

Nursing Narratives of Assisted Dying Implementation in New Zealand

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2022

School of Nursing

A thesis submitted to Auckland University of Technology

In partial fulfilment of the requirements for Master of Health Science in Advanced Nursing
Practice

Abstract

Background: New Zealand is a country with a health system built upon both Western and Māori world views and care is delivered to, and by people from culturally diverse backgrounds. In November 2020, the End-of-Life Choice Act was passed in New Zealand following a referendum, with assisted dying subsequently legalised in November 2021. Some form of assisted dying has been legalised in several countries and jurisdictions globally, wherein nurses play a significant role at different stages of the assisted dying process, thus impacting nursing practice and policy. However, nurses were not mentioned in the End-of-Life Choice Act in New Zealand. There is limited assisted dying literature from New Zealand, categorically nursing focused to comprehend the implications of this change for nurses, and nursing practice and policy.

Aim: The aim of this research was to develop an understanding of how assisted dying legislation and subsequent implementation impacts upon practice and policy for nurses in New Zealand.

Methods: This qualitative research was conducted through narrative inquiry and grounded within a social constructivist paradigm in the field of nursing research. Participants were ten nurses working in a range of end-of-life care settings across New Zealand. Interviews were conducted after the End-of-Life Choice Act was passed, but two to three months prior to the date where it was enacted. Thematic analysis was applied to make sense of the data and generate meaningful themes.

Results: The overall finding from this research was that, the assisted dying implementation in New Zealand challenged the professional identity of nurses. The nurses' narratives deepened the understanding that nursing is a human profession, and nurses' roles include compassion, care, intuition, advanced clinical skill and intricate knowledge of their communities. Nurses were not recognised as stakeholders by local boards and policymakers, showing a lack of cognisance of the significance of this legislative and social change for nursing. Participants described being excluded during implementation processes, education and resource provision thus, lessening the meaningfulness, confidence, and understanding of what it meant to be a nurse who would support patients, families, and other health professionals through this new type of death. The nurses felt that this had the potential to compromise patient care, and safety. Consequently, resulting in assisted dying challenging the professional identity of nurses, as they were unprepared to understand and fulfil their roles in assisted dying practice and policy.

Conclusion: The results suggested there is a need for change to assisted dying policy specific to nursing practice, and increased support, education, and resource allocation to better prepare

nurses for assisted dying in practice. It is proposed that including the role of the nurse in the End-of-Life Choice Act, could place responsibility on policymakers and organisations, to better resource and support nurses with this legislative and social change. As nurses' roles and responsibilities continue to grow to meet population requirements there is a growing need to clearly define nurses' roles through the way the government shapes policy, recognising nurses as key stakeholders in any healthcare practice and policy change.

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Attestation of Authorship

I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person (except where explicitly defined in the acknowledgements), nor material which to a substantial extent has been submitted for the award of any other degree or diploma of a university or other institution of higher learning.

Signature

Date 31/07/2022

Acknowledgements

I first acknowledge Dr Rhona Winnington whose wise words from day one set me up for success in completing this thesis. She supported me through the difficult decisions of changing the direction of this research, was available, accessible, prompt in her responses, and thorough in her feedback. She kept me motivated to keep going but knew when I needed breaks.

To Shoba Nayer for her incredibly prompt and accurate transcriptions as well as for being a genuinely lovely person to work with.

To my incredibly loving fiancé Bryce. This work is ours. For the endless dinners, cups of tea, treats and ocean swims. You kept me complete while I devoted my time and energy to this thesis.

To my dear friends and family, who have always been so incredibly supportive. Special note to Kathryn always has been the best nursing mentor a girl could ask for (despite being knee-deep in her own PHD), Erin for reminding me why we sign up for these things, because these things we do make a difference, not just to us, but actual people's lives, and Cass for teaching me to interview and for looking up to me in my nursing, it helps me want to keep doing more. And of course my 'spice girls' for always spicing up my life.

To all of the mentors, managers, colleagues, and friends I have at Waitematā District Health Board, who have supported me since starting as a junior nurse, allowing me space and resources to grow myself as a nurse and continue to make a difference in future nursing practice. You have allowed me to recognise my vocation and where I fit in the world. Also for granting me the Health Workforce New Zealand scholarship that allowed me to dedicate time to this project.

And last but not least to the ten amazing and inspiring nurses that gave their time and energy not only to this project but for the work they do every day. It humbled me to speak with nurses who have such passion for their roles as nurses. Whenever I was stuck, reading back on the transcripts of their raw and true accounts reminded me why I am doing this, of why we do what we do, and inspired me to keep going.

Ethics Approval

This study was granted ethics approval 21/179 from the Auckland University of Technology Ethics Committee on 6th July 2022 (Appendix A)

Chapter 1 Introduction

1.1 Introduction

The End-of-life Choice Act 2019 (the Act) was passed in New Zealand (NZ) in November 2020 through a binding referendum, with assisted dying subsequently legalised in November 2021. This was following a 25-year history of attempts to change laws, to allow for assisted dying (NZ Parliament, 2018; The Act, 2019). Within the nursing workforce in NZ, there was significant concern about the role of nurses in assisted dying, as nurses were not mentioned in the Act except for nurse practitioners, who could act as prescribers and administrators (Ingham & Marshall, 2020; Tsai & Menkes, 2020). Many of the people eligible for assisted dying will require nursing care to manage the disease progression and related symptoms thus, it will invariably impact upon nursing practice, and pose challenges to the individual values and beliefs of nurses. While there are multiple contentious topics in relation to assisted dying, the focus of this master's thesis is to review the implications that the implementation of assisted dying will have on nursing practice and policy in NZ. 'Nurse' is used within this research pertaining to registered nurses. For this study, I recruited nurses from a number of different end-of-life care settings. End-of-life care settings is a broad term, as these settings vary significantly. This can include hospitals where nurses often work as part of wider multidisciplinary teams, or community settings where nurses may work within smaller nurse led teams, with unqualified staff or families to support in the end-of-life care of patients. I chose nurses from end-of-life care settings, as I recognised that they would likely be impacted upon by this change. However, due to the broadness of these settings, it is hoped the insight gained from this research will be applicable for nurses across multiple areas of practice. Interviews were taken after the passing of the Act but two to three months prior to the date it came into force.

1.2 Contextualising the research and Overview of the Act

In 1995, Member of Parliament Michael Laws introduced his Death with Dignity Bill, it was voted down 61 to 29 (NZ Parliament, 2018). Other attempts were made to legalise assisted dying, including an individual request in 2015 by a NZ lawyer, Lecretia Seales who was diagnosed with terminal brain cancer (NZ Parliament, 2018). The NZ High Court ruled against the request, asserting that the legal, philosophical, moral, and clinical issues raised, could only be addressed by Parliament passing legislation to amend the effect of the Crimes Act (Seales v Attorney-General, 2015). In 2017, Member of Parliament David Seymour's End-of-life Choice Bill was drawn from the Members' Ballot in Parliament. The End-of-life Choice Bill received over 35,000 submissions during its public consultation period, the most submissions for any Bill presented in NZ parliament (NZ Parliament, 2018). This was subsequently passed following a

binding referendum at the 2020 General Election, where 65.1% of those who voted, supported the Act coming into force (NZ Parliament, 2018).

As of 2021, some form of assisted dying is currently legal in a number of countries and jurisdictions globally, including the Netherlands, Belgium, Canada, Colombia, Luxembourg, Switzerland, ten USA states, and two Australian states (McDougall & Pratt, 2020). A growing number of other countries and jurisdictions are in the process of, or have recently passed legislation to allow for assisted dying such as Scotland where a Bill is being developed, and the remaining four Australian states that have all recently passed assisted dying legislation (The Scottish Parliament, 2021; Queensland University of Technology, 2022). The circumstances under which assisted dying is permissible and the regulatory guidelines governing the practice vary in different countries and jurisdictions and have been used to make way for the passing of the Act, and to develop legislation in NZ (Walker et al., 2020). Table 2 summarises key legislative points from the Act in NZ.

