999 ext. 6038.

Who do I contact for further information about this research?

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

- *Researcher Contact Details:*

Lisa Faye Maritz
Email: fzt1492@autuni.ac.nz

- *Project Supervisor Contact Details:*
  - Associate Professor Liesje Donkin
    Email: liesje.donkin@aut.ac.nz
  - Professor Jason Landon
    Email: jason.landon@aut.ac.nz
  - Penelope (Penny) Hayward
    Email: penny.hayward@aut.ac.nz

Approved by the Auckland University of Technology Ethics Committee on 16 April 2025, final ethics approval was granted, AUTEC Reference number 25/38

Appendix C - Consent Form

Project title: *The final journey of Metastatic Prostate Cancer: Facilitating collaborative discussion in end-of-life care for Aotearoa, New Zealand*

Project Supervisor: *Associate Professor Liesje Donkin and Professor Jason Landon*

Researcher: *Lisa Faye Maritz*

- ○ I have read and understood the information provided about this research project in the Information Sheet dated 15 February 2025.
- ○ I have had an opportunity to ask questions and to have them answered.
- ○ I understand that notes will be taken during the interviews and that they will also be audio-taped and transcribed.
- ○ I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time without being disadvantaged in any way.
- ○ I understand that if I withdraw from the study then I will be offered the choice between having any data that is identifiable as belonging to me removed or allowing it to continue to be used. However, once the findings have been produced, removal of my data may not be possible.
- ○ I agree to take part in this research.
- ○ I wish to receive a summary of the research findings (please tick one): Yes□ No□

Participant's signature: ……

Participant's name: . . . .

……

Participant's Contact Details (if appropriate):

…… .

…… .

…… .

…… .

Date:

Approved by the Auckland University of Technology Ethics Committee on 16 April 2025 final ethics approval was granted, AUTEC Reference number 25/38

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

Appendix D - Oral Consent

Oral Consent Protocol

Project title: *The final journey of Metastatic Prostate Cancer: Facilitating collaborative discussion in end-of-life care for Aotearoa, New Zealand*

Project Supervisor: *Associate Professor Liesje Donkin and Professor Jason Landon*

Researcher: *Lisa Faye Maritz*

The participant joins the videoconference

- Do you agree to my recording your consent to participate?

If they agree, then the record function will be activated, and they will be asked the following:

- Have you read and understood the information provided about this research project in the Information Sheet dated 15 February 2025?
- Do you have any questions about the research?
- Do you understand that notes will be taken during the interviews and that the interview will also be audio-recorded and transcribed?
- Do you understand that taking part in this study is voluntary (your choice) and that you may withdraw from the study at any time without being disadvantaged in any way?
- Do you understand that if you withdraw from the study then you will be offered the choice between having any data that is identifiable as belonging to you removed or allowing it to continue to be used? However, once the findings have been produced, removal of your data may not be possible.
- Do you agree to take part in this research?
- Do you wish to receive a summary of the research findings? (please tick one): Yes☐ No☐
- Do you want me to send you a copy of the audio recording for this consent? Yes☐ No☐
- Please confirm your name and contact details

Participant's name: . . . .

……

Participant's Contact Details (if appropriate):

…… .

…… .

…… .

…… .

I will now turn off the recording of the Consent and then will start a separate recording for the interview.

Approved by the Auckland University of Technology Ethics Committee on 16 April 2025, final ethics approval was granted, AUTEC Reference number 25/35.

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

Appendix E - Advertisement



Appendix F – Interview Guide

Healthcare Professionals Interview Questions

1. Understanding of End-of-Life (EOL) Care
    - How do you define EOL care in your clinical practice?

2. Experiences with EOL Care
    - Can you describe your experience providing EOL care to men with mPCA?

3. Cultural Perspectives on EOL Care
    - How do you incorporate cultural beliefs and practices into EOL care?

4. Communication and Support
    - How do you communicate prognosis and EOL care options to patients and their whānau?

5. Coping and Accepting Death
    - How do you support patients and whānau in accepting death?

6. Barriers and Challenges
    - What are the biggest challenges in providing EOL care for men with mPCA?

7. Improvements and Recommendations
    - What improvements could enhance EOL care services and communication?

8. Closing
    - Is there anything else you want to share about your experience in EOL care?

Appendix G – Phase 2a (Initial Coding)

Examples of Phase 2a Coding in Reflexive Thematic Analysis.