Table 1 *The End-of-life Choice Act (2019) summary of key points*

Eligibility for assisted dying:	Competence	Health practitioner (undefined) duty	Health practitioner (Medical) duty
18 years or over	Understand information about assisted dying	Must not initiate any discussion about assisted dying if they do, they can be reviewed and deemed guilty of professional misconduct by the Health and Disability Commissioner or held by the Human Rights Review Tribunal	Ensure the person aware: They can decide at any time before administration not to receive the medication
NZ citizen/ permanent resident	Retain that information to make the decision		Other options for end-of-life care
Terminal illness- prognosis likely less than 6 months	Use or weigh information as part of the process of making the decision		Encourage them to discuss their wish with others
Advanced irreversible physical decline			They are not obliged to discuss their wish with anyone
Unbearable suffering not relieved in a manner the person considers tolerable			Assess they are free from pressure/ coercion
Make the explicit request for assisted dying independently to a medical practitioner			Advise options in methods for administration
Deemed competent			

While there was a clear majority in support of assisted dying in the 2020 referendum in NZ, there was debate leading up to the referendum about multiple intricacies of such a significant social and legislative change, including the publics' understanding of assisted dying, the ethics of assisted dying, the slippery slope, informed consent, vulnerable populations, coercion, palliative care services, and meeting the Crowns obligations under Te Tiriti o Waitangi, and the Act itself, including the ambiguities within it (Jaye et al., 2021a, 2021b; The Act, 2019; Tsai & Menkes, 2020; Young et al., 2019). These issues were raised by nursing professional bodies, at

nursing conferences, on nursing forums, and in opinion and academic articles (College of Nurses Aotearoa (NZ) Inc, 2018; Ingham & Marshall, 2020; Meares et al., 2020; New Zealand Nurses Organisation [NZNO], 2016; Tsai & Menkes, 2020). From a nursing perspective, a key concern was the lack of clarity of nursing responsibilities within the Act, as nurses were not mentioned in the Act except for nurse practitioners who could act as prescribers and administrators, thus, leading to uncertainty surrounding nurses' specific responsibilities as health practitioners within the Act (Tsai & Menkes, 2020). Thus, the focus of this research is to review the implications that the implementation of assisted dying will have on nursing practice and policy in NZ, as nurses have a distinct role in the care of patients and families in end-of-life care in NZ (Peach, 2001), thus the nursing voice is important in this discourse.

Understanding the history of assisted dying in NZ, is important in recognising the significance of this social and legislative change for the general public, patients, their families, and those providing care to people who make requests for assisted dying. 'Patient' is used in this research as a term for the person living with advanced illness that may make a request for an assisted death, recognising the existence of unique nurse-patient relationships, and the professional responsibility of nurses when a person is a 'patient' (Molina-Mula & Gallo-Estrada, 2020). 'Family' is used pertaining to the network of people surrounding the person living with a life-limiting illness, whether relatives, friends, or other support people. 'Implementation' is used throughout this thesis referring to the time between the date the Act was passed at the referendum in 2020, and the date it was enacted or came into force in November 2021. As, interviews were taken in the period of 'implementation' and this is recognised as a distinct period of relevance, while acknowledging ongoing implementation activities continued beyond the date it came into force.

1.3 Positioning this research

The aim of this research was to grow the understanding of the ways in which assisted dying legislation and subsequent implementation impacts upon practice and policy for nurses in New Zealand. This understanding is sought to be obtained through exploring nurse's narratives of nursing patients and their families at the end-of-life, and their perceived implications of assisted dying implementation on practice. This includes the emotional, spiritual, social, psychological, and physical support that nurses' offer within their roles (Heath et al., 2021; Nikbakht-Nasrabadi et al., 2018). Nurses walk alongside patients and families to help navigate this complex, often scary, burdensome time, using their expertise and moral maturity to provide reassurances, alleviate fear and suffering, and help to manage the health care journey, and encourage autonomous decision-making and empowerment (Hendricks-Ferguson et al., 2015; Molina-Mula & Gallo-Estrada, 2020). In my experience, this role can be incredibly rewarding and it can require emotional labour. I contemplated the meaning of being a nurse in end-of-life

care, how nurses consider their duty to the patient and their family, and where assisted dying fits into this area of practice, and subsequently the impact of nurses' involvement in assisted dying on individual nurses, and the nursing profession. By finding meaning in the experiences of end-of-life care nurses, it is anticipated that this study will demonstrate the need for future research that will continue to add knowledge and depth to this topic. This is not only in nursing, but in the wider multi-disciplinary teams providing care at the end-of-life and supporting people and their families when assisted dying is requested to hasten death. As this study is in response to new legislation and is being undertaken during the process of policy development, it is hoped this research may add to the limited body of nursing knowledge on assisted dying in NZ, to better inform practice and policy for nurses.

This research is situated within the field of nursing research, and is underpinned by key concepts within social constructivism and nursing professional identity. Nursing research is a means for nurses to explore and discover new knowledge about issues of importance to nursing, to refine and expand the body of nursing knowledge, and advance nursing practice (Borbasi et al., 2010; Parahoo, 2014). Research is playing an increasingly essential role in nursing practice, as the roles of nurses are growing and adapting, and as nurses are practicing more autonomously (Parahoo, 2014; Van Der Cingel & Brouwer, 2021). Nursing research has contributed to growth in nursing professional identity and has adapted to years of change, growing population needs and developing autonomy of nurses as nurses bring a unique contribution to healthcare internationally and in NZ (Peach, 2001; Van Der Cingel & Brouwer, 2021). Social constructivist theory will build understanding of the truths of the experiences for nurses and their practice within the current socio-historical context.

This research is grounded in a social constructivist paradigm. Within social constructivism, it is accepted that individuals construct meaning based on the events and experiences in their lived worlds, underpinned by the philosophy that meaning and knowledge is constructed rather than discovered (Gergen, 2015). The social constructivist paradigm is heavily influenced by Vygotsky, who believed that community plays a central role in the process of making meaning (Vygotsky, 1981). For Vygotsky, the site of learning is within relationships, in activities with others, as one metaphorically steps outside the self and takes on some aspect of the other (Gergen, 2015). Vygotsky's theories sparked the development of the cultural psychology, or folk psychology (Gergen, 2015). Bruner (1990) proposed, that the everyday accounts of why people act as they do, our lives and experiences, are shaped through our learnt understanding, and are only understood to ourselves and others through cultural systems of interpretation. From the cultural standpoint, the focus of the educational process moves from the mind of the individual learner, to relationships between teacher and learner, and amongst learners themselves (Gergen, 2015). Participants are enabled to describe their own experiences, and researchers are committed to listen and attempt to understand the experiences to answer the

research question and need to be aware of their own biases and influence on the outcomes (Kim, 2014). As the researcher, I am the learner and the participants are the holders of knowledge. Consequently, research methods must be underpinned by an epistemological stance of intersubjectivity. There is a notion of mutual causality and openness between researcher and participant known to influence the richness of the data as the outcome of the research is co-constructed (Kim, 2014). The research is a product of the values of myself as the researcher and cannot be independent of them (Van der Wath & Du Toit, 2015).

Social constructivism is a philosophical paradigm, that provides a framework for qualitative research approaches, where the participant is seen as the holder and sharer of knowledge (Gergen, 2015). Nurses were situated as the experts of their own lived experiences, accepting that their truths are the reality of their experiences. Assisted dying is a complex social issue, thus, being guided by a social constructivist paradigm embodies the importance, and sensitivity of this issue, in holding the meaning of the stories, and placing the nurses as the holders of the knowledge, and the experts of this experience. Researchers in the social constructivist paradigm accept that research often elicits more questions than answers (Gergen, 2015), the goal is to find a consensus of meaning from the realities of participants. However, I as the researcher accept new explanations are possible, with the benefit of experience and further information (Van der Wath & Du Toit, 2015). Positioning research that impacts upon nursing practice, within the specific nursing research field, from the lived stories of nurses, facilitates the development of nursing as well the professional identity of nurses (Yu & Song, 2021).

Professional identity is the long-understood sense of oneself influenced by the characteristics, norms, ethics, and values of nursing practice, within specialised fields, and within current society (Öhlén & Segesten, 1998; Van Der Cingel & Brouwer, 2021). A nurse having a robust professional identity, improves self-esteem, self-perception, professionalism, and professional self-image (Kristoffersen, 2021; Öhlén & Segesten, 1998). It is central to higher staff retention and higher job satisfaction (Borbasi et al., 2010; Kristoffersen, 2021). There are dominant public depictions of the nurse as a compassionate, kind, doer, but these are outdated yet can still impact upon nurses roles through poor public understanding and subsequently impact upon a nurses own professional identity (Hallam, 2012; Ten Hoeve et al., 2014). More recent definitions of nursing, see the role as collaborative and innovative. Nurses' roles include physical nursing care, nurse leadership, health maintenance, promotion, and research (Van Der Cingel & Brouwer, 2021). Assisted dying is a significant social issue as well as a legislative change, and it is well understood that the way nurses are perceived, impacts upon their perceptions of themselves, and their understanding of their roles (Hallam, 2012; Ten Hoeve et al., 2014). Thus, drawing on philosophies that define the ways nurses perceive themselves, helps to contextualise why assisted dying can impact upon nursing and the growing role of nurses, and is a means of future-proofing the profession and the understanding of being a nurse.

It has been acknowledged, that despite growing roles and responsibilities, some nurses conform to these simplified images of the nurse, reducing their role satisfaction, increasing burn-out and compassion fatigue (Drury et al, 2014; Ten Hoeve et al., 2014; Van Der Cingel & Brouwer, 2021). However, contesting these minimalist portrayals of the nurse can help both nurses, and the public recognise that nursing is, and can be a fulfilling job for men and women alike, in which they can do good and be of importance to others (Van Der Cingel & Brouwer, 2021; Edwards & Goussios, 2021). Van Der Cingel and Brouwer (2021) suggested role modelling, discussing workplace culture, self-reflection, debating, and addressing the basic moral values of nursing, are key strategies for enabling professional identity and keep up with societal changes impacting upon the ever-changing world for nurses. Thus, active inquiry through research, is central to growing nursing professional identity and the key issues relevant to nursing, for subsequent development of practice change and quality improvement in healthcare settings, and through this, detrimental stereotypes will have less chance to persist (Yu & Song, 2021). Assisted dying is a significant change to nursing practice. Thus, this research is central to ongoing nursing development and strengthening nursing professional identity through growing the representation of nurse's roles. As the researcher through both examining past literature, and engaging with participants, I grew in my understanding of how assisted dying would impact upon myself, my practice, and the possible policy challenges, deepening my own professional identity. As a nurse, and nurse researcher, I was discovering meaning and understanding through active involvement, situated as part of the research and part of co-constructing meanings.

1.4 A personal perspective

I am currently in my eighth year of nursing practice and have worked in a range of settings, including medical-surgical wards, emergency care, outpatient clinics, and a specialist oncology ward in Saudi Arabia. I have recently specialised in palliative care working in a community hospice and subsequently as a clinical nurse specialist in palliative care at a tertiary hospital. At the start of this research journey, I was working in a community Hospice setting and had enduring relationships with patients and families. Through working with patients with advanced illness, I saw the impact, the discussion of assisted dying had on how they reflected on the process of dying and what it meant to die. As a nurse that is of Western and Māori ancestry, I am passionate about bi-cultural approaches to research, and pursue to ensure holistic, spiritual practices around dying are maintained, especially with a change to the dying process as significant as assisted dying, acknowledging, the well-known, underrepresentation of Māori narratives within palliative (Gott et al., 2017b). As a health practitioner working in a palliative care setting, a central concern is supporting nurses to protect and support patients and families and uplifting them to have governance over the care they receive (Dobrina et al., 2014). As a

nurse, I also care greatly for the nursing profession and thus was driven to question the practice and policy implications of this change for nurses and nursing in NZ.

Throughout my career, I have had extensive experience nursing people approaching end-of-life, whether the final months, days, or hours of life. My roles have provided insight into the complex road that many patients and families are on at this time of life. It has provided me with insight into life, death, comfort, suffering, grief, anguish, shock, and acceptance. It has elicited passion in reducing suffering through providing holistic care, clear communication, and patient and family advocacy. I have recognised that nurses have one of the greatest responsibilities in end-of-life care, not only in the support of the patient to have a dignified death, but supporting other health professionals and families in how that death is remembered. The words of Dame Cicely Saunders still remain relevant:

How people die remains in the memory of those who live on (Saunders, 1989, p624-631).

After starting as a registered nurse in 2015, I completed several post-graduate papers through the Auckland University of Technology (AUT). The knowledge gained from these papers led to me engaging regularly in reflective practice throughout my nursing. I apply critical analysis to the work we do as nurses, the interactions we have in our roles with patients, families, colleagues and in our own world and society. I have a strong interest in the nurse's contribution to the health workforce, and currently provide palliative care nursing education. I have worked with nurses whom I respect and admire greatly, and have learnt significantly from their skill, compassion, and knowledge. I also gain great satisfaction being an educator myself and sharing knowledge to develop the future generation of nurses.

As the researcher, I am neither strongly for, nor against the practice of assisted dying and situate this thesis in the space of nursing research. As a nurse working in an end-of-life care setting, I recognised significant tensions with the impending assisted dying legislation enactment, with health professionals' views being polarising either for or against assisted dying. There was increased apprehension from nurses, a lack of open discourse in workplaces due to the taboo nature of the subject, and a lack of education aimed at generalist and specialist nurses providing end-of-life care. Within my role I have a professional obligation to contribute to nursing research and act on issues identified that can impact upon patient care, practicing under the code of ethics (NZNO, 2019), code of conduct (Nursing Council of New Zealand [NCNZ], 2012) and related competencies and local policies. At the start of this research journey, I did not understand my role as an end-of-life care nurse in assisted dying, or my legal and ethical practice requirements in relation to the Act. I recognised that even with policy in place there will likely be deeper practice and policy implications for nurses working with patients who chose this mode of death, and in supporting the family of those patients. Assisted dying will

impact upon the practice of nurses, and robust policy is required to support and protect nurses as well as improve outcomes for patients and family members. When reviewing literature, it was clear there was a significant gap in knowledge on practice and policy implications of assisted dying implementation for nurses, and literature was especially scarce from NZ health perspectives. From this study, I hope to fill this gap in literature, and provide clarity on the practice and policy implications of assisted dying implementation for nurses in NZ, from the voice of nurses.

1.5 Thesis Structure

Within this chapter, an overview of the context of assisted dying implementation as a legislative and social change in NZ has been provided. It has situated this study within the field of nursing research, from a social constructivist paradigm, with recognition of nursing professional identity theory, to understand assisted dying as an issue relevant to nursing practice and policy within the NZ health context. There was also discussion of my own relationship with assisted dying, grounded by my Western and Māori world views and my experiences as an end-of-life care nurse that ultimately inspired this research.

Chapter two is the literature review chapter, providing a comprehensive exploration of current knowledge pertaining to assisted dying and nursing practice giving rationale for the need for this research. This includes defining the history of this change as a new type of death reflecting on ideas of a good death. Current practices at end-of-life are examined in relation to the nurse's role. The extensive literature in this section reflects how significant of a change assisted dying is both internationally and in NZ, and delivers clear rationale of the need for this research in NZ though the gaps in literature specific to the NZ health and nursing context.

Chapter three is the methodology chapter, providing methodological frameworks and underpinnings of this study. This includes the development of the research question, aims and objectives, the rationale for a qualitative design and narrative inquiry. It comprises how research was collected in an ethical manner, processes and interactions with participants and the means for data analysis through thematic analysis.

Chapter four is the findings chapter, wherein the overarching theme is introduced: *Assisted dying challenges the professional identity of nurses*. Findings are presented within the three subthemes. Own world: *Being human makes a nurse*; Patient and family world: *We are here for them* and; Professional world: *I feel very unheard*.

Chapter five is a brief reflection and a reflective poem, this compiles the truths of the attitudes, feelings, and ideas of participants while holding onto the depth of narratives and meaning, as a segue to the discussion of findings in the next chapter.

Chapter six is the discussion chapter, drawing together the findings, and discussing these in the context of the current literature base. Social constructivism is drawn on to build meaning of narratives, and to contextualise the impact of assisted dying as a change to practice and policy for nurses and the impact of the change to answer the research question.

Chapter seven is the conclusion including the key findings, strengths and limitations of this study, the implications for nurses, recommendations, and the indication for future research. This is summarised with a conclusion and final thoughts to complete this research.

Chapter 2 Literature review

The identification, analysis, and discussion of literature in this chapter will synthesise what is already known about the practice and policy implications of assisted dying services for nurses in NZ, thus, identifying gaps in the current body of knowledge to validate the need for this research. Definition of search methods, key terms, and concepts relating to this research will be explained. The review of literature will be divided into two key sections. The first will be a review of socially constructed notions about assisted dying as the good death, with a subsequent review of current end-of-life practices and the role of the nurse. Section two is focused more on assisted dying as a practice and policy change, with specific identification of nursing roles in end-of-life care settings in NZ drawing on the impact of assisted dying implementation in these settings internationally and how this relates to assisted dying from both an international and a NZ health and cultural context. This will contextualise assisted dying implementation in the current socio-historical context.

2.1 Search methodology

A comprehensive database search was undertaken of CINAHL, EBSCO, research gate and AUT Google scholar. Only literature published in English was used. A population, intervention, control, and outcomes (PICO) format was used to examine literature to identify a searchable evidence based research question and reveal appropriate evidence (Melnik & Fineout-Overholt, 2005).