Lines	Data Extract	Initial Code	Reflexive Analytic Note
P02, L38–L40	"A diagnosis does not stand alone… it has different meanings and impacts across the whānau unit… support not just the patient but the whānau around them. "	Illness experienced collectively within whānau	The participant explicitly frames cancer diagnosis as relational rather than individual, reinforcing the centrality of whānau in understanding illness experience.
P03, L52–L54	"I am hugely aware of the need to make the focus the person, the patient and their whānau… and to make sure that my cultural and spiritual beliefs are not at the fore of that. "	HCPs' reflexivity in letting patient worldviews lead care	I interpret the participant's point as highlighting the importance of clinicians consciously stepping back from their own cultural and spiritual frameworks. I see this as a purposeful form of reflexivity in which the clinician intentionally makes the patient's perspective the centrepiece of their supporting environment.
P01, L73–L78	"Family may want the body to always be with the whānau… if the person has to go to the morgue… distressing… if they cannot be released… trauma…"	System delays contribute to cultural harm.	The participant notes that some aspects of healthcare bureaucracy can conflict with cultural expectations. I would suggest that the participant reveals a disconnect between institutional time and cultural time; in some cases, bureaucracy has created delays that cause trauma due to the slow pace of institutional processes.
P04, L43–L47	"…some of them sell their stuff… house or car… they always feel guilty… if something doesn't work…"	Financial sacrifice and moral burden	The researcher sees the participant as having framed the financial sacrifices families make during the treatment journey as significant emotional burdens. Families who have sold their houses, land, and/or cars show how financial or economic decisions can become moral decisions, linked to hope and responsibility. This illustrates how funding inequities within the structure can shift the emotional and moral burden for whānau accessing privately funded end-of-life services.
P05, L61–L65	"People who have meaning tend to cope a little bit better… if there is a belief… it seems to bring people peace…	Meaning-making as a buffer for distress	I see the participant defining meaning from a psychological and spiritual perspective as an anchor for individuals facing death. In other words, she believes that all beliefs

	they can almost look forward to leaving this world…"		(regardless of what they represent) provide a reference point for individuals to help them transform fear of death into acceptance of dying. My interpretation is that she conceptualises coping not as an individual attribute but as a relational, existential experience grounded in the individual's beliefs.

Appendix H – Phase 2b Clustering Development

Phase 2b Candidate Patterns of Shared Meaning

Cluster Name	Pattern of Shared Meaning	Participants	Reflexive Analytic Note
Relational care means that many parties (patient, whānau, and HCPs) participate in the patient's care.	The dying process is a shared event for everyone in a relationship, rather than something that a person experiences in isolation.	P01–P07	Participants who are caring for a dying patient develop a relational frame of reference for their experience of dying, and this understanding includes caring not only for the individual who is dying but also for the patient's whānau and the members of the patient's HCP team.
Death-related communication relies on relationships.	There are multiple relational factors that affect how individuals communicate about death, such as emotions, culture, and relationships.	P02–P07	Communication occurs within the context of a relationship and is shaped through negotiations among its members. Communication about death must include trust, each person's emotional readiness to discuss death, and a balance of the ethical considerations of honesty and compassion.
Cultural identity plays a significant role in how individuals comprehend and experience loss.	Communication, ritualistic practices, and community support during the EOL are largely shaped by culture.	P01, P02, P03, P06, P07	Our cultural identity influences the way that we experience death when it occurs and the way we care for individuals who experience dying.
In providing relationally and culturally responsive care at EOL, culture will impact how we provide that care.	Healthcare systems create barriers to providing relational care, with time constraints and those imposed by organisational policies and procedures.	P01, P02, P03, P04, P06	The conflict between the values associated with relationally based care and the structural constraints of the healthcare system leads to an emphasis on delivering care as economically as possible.
Healthcare system inequities are structural in nature and contribute to	Systemic factors contribute to differential access to and experiences of	P01–P05	The inequities throughout the healthcare system are systemic, not the result of individual efforts or