Table 2 *PICO search format*

Population	Intervention	Comparison	Outcome
Nursing	End-of-life Choice	Palliative care	Policy
Nurse	Act	Hospice	Practice
New Zealand	Assisted dying	End-of-life care	Professional identity
Māori	Euthanasia	Death	Legislation
Pacific	Physician assisted	Dying	Quality improvement
Indigenous	dying		
	Assisted suicide		

Other relevant articles were subsequently identified when referenced within articles. Relevance of articles was assessed by title and abstract. The methodologies of the studies were also critiqued to determine validity (Borbasi et al., 2010). Literature was prioritised from the last ten years however, older work was reviewed where limited data existed or for seminal pieces of work (Borbasi et al., 2010). This literature review was not intended to be an exhaustive collation of all research on assisted dying and implications on nursing practice and policy in

NZ, but aims to address the common themes identified, with the current published body of knowledge. As this is an emerging topic in NZ and there is a small body of unpublished work, thus academic databases for NZ universities were also searched for relevant unpublished research. Due to this being new to practice in NZ, the availability of data was constantly changing, requiring revision of available academic literature, and grey literature. A brief review of commentaries, editorials, ethical and legal arguments, and position statements were included to show an overview of views and public and nursing opinion, contextualising assisted dying where a lack of literature existed (Borbasi et al., 2010). Overall these methods were applied to focus on work that gives a current understanding of assisted dying, and the practice and policy implications for NZ nurses, to understand what is missing from this data and identify the significance of this research.

2.2 Section one: Defining assisted dying, the good death and end-of-life practices

Understanding what is, and what is not assisted dying, current end-of-life practices, and the role of nurses in the care of patients with life-limiting illness is useful to contextualise why this research is needed. Prior to the passing of the Act, there were already practices common in end-of-life care such as withdrawing active treatment, subcutaneous medications, ceasing food and fluids, and palliative sedation therapy that are often poorly understood by the general public, and some health professionals (Collins et al., 2017). One critique of the polls, surveys, interviews, and social media data showing large percentages in support of assisted dying, was that respondents may not have a deep knowledge of assisted dying and the medical treatments or choices to withdraw from treatment already available (Walker et al., 2020). Assisted dying is first discussed to define what is assisted dying and contextualise this within the sociology of a ‘good death,’ subsequently, these common end-of-life practices including palliative care, future care planning, transitions to palliative treatments are explored. This is to ensure clarity over what is and is not assisted dying as well as to provide understanding of the roles of nurses in end-of-life care settings and why this change to practice and policy is impactful.

2.2.1 Defining assisted dying

Terminology is not consistent in the literature relating to assisted dying, but this is the phrase adopted by the NZ legislation. Terms used interchangeably with assisted dying include death with dignity, assisted suicide, medical assistance in dying, and voluntary assisted dying (Friesen, 2020). Often this is dependent on the country and the terminology used in legislation, such as voluntary assisted dying (Australia) and medical assistance in dying (Canada). The terminology used can depend on the personal stance of the researcher being either for or against assisted dying practices, with the use of terms such as assisted suicide and medicalised killing being associated with a negative standpoint or attempting to disassociate assisted dying from

suicide (Friesen, 2020). In some literature physician-assisted death is likened to suicide (Friesen, 2020) and this was raised in the discourse in NZ prior to the legalising of assisted dying (Wardle, 2016; Young et al., 2019). For patients considering assisted dying in NZ prior to it being legalised, it was found that they opposed likening assisted dying to suicide (Young, 2020). What patients wanted was control, the desire to be pain-free, surrounded by family at the end-of-life, and they stated it was distinct from suicide as they all were experiencing significant physical suffering, and due to their terminal diagnosis had a risk of an undignified death related to disease, and had a prognosis of less than 12 months. They stated that this is different to the suffering of mental illness that precedes suicide where death due to disease is not imminent (Young, 2020). Some countries have shifted away from assisted suicide as terminology due to the connotations with negative standpoints or due to the perceptions of those seeking assisted dying, seeing this as distinct from suicide (Young, 2020). There are practical and philosophical differences between euthanasia and physician-assisted dying that are often misunderstood or incongruent, so it is important to first define these (Macleod et al., 2012). Euthanasia refers to, when the medication given to hasten death is administered by the attending health professional, whereas physician-assisted death refers to when the person is provided the medication to self-administer (Stokes, 2017). Assisted dying is a general term for both of these means of administration and refers to the intentional act of medically hastening death to relieve suffering triggered by the person or the attending medical officer or nurse practitioner (Radbruch et al., 2015; The Act, 2019). In some literature, euthanasia is discussed separately to physician assisted death. Occasionally these will be differentiated in this thesis if distinguished in the literature. Assisted dying will be used predominantly throughout this thesis as a general term for consistency, neutrality, and as this is the term used in the Act.

In the Act in NZ the medication to hasten death was not defined and this information would only be given to those that were either preparing or administering the lethal medication. The methods of administration for the lethal medication described in the Act include oral ingestion, taken by the person, intravenous delivery, triggered by the person, ingestion through a tube, triggered by the attending medical practitioner or an attending nurse practitioner, or intravenous injection, administered by the attending medical practitioner or an attending nurse practitioner (The Act, 2019). In media during legislative debate there were some concerns regarding what preparations would be given (Martin, 2020). For lethal injection and assisted death in the United States a three-drug combination was previously used until 2007, of sodium thiopental as an anaesthetic to induce unconsciousness, pancuronium bromide as a paralytic agent that disables a patient's ability to control the lungs through paralysis of voluntary muscles and potassium chloride to induce cardiac arrest and cause death (Druda et al., 2019; Human Rights Watch, 2006). This combination was challenged as potassium chloride is known to be painful when injected intravenously, and pancuronium bromide has the potential to instil a sense of suffocation with concern that the person may have been aware, but would have no way to

communicate that they were suffering a sense of suffocation or pain (Human Rights Watch, 2006; Riley, 2017). Secobarbital, pentobarbital and phenobarbital are now reportedly given for euthanasia and reported to cause death within 15–30 minutes (Druda et al., 2019; Riley, 2017). It is reported that many drug companies are averse to their drugs being used for lethal injection or assisted dying, thus, use is predominantly off-label (Riley, 2017). There have been reports barbiturates having complications of delayed death including delays post administration to death anywhere from hours to days inciting significant distress for family, and possibly suffering or distress for the patient (Harty et al., 2019; Simpson, 2017). The lack of guidance around drugs used, and potential adverse events puts nurses at risk as possible support people present during the administration of the lethal medication.

In a review of family perspectives of assisted dying it was found that the method of administration of the lethal medication affected the experience for family members (Bravo, 2021). There are major complications with oral medication in that it can be unpalatable, cause nausea, gagging, and prolonged time to death, or failure to cause death, causing greater distress for the patient and family (Harty et al., 2019; Riley, 2017; Simpson, 2017). If these are distressing for patients, they will likely be distressing for the nurses providing care if adverse events occurred that they were unprepared for, and may also lead to moral distress (Van Zandt, 2016). Nurses may be involved in the administration of pre-emptive medications such as anti-nausea medications, and other symptoms relieving medications prior to the administration of the lethal drugs to induce death. They may also have roles in post-bereavement follow-up, post-bereavement distress for families could create increased complexities for nurses to address (Bravo, 2021; Fridh, 2014; Gagnon & Duggleby, 2014; Van Bruchem-Van de Scheur et al., 2007). In the training provided thus far, information about such side effects or complications with the different routes of administration have not been presented in the information for health professionals (MOH, 2021b) even though nurses are commonly involved in much of the management and education around medications usually used at end-of-life (Andersson et al., 2016; Kim et al., 2020). In the US, there were reports that people received little information or education about possible complications such as the nausea, delayed time to death or failure to cause death (Harty et al., 2019; Simpson, 2017). Assisted dying is sold as the ‘good death,’ with little focus on possible complications for those seeking assisted dying or those supporting people through this process (Harty et al., 2019; Van Zandt, 2016). To better understand this societal goal of a good death, a critical exploration into death and dying and the good death contextualises this research, and the impact of assisted dying on nursing practice and policy.

2.2.2 A ‘good death’

Assisted dying is often painted as a good death. The term euthanasia is derived from the Greek word ‘Eu’ meaning ‘easy’ or ‘good’ and ‘Thanatos’ meaning death (Draper & Slowther, 2008). As a means of understanding what constitutes a good death, however, we need to consider how

societal perceptions and practices surrounding death and dying beyond nursing, healthcare, palliative care, and end-of-life practices are seen as social constructs influenced by societal and cultural changes (Seale, 1998). Societal changes, as well as technological advances have influenced the ability to treat illness, prolong life, and have changed how death is approached and what is considered to be a good death in the twenty-first century (Cohen, 2020; Wilson et al., 2020a). New Zealand is built upon bicultural models of health wherein Western and Māori practices have shaped approaches to death (Moeke-Maxwell et al., 2019a) thus, these will be examined to understand the good death in a NZ health and nursing context.

Berger (1969) argued that social order exists in relation to the imminent threat of death, death is a part of the human experience and all who live will ultimately die. Death, dying, the subsequent rituals, and mourning have been depicted in early texts and art, across different societies, over several thousand years (Garland, 2001; Higham et al., 2007; Wilkinson & Weeks, 2016) providing evidence of death as a dominant part of society holding symbolic meaning (Mark, 2017). Historic practices of assisted death have been written about since Roman times, with beliefs that ancient Greek and Roman physicians likely performed mercy killings to those nearing death (Van Hooff, 2004) and it is believed that in some Māori tribes, there were traditional means of hastening death to alleviate suffering (Malpas et al., 2017). As such, it would appear that the pursuit of a good death, one with less perceived suffering is not a new ideal. Puri (2021) described that sociologists began reflecting on matters of death, bereavement, and what constitutes a good death from the 1830s, with this consolidated into a subfield of sociology in the twentieth century following on from work such as that of Berger (1969) and Ariès (1974).

Puri (2021) recounted that Martineau and Durkheim are the initial sociologists to have dealt with the subject of death as a social construct through the study of suicide in their books, *How to observe morals and manners* (Martineau, 1838) and *Suicide* (Durkheim, 1897) with Martineau gesturing to disparities in position and power in death and dying and what is a good death (Puri, 2021). Martineau (1838) described suicide as the voluntary surrender of life for any cause, and acknowledges that every society has suicides of some description. She contemplates how these are perceived by society based upon religious sentiment, morality, or those who have dim anticipations for their futures. This highlights the way in which the hastened death can be condemned, commemorated or romanticised based upon social constructs. Martineau (1838) reported, that those who sacrifice themselves such as in war, are hailed as hero's, these contrast stories such as the taking of life on learning that one has terminal disease, or slaves who would chose suicide over a life of being reduced a possession, thus worthless to traders (Martineau, 1838). She reflects on the condemning of suicide describing its removal from the public eye, writing

If a young lady and her lover shot one another with pistols tied with pink ribbons, two or three suicides amidst blue and green ribbons were sure to follow the announcement of the first in the news, till a sensible physician suggested that suicides should not be noticed in newspapers or should be treated with ridicule: The advice was acted upon and proved by result to be sound (Martineau, 1838, p98).

Her early reflections of death were said to aid in understanding a nation's normative social codes and social behaviour. These early reflections had ties to the recognition of a good death wherein dying as sacrifice was hailed as honourable, or the contrasting 'bad death' wherein it could be seen as wasteful and something to be ridiculed where suicide was hidden from the public eye and thus aligning with later recognitions of the taboo nature of the hastened death that still prevail today (Winnington & MacLeod, 2020). An assisted death is considered by many as a good death, however, the wording in the Act (2019) somewhat maintains assisted dying as something that is to be concealed from society contradicting with the idea of assisted dying as a 'good death.' The methods or place of administration of lethal medication cannot be named and nor can the details of those involved, in any newspaper, journal, book, audio, or visual recording without being liable to a fine (The Act, 2019). With claim that this is to protect the individuals who choose this mode of death and those that choose to assist them, with the sentiment that they need protecting reflecting how this mode of this is perceived requiring secrecy surrounding it.

In Philippe Ariès (1974) *Western attitudes toward death from the middle ages to the present* he describes a lineal approach to changing attitudes towards death influenced by social constructs, as well as what constitutes a good death. In medieval times, he reports people were aware, prepared for, and accepted their imminent death, it was witnessed by friends and family although without the dramatisation and great showing of emotions seen in later times (Ariès, 1974). Ariès (1974) goes on to explore the personalisation of death, in which the individual came to the forefront with religion altering perceptions of death through the idea of judgment passed on one's soul after the moment of death. Ariès (1974) noted, that the actual moment of death began to gain greater consequence through the belief that a person's deathbed behaviour and personal reflection on their actions through life could influence heavenly judgment bringing focus upon the moment of death. Jalland (1996) describes the need for unwavering faith and a readiness to submit to the will of God at the moment of death, the good death could be attained even if this involved prolonged physical suffering, as this suffering was seen as a spiritual test that might result in everlasting life. In this time, a hastened death would be a 'bad death' as it would go against the trust in God, as life is a gift from God, a sentiment that persists today, where religiosity is closely linked with views against assisted dying, this is reflected both in the general public and in nurses (Barnett et al., 2020; Bulmer et al., 2017).

By the early eighteenth century, Ariès (1974) reported that there was a change in the Western attitudes toward death, it was dramatised, feared and unfamiliar. In NZ, Best (1934) noted that although death was mourned by Māori, attitudes to dying were different to the West. Much of the early references drawn upon to understand death traditions for Māori are accounts recorded by non-Māori academics, however, they provide some insight into contrasting practices while recognising Māori are not one people, and each iwi (tribe) have their distinct practices (Moeke-Maxwell et al., 2019a). In contrast to the fear at the time of death in the West, Best (1934) described that:

The Māori was fortunate in not having a priesthood whose ambition it was to make him fear death, hence he had no fear of the hereafter, and death-beds were remarkable for the calmness of the passing sick man, and the collected, clear-minded way in which he expressed his last wishes (Best, 1934, p105).

Best (1934) states that the dying Māori did not fear natural death, instead were made to feel calm and clear-minded, this enabled them to express their last wishes, or in the case of an infectious disease, may have been taken to temporary shelter to avoid the spread of sickness. Best's (1934) descriptions of death for Māori were depictions of a good death as a death that was peaceful and calm, where the dying had a chance to say final words to those around them and spiritual practices were performed which contrasted to the rising fear and unfamiliarity of death in the West (Ariès, 1974).

In late nineteenth and early twentieth century with colonisation in New Zealand, many Māori were dying from the influx of diseases such as influenza, dysentery and tuberculosis, and death due to land wars (Walker, 1990). For Māori, treating illness and death was, and still is, by many considered a spiritual phenomenon. Tohunga (expert practitioner of any skill or art such as healers) were present to administer spiritual care to the ill or dying person, and the person was at the heart of their whānau (family) and their community (Hiroa, 1950; Moeke-Maxwell et al., 2019a). Legislation such as the Tohunga Suppression Act (1907) was intended to stop people using traditional Māori healing practices which had a spiritual element to help Māori to survive new communicable illness brought by colonisers and encouraging adoption of more Western lifestyles to ensure the survival of Māori. This, and other colonial restrictions, further displaced traditional Māori customs that were already being eroded through colonisation, limiting Māori practices and traditions that offered them a good death (Moeke-Maxwell et al., 2019a). The legislation was never really enforced, the main consequence was that it pushed the practice of Rongoā Māori (Māori healing) underground and matters of Rongoā were never discussed outside of Māori communities until more recently, with the Tohunga Suppression Act repealed in 1962 (Durie, 1994). However, in New Zealand, the biomedical approach often remains dominant and the indigenous aspiration for complimentary, spiritual, holistic comfort treatments is often unsupported within the mainstream health system despite attempts to include Māori

objectives in healthcare and reduce inequities (Moeke-Maxwell et al., 2019a). For Māori, impacts of both the historic and ongoing colonisation processes have meant not all Māori individuals or whānau have been able maintain their traditional care customs, although generally, Māori maintain more confidence and expertise than their Western counterparts at caring for the dying at home (Mason et al., 2018). In the nineteenth and twentieth century in NZ and internationally, the site of death was temporarily displaced to hospitals in the hands of trained doctors and nurses, there has been a shift again and dying at home, surrounded by family is assumed to be a high priority however, hospitals retain their place as a principal and familiar site of death for many people in the twenty-first century (Gott et al., 2017a; Walter, 2017).