limited access to care.	care across groups of people.		personal choices related to healthcare.
The way people respond to the process of dying is heavily influenced by their spiritual beliefs and how they create meaning from life events.	The belief system helps a person understand the significance of life and, therefore, influences how they deal with death.	P02, P03, P05, P06	The researcher believes that how you identify and negotiate how to die is how you will create a meaning for your own experience of death, as well as how your whānau and loved ones create meaning from their own experiences related to your dying experience.
The whānau influences how decisions related to dying and how patients cope with dying are made.	The degrees of whānau interaction will dictate how whānau feel emotionally towards the decisions HCPs make around treatment.	P02, P03, P05, P06	Decisions about a patient's treatment will be made by whānau through relational negotiations among themselves rather than by the patient.
The use of cultural humility and a reflexive approach will inform clinical practice.	HCPs engage in intentional reflective practice, and their care is adapted to the individual differences in cultural background.	P02, P03, P07	Most HCPs are making conscious efforts to decentre their own biases when providing culturally competent care.
Holistic support is provided through an interdisciplinary, collaborative model.	Providing healthcare as a team-based service enhances overall continuity of care.	P01, P03, P07	Healthcare services provided by HCPs may be less connected within their professional networks, but they remain interdependently linked by the relational networks in which they operate.
Caring involves emotional effort and involves how much a caregiver becomes attached to someone who is dying.	Relational care is about giving emotional support and emotional care.	P05, P06, P07	The emotional labour involved in relational care has an ethical dimension associated with the provision of care.
Hope is an essential tool for coping and reducing stress in clinical settings.	Providing care to balance a patient's hope and reality is challenging for HCPs.	P04, P05, P06	The researcher believes that the function of hope is two-fold, supporting both HCPs and patients. Additionally, hope creates tension in both the clinical and relational contexts.
The timing and readiness of patients and whānau impact	The patient or whānau emotional readiness will	P03, P05, P06	While it is ultimately the HCPS's responsibility to decide when to initiate a

the outcome of a conversation.	frequently determine whether they participate in the conversation.		conversation, a relational consideration must be considered. Emotional readiness needs to be considered.
Patients may have difficulty understanding information due to communication barriers such as language and health literacy.	Inequalities in how care is delivered will be present if there is a communication barrier.	P02, P03, P05	Differences in the patient's language and literacy are contributing to inequitable care delivery.
The perception of masculinity will be influenced by metastatic prostate cancer.	There may be a disruption to the traditional social constructs of masculinity or manhood due to illness.	P04, P05, P07	Traditionally constructed masculinity can be challenged by illness, which alters identity and dependency.
HCPs feel morally pressured when treatments do not work as intended.	HCPs feel guilty about sacrificing the patient and the treatment outcome.	P01, P04	HCPs experience moral distress due to pressure to treat patients successfully within the healthcare system, combined with patients' own contributions to their care.
Dying alters how people view themselves and relate to others.	After being diagnosed with a terminal condition, the individual no longer views themselves the same or fits into the same social role.	P04, P07	The researcher believes that both the individual's relationships and their interactions will change because of the illness.
Death can change how a person identifies culturally and how they will connect and relate to others	The quality of EOL care received will depend on the patient's physical setting during the dying process.	P02, P03	The care setting will enable or hinder openness to culture within the context of relationship-based care.
HCPs and patients face a difficult problem in deciding collaboratively about a patient's EOL care because they are both uncertain about the patient's prognosis and how to make that decision.	Uncertainty plays an important role in the making of both clinical and relational decisions.	P01, P05	Uncertainty will consistently lead to ongoing difficulties in the relationships among HCPs, patients, and whānau. Therefore, all these parties will need to negotiate on an ongoing basis throughout their relationship.