In the eighteenth and early nineteenth century, nurses in the West were often untrained and had a reputation for being dirty and untrustworthy, had no formal training, capable of carrying out only menial tasks in care for the sick in the home to assist family carers (Helm, 2012; Mellor & Shilling, 1993). This aligned with reputations of hospitals as a place for the poor where one often became sicker due to care provided by the untrained peasants (Helm, 2012). Martineau became acquainted with Florence Nightingale and they worked together on the book *England and her Soldier* (1859) depicting the work of Florence Nightingale during the Crimean War 1853-1856 advocating for reform in health approaches to ensure the future good health of Britain's armed forces. Nightingale also published work such as *Notes on nursing: What it is, and what it is not.* (1860) that was a guide for professional nursing practice and described the role of the nurse in providing both medical as well as holistic support. Alongside many other prominent nurses, these changes that led to professionalisation of nursing practice prefaced the modernisation of both healthcare and perceptions of hospital care. This led to growing confidence in both nurses and modern healthcare and nursing became a respectable profession (Helm, 2012). Women started receiving training to become professional nurses and hospitals grew larger and education became more comprehensive. The greater presence of trained nurses who orchestrated a more medicalised regime of care, contributed to the process of distancing dying from the everyday activity of the household, allowing change in perceptions of hospitals necessary for dying to migrate to the hospital in the following century (Mellor & Shilling, 1993). Before modern medicine and large institutions to care for the sick, in both the in the West, and for Māori, care was predominately provided by family alongside healers, doctors or priests, however, the site of care changed to hospital through the rise in war and communicable disease (Best, 1934; Ariès, 1974). Due to this shift in the place of death, family who would have provided the nursing care became unaccustomed to facing death and dying, or caring for the dying person and a good death became one that was in the hands of trained nurses and doctors (Helm, 2012; Mellor & Shilling, 1993).

Ariès (1974) described that the extreme emotions in the previous period were replaced with an equally extreme avoidance of death and suppression of emotion that became dominant in the

twentieth century (Ariès, 1974). The dying person became a patient, dying became sequestered in medical institutions and death became unfamiliar (Howarth, 2007; Walter, 2017). When death finally came, it was, and still for many people, considered a failure of medicine rather than a normal occurrence, thus, rendering death as being bad and taboo (Howarth, 2007; Walter, 2017). Citing trends in literature, such as the work of Tolstoy, Ariès (1974) argued that the feeling surrounding death changed in the early twentieth century before its actual rituals did. This is clearly depicted in Tolstoy's *the death of Ivan Illich* wherein Illich falls ill and it becomes clear his condition is terminal however, he attempts to find cure. As his pain worsens, he is condemned to his bed and must face his mortality. During the process of dying, Illich dwells on the idea that he does not deserve his suffering because he has lived justly, so pain and death must be arbitrary and senseless. He begins to resent his family and doctors for avoiding the subject of his death, pretending he is only sick and not dying, he finds his only comfort in his boy servant, the only person in his life who does not fear death, and the only one, apart from his son, who shows compassion for him. This text of Ivan Illich is referenced as the recognition of a 'bad death' in the need to combat the over medicalisation, and denial of death to attain a good death in the future of medicine (Gawande, 2014). Death denial is common across death literature and is associated with a 'bad death' as death became something to fear because it was an unknown (Ariès, 1974; Berger, 1969). The fear of death, and what death is, is linked to existential suffering that people still describe today, and this existential suffering influences requests for assisted death because of the fear of the unknowns of death and the ongoing belief that death and dying are something to fear (Gaignard & Hurst, 2019).

By the late nineteenth century, people in the West were living longer and mortality rates were falling, thus the prospects of living into old age began to increase for many people (Clark, 2016). Previous fears of sudden demise brought on by infection, disaster, and plague, were replaced with fears of lengthy dying and the suffering that it might entail with the emerging chronic diseases of the modern era, due to increased longevity (Clark, 2016). Porter (1999) noted that while Ariès (1974) was critical of hospital death, calling it cruel and impersonal, many people felt that dying in the care of a doctor was a good death, and doctors were commended for their ability to ease pain in the final hours of life to alleviate suffering. Jalland (1996) described that the past ideals of the good death and suffering as a test of god were eroded in the period from 1870 to 1914 with the declining influence of religion, leading to an increasing preoccupation with matters of pain and other symptoms. The use of opiates, and opium including the development of morphine developed intermittently over the nineteenth and twentieth century (Clark, 2016). These were initially readily available to all however became more regulated and restricted, the prior abundant public and medical use of morphine began to change at the start of the twentieth century. The Brompton Cocktail (made often from morphine, cocaine, highly-pure ethyl alcohol, and sometimes with chlorpromazine) had a special place in the history of twentieth-century hospice and palliative care and was given to terminally-ill

individuals to relieve pain and nausea in those imminently dying (Clark, 2016). The purposes of such drugs began to vary in the minds of physicians, in time, a wider philosophy of modern hospice and palliative care as a speciality of medicine in its own right took hold. The titrated use of opiates by palliative specialists became part of the good death and although often denied in the field of medicine there was, and continue to be reports of these being used (or misused) to hasten death where death is already imminent (Clark, 2016; Collins et al., 2017; Woods & Rook, 2016).

Through greater restriction of opioids, access was somewhat exclusive to the middle and upper-class that could afford healthcare (Clark, 2016). Similarly, with assisted dying, although the legislating of this practice is said to make it accessible, there remain boundaries in place within the somewhat restrictive wording in the Act for those who may not have the awareness to access this service. Only one who has access to media to know assisted dying is now legal, and has the knowledge to understand the Act (2019) and the specific language that must be used to constitute a clear wish for an assisted death, has the right to have access to this death. Simply saying I want it all to be over- or I want to die is not enough to constitute legal request. Like a secret passcode to enter an exclusive club, the words I want assisted dying, or I want euthanasia must be directly used to a health practitioner with the right knowledge who can then either provide the documents or direct the requestor where to find them. These intricacies within the legislation reflect a lack of trust placed on medical professionals including both that of doctors and nurses, and their ability to present options to health consumers in an appropriate and timely way, without being seen to be coercing them into a hastened death (Tsai & Menkes, 2020). This seems to place the assisted death within the realm of the forbidden death that Ariès (1974) described. It is unclear whether society sees assisted death as a good death or a ‘bad death.’ From past learnings a good death is one that is somewhat normalised by society as a part of life, that is calm, wherein physical, spiritual and emotional suffering is addressed, where one can be repented for their sins, is shared and where dignities can be intact, and the bad death is one that is feared, hushed, shameful, and hidden. It would seem based upon legislation that assisted death although portrayed as a good death has also been legislated as a ‘bad death’ through the taboos surrounding this mode of death within the Act and contradicting the normalising and open awareness of death and dying.

The shift to open awareness of death and individualised decision making has likely contributed to the societal move that has made space for assisted dying. Palliative care philosophies include promoting death awareness, viewing dying as a normal process and helping patients and their families come to terms with mortality (Hospice New Zealand [HNZ], 2019; Lowey, 2015). Kübler-Ross is recognised for bringing death and dying into the public arena for discussion through her theory on the five stages of grief as experienced by terminally ill patients. The final stage of Acceptance is “an existence without fear or despair”, “almost void of feelings” (Kübler-

Ross, 1969). This theory was part of a revivalist discourse to humanise medicine and acknowledge dying (Walter, 2017). It now receives little empirical support as the experience of grief is not linear (Corr, 2019). However, the end goal of acceptance remains a powerful guide for end-of-life care (Zimmermann, 2012). With a move to expectations of individualism and choice, people started to have the option to plan their death which appealed to the middle-class who were well educated and sought out services and opportunities to improve the quality of their lives (Walter, 2017). To accept death and consider hastening it, the person with life-limiting illness must be aware of the limited life expectancy, the shift to open awareness of dying allowed for open discourse about death and dying and planning for a good death (Cohen, 2020; Van Brussel & Carpentier, 2012).

People now have more access to information which has accelerated in the twenty-first century driving freedom in decision making in many aspects of life thus can be assumed people also desire choice in their death (Walter, 2017). A good death is defined in the twenty-first century often as one where physical, psychosocial and spiritual needs are met, dignity and autonomy is maintained, in the presence of people that care, a lack of financial burden, with many studies involving patients their priority is for a quick, painless and peaceful death (Meier et al., 2016). Although these are the goals that good palliative care aims to provide (Lowey, 2015), an assisted death delivers the full control and alleviates the fears of the unknown and the fears of a loss of control in the final days or hours that palliative care cannot guarantee (Schuklenk, 2016). The right-to-die movement is at the forefront of the struggle over what constitutes a good death and the societal change leading to legislating assisted dying (Van Brussel & Carpentier, 2012).

Understanding the contexts that have changed societal views of a good death and have made way for assisted dying and how they interact with other practices at end-of-life currently available such as palliative care is significant to this study and the nurse's role in end-of-life care in NZ. In the twenty-first century we are now in an age wherein we can exercise choice in most aspects of life, autonomy and independence is highly valued as is the desire for life on demand (Walter, 2017). Waiting for death seems arbitrary in a society where we receive instant access most other experiences in life, thus a good death is now one that is sudden, quick, pain free. The designer death or at least the option for it, it seems by many, is now desired (Schuklenk, 2016). This limits opportunity for people to experience themselves, or others, as 'dying' (Richards & Krawczyk, 2019). Assisted dying is perceived in society, and media portray it, as a good death whereas palliative care and the dying phase is viewed as a somewhat redundant phase of life or one filled with suffering including the suffering of pointless waiting for what we know, is imminent (Richards & Krawczyk, 2019). The assisted death was theoretically desired by society as voted in by the population, however, there are questions of the societies actual understanding of other practices that were already available (Collins et al., 2017) and the readiness of society for this change. This includes how assisted dying will impact

upon those that walk alongside people and support them through death such as nurses, as this is a change to their practice and policy and still holds its taboo place in culture that is woven into the legislation itself, keeping this form of death somewhat hidden from the public view (Richards & Krawczyk, 2019). I will now further examine current end-of-life practices and reflect of the nurses' role to further contextualise this research.

2.2.3 Palliative care, and advanced care planning

Palliative care refers to a holistic approach to care aimed at alleviating suffering and improving the quality of life of patients, and their families faced with problems associated with life-limiting illness, including both malignant and non-malignant conditions (Douglas et al., 2018; HNZ, 2019; World Health Organisation [WHO], 2018;). Palliative care is applicable early in the course of disease alongside therapies that are intended to prolong life such as chemotherapy, dialysis, and diagnostic investigations. Importantly, palliative care provides support to the family during the illness and bereavement (Macleod & Macfarlane, 2018). Internationally, specialist palliative care services are involved with the majority of patients who choose assisted dying although usually distinguishing palliative care as being a supportive mechanism, distinct from hastening death practices (Bernheim et al., 2008; Dierickx et al., 2018). Palliative specialists are trained in early identification, assessment, and treatment of symptoms of disease including physical, psychosocial, and spiritual needs (Lowey, 2015; WHO, 2018). Specialist palliative care services are usually provided by doctors, nurses, and other multidisciplinary team members with specialist palliative care training.

In NZ, specialist palliative care nurses complete thorough advanced patient assessments and provide support to patients' families and other health professionals (Ministry of Health [MOH], 2017). This includes ward nurses, community nurses, and prescribing recommendations for symptom relieving medications to non-palliative trained doctors guided by policy and their advanced knowledge of palliative care. This is different from a nurse practitioner working in palliative care, who can independently prescribe and are mentioned in the Act whereas registered nurses are not (The Act, 2019). Registered nurses working in general end-of-life care settings, palliative nurse specialists and clinical nurse specialists are not mentioned within the Act despite the significant involvement they have in the support of other health professionals, and the care of patients and who will be applicable for assisted dying under the Act (Tsai & Menkes, 2020).

Specialist palliative care services are becoming increasingly overwhelmed by the demand for services, and are struggling to meet population palliative care needs both locally in NZ, and internationally, resulting in an increased demand on the roles of the nurse (MOH, 2017). This increased demand for palliative care services is due to the aging population and people living longer with chronic disease as well as an aging workforce meaning many nurses are retiring or

nearing retirement (MOH, 2017). Palliative care services are often looked to when considering care of the dying person thus assisted dying is assumed to be a part of palliative care. In Australia, palliative care doctors felt that care of the patient requesting assisted dying was the role of the wider role of the health care team however, training for other medical specialists was inadequate to prepare them to provide the necessary support to patients and families considering assisted dying (Philip et al., 2020).

Internationally nurses in palliative care settings views do not necessarily align with that of doctors when it comes to assisted dying (Pesut et al., 2019) however the views of nurses in palliative care roles in NZ towards assisted dying was not well understood in past literature. Regardless of the palliative specialists support for or against assisted dying, their primary goal was to support people to live and die well, ensuring that people with palliative care needs had access to palliative care however access to specialist palliative care was as an ongoing issue limited by resource (Philip et al., 2020). Physicians in NZ reported similar concerns about the implementation of the assisted dying service in practice and the expectations of palliative care services to be involved in this service when already struggling with lack of resource (Tsai & Menkes, 2020) although this was specific to doctors and not nurses, a lack of resource will impact of nurses and the care they can provide. Many palliative care providers although well versed with supporting in decisions at end-of-life were not willing to be a part of assisted dying (Philip et al., 2020). Education and training of non-specialist palliative care providers including nurses, doctors and other members of the multidisciplinary team in management of end-of-life care is a cornerstone of palliative care in many countries, including NZ (Lowey, 2015; Philip et al., 2020). Prior to this research, however it was unclear how assisted dying would impact upon the palliative care nurses who held significant roles in specialist palliative teams supporting education for health professionals and health consumers around end-of-life decisions. Nurses have a key role in guiding future care planning discussions and decision making at end-of-life to support a good death (Fridh, 2014; Gagnon & Duggleby, 2014; Lowey, 2015) but it was not clear how assisted dying fit within this as assisted dying cannot be presented as an option when discussion other choices in end of life decision making (The Act, 2019).

Advanced care planning is the process of thinking about, talking about and planning for future health care and end-of-life care and started to become more predominant in NZ in 2010 (Brown et al., 2020). Advanced care plans are usually targeted at people who have been diagnosed with a life-limiting illness or chronic disease, but the target is for them to also be completed with people in good health supported by doctors, nurses and social workers (Brown et al., 2020). If these conversations occur before a health care crisis, the person has time to consider their choices and talk with loved ones and they are seen as a means of empowerment (Frey et al., 2017). Although assisted dying cannot be requested as an advanced directive it is possible that the discussion of these advanced wishes will initiate a conversation about assisted dying

(Connolly et al., 2014). There is variation in nurse's confidence having future care planning discussions across care settings, those with palliative care training and with closer relationship or more familiarity with their patients are generally more confident and in acute hospitals or aged residential care settings are less confident (Cheung et al., 2017; Fan & Rhee., 2017; Frey et al., 2017). However, through training and support they can gain more confidence in these discussions (Frey et al., 2017). It is possible assisted dying is another topic of discussion that will increase this feeling of unpreparedness in conversations about end-of-life and where nurses will require additional support and it was unclear if anything during implementation was done to combat this.

There is considerable evidence that advance care planning is poorly undertaken, and that discussions about end-of-life often transpire when crises occur and life-sustaining treatments have been instituted despite issues of poor prognosis, and when people are not capable of making decisions about the care they want (Cheung et al., 2020; Davoodvand et al., 2016). Nurses do not only discuss patient's decisions through completing pre-empted advanced care planning. These conversations can be informal, at the bedside during care delivery, when a patient has "had enough," or during a routine clinic appointment (Borhani et al., 2015; Thurston & Waterworth, 2012). Prior to assisted dying, there were common practices such as withdrawing burdensome treatment to promote comfort and ensuring a dignified death (Cheung et al., 2020). Nurses in many care settings are often the first to receive requests to stop treatment and act as advocates for patients, and conduits between the patient, their families and doctors (Cheung et al., 2020; Davoodvand et al., 2016). The significance of good communication between the nurse, patient, and their family cannot be overstated and has been found to be a central part of the nurse-patient relationship and is based on the formation of trust (Lowey, 2015). A key role of the nurse in advanced illness, is communicating honestly, genuinely, with care, and follow through (Dahlin et al., 2010; Lowey, 2015).

2.2.4 Prolonging life or hastening death?

The withdrawal of burdensome or futile life prolonging treatment is not assisted dying (Australia and New Zealand Society of Palliative Medicine [ANZSPM], 2019). Withdrawal of treatment practices have long been permissible and are common practice especially in palliative care or end-of-life care settings under in section 11 of the NZ Bill of Rights Act (1990) even if it is thought that the treatment would prolong life (Ministry of Justice, 2013). Many patients and the general public are unaware that they have the choice to stop treatments and interventions such as blood transfusions, dialysis and long-term medications, such as cardiac medications, oxygen therapy or artificial ventilation (ANZSPM, 2019; Walker et al., 2020). Many of these medications or interventions are life prolonging, and stopping them depending on the severity of disease a person could die in some cases within hours or others within short weeks (Walker et al., 2020). Many people are also unaware they can choose not to treat

complications of disease such as infections or blood clots. In many settings patients and families speak to nurses first about stopping treatment and a changing from life prolonging approaches of care, to comfort and quality of life focused approaches (Borhani et al., 2015; Fan & Rhee, 2017). Nurses advocate for further discussion with medical teams to withdraw burdensome treatments, or educate people that they have a choice in deciding to stop these interventions, and ensuring symptoms are managed for a dignified death (Davoodvand et al., 2016; Gagnon & Duggleby, 2014; Tully, 2015). Although internationally nurses are also often the first to receive requests for a hastened death (Pesut et al., 2019), it is unclear the ongoing role nurses will have in advocacy, decision making and as vectors for clear communication surrounding requests for an assisted death in NZ.

As death approaches and the body begins to shut down, the person's appetite diminishes as does their ability to swallow, ingest and metabolise food and fluids (LiPuma & DeMarco, 2016; Zitter, 2017). Some people view the withholding or stopping of food and fluids as a means of euthanasia however this is denied within the field of palliative care (ANZSPM, 2019). Anorexia is the loss of appetite with reduced oral intake while cachexia is often the result of anorexia and is the 'wasting away' from lack of adequate nutrition (LiPuma & DeMarco, 2016). Cessation of eating and drinking can naturally happen and nurses often provide interventions to manage any symptoms associated with this such as managing dry mouth. Nurses often discuss changes with the patient and family to alleviate distress and fears about the stopping of food and fluids, and other changes at end-of-life. This natural loss of interest in food and drink is different to voluntary stopping of eating and drinking. This is an uncommon practice but has a place end-of-life care although can burden the dying person with a slow death (LiPuma & DeMarco, 2016). As these natural changes occur, nurses have a significant role in helping both patients, families, understand these as a natural process, and are part of holistic nursing care of the dying person. Nurses are often involved in supporting junior staff including junior nurses, physicians and other health professionals in understanding these changes at end of life.

Nursing interventions when patients have reduced oral intake or dysphagia include education on oral care to keep mucous membranes moist and to provide comfort, emotional support and help families understand the symbolism associated with mealtime and encouragement around eating their favourite foods or foods that align with minimising adverse symptoms (Dahlin et al., 2010; Lowey, 2015). These nursing roles in care of the dying are significant in relation to assisted dying as they have developed overtime as special skills and knowledge and nurses are often looked to as guides at end-of-life and normalising dying as a natural process. However, there is uncertainty what role they will assume with this new type of death, including ongoing management of medications on the lead up to this new type of death. Nurses are commonly involved in managing symptoms related to the dying process, especially when the oral route of

medication is no longer tolerable transitioning to medications given subcutaneously (Huisman et al., 2020).

Untrained health professionals can misunderstand medications used at end-of-life such as those given via the subcutaneous route (Collins et al., 2017). These are usually started in cases such as swallowing difficulty, a decreased level of consciousness, persistent nausea, severe unstable pain or bowel obstruction (HNZ, 2017). It is a common misunderstanding that once a continuous subcutaneous infusion is started this hastens death (Woods & Rook, 2016). In a questionnaire sent to NZ general practitioners (GPs) Malpas et al. (2015) found that the 359 GPs, who reported making a medical decision in end-of-life, 16 (4.5%) attributed death to a drug that had been prescribed, supplied or administered explicitly for the purpose of hastening the patient's death. This was before any assisted dying legislation in NZ. It is not known whether any of these GPs had specific specialist palliative care training to fully understand the nature of these prescribing decisions or claims. Claims that medications are already commonly given to hasten death are described as disturbing, grossly inaccurate and do nothing to help people understand palliative care treatment, instead perpetuate people's fear around death and dying (ANZSPM, 2020; Woods & Rook, 2016). Medications given via this route are intended to be carefully monitored and titrated to best control symptoms, without causing excessive sedation, and are not given to hasten death (HNZ, 2017). A continuous subcutaneous infusion with medications such as opioids, antiemetic's, antipsychotics and anxiolytics may be used as a temporary measure to control symptoms, and ceased after symptoms improve, or may be continued until death. Studies have shown that the presence of a syringe driver and these medications do not shorten the dying phase where death is already imminent (Collins et al., 2017). There is not extensive research in the area, as it would be unethical to withhold medications aimed at relieving symptoms at end-of-life. The use of these medications to alleviate symptoms aligns with the idea of a good death as a death where symptoms are managed, so suffering is reduced, and dignity is maintained. Routine use of continuous subcut infusions is different from palliative sedation.

Palliative sedation therapy is also used within a specialist palliative care settings, and is often seen as a last resort for the control of symptoms, to achieve a good death for a minority of people, who experience severe, refractory, and untreatable suffering at the end-of-life and in accordance with specific evidence based guidelines (Cherny & Radbruch, 2009). It not intended to hasten death as its effects are reversible, thus, from many palliative care perspectives it is claimed this does not constitute assisted dying (ANZSPM, 2020; Maltoni et al., 2012). Nurses assess the efficacy medications utilised in the final stages of illness and the ongoing symptom burden. Nurses educate patients, families, and other health professionals about the need and use of these medications, and communicate to doctors any ongoing symptom management issues requiring further changes to palliative treatments (Huisman et al., 2020; Lowey, 2015). Nurses

already have a significant role in patient's choices around the cessation of treatment and the subsequent management of symptoms (Wilson et al., 2020b). A significant part of this role is advocacy, and education, for not only the patient and family, but often for other health care professionals, including other nurses, doctors and often the wider multidisciplinary team involved in patient care (Lowey, 2015).

Nurses, through the repeated exposure and normalisation of death are distinct from other members of society in that they have mortality salience, an awareness of the inevitability of one's own death thus their views towards death can differ to that of the general public (Nia et al., 2016). Many nurses have repeated exposure to death in their roles, especially those in end of life care settings, and it has been noted that this can negatively impact upon nurses and they require coping strategies for managing death anxiety to offset negative consequences such as leaving positions, and decrements in personal health and quality of life (Nia et al., 2016). It is unclear from legislation and current literature what the nursing role will be in assisted dying, achieving a good death, and whether they will be prepared for ongoing education requirements and needs of patients, families, and other health professionals. This includes their own ideas of death and continued exposure to death, and whether this new death will be different and require a new set of skills and coping mechanisms. It can be assumed assisted dying as a societal change in death will require further space for reflection to understand this new form of death and their roles and how this relates to nurses own morality and mortality, and their overall practice and policy as this is a change to practice and policy.

2.3 Section two: Practice and policy change and the nurses' role in advanced illness

Despite all international assisted dying legislation reviewed for this study not including the role of the nurse (Dutch law on Termination of life on request and assisted suicide Act, 2002; End-of-life Choice Act NZ, 2019; Medical Assistance in Dying Canada, 2021; Oregon's Death with Dignity Act, 2019; Voluntary Assisted Dying Act Australia, 2017), it is evident in all international literature reviewed that nurses have a significant role in patient care leading up to and after an assisted death and also face moral challenges whether for or against the practice of assisted dying (Beuthin et al., 2018; Pesut et al., 2019; Wilson et al., 2020a). The role of the registered nurse was not included within the assisted dying legislation in NZ despite this being a significant practice change for the profession (Tsai & Menkes, 2020). Situating this research within practice and policy change literature is significant in contextualising the meaningfulness of assisted dying implementation for nurse's practice and policy.

Involvement in practice and policy change, are within the ethical and professional responsibilities of nurses (NZNO, 2019; Raines, 2012). Recognising nurses as distinct members

of the healthcare team and involving them in change leads to increased role meaningfulness and higher job satisfaction (Both-Nwabuwe et al., 2020; Rongen et al., 2014). Nurses are central in initiating, leading and implementing quality improvement changes in healthcare however, can have hesitancy regarding change especially when not involved in the change process (Rainey, 2012). Providing them with the time, resource, responsibility, accountability and authority to act in decision making, quality improvement or practice change initiatives is essential for nurses to engage in change (Mitchell & Waterworth, 2012; Rongen et al., 2014). Albeit only temporarily, when the Liverpool Care Pathway was introduced in NZ nurses had positive experiences of this change including improvement in their knowledge base and ability to make sense regarding care of the dying patient (Thurston & Waterworth, 2012). Nurses appreciated having a clear pathway to follow and the corresponding documentation helped as a means of debriefing and growing understanding of care for the dying person as an active rather than passive role (Thurston & Waterworth, 2012). Through investment in skilled workforce, dedicating time, and resources to support nurses through the practice and policy change, there was an increased likelihood of sustained practice and organisational change, leading to positive patients and family experiences in the delivery of care at a time in their lives when they are most vulnerable (Thurston & Waterworth, 2012). Thurston and Waterworth (2012) however, recommended that earlier involvement of nurses in this change would have been beneficial. For assisted dying implementation it was unclear whether a similar approach and dedication was made to training and preparing the health workforce, to make the most of the opportunity to upskill health professionals on care of the patient with a life-limiting illness and the involvement of nurses in this practice and policy change.

The lack of nurse involvement in policy development locally and at a national level is multifactorial in government and societal perceptions of nurses being restricted by hierarchies, time, management support, gender-bias, as well as professional nursing issues (Hajizadeh et al., 2021; Juma et al., 2014; Manning & Kriebel, 2020). In NZ, it was found nurse leaders can suffer from tall poppy syndrome and despite a significant clinical knowledge including both policy and political sophistication, they are often not viewed by the public or themselves as health leaders which potentially obstructs their active involvement in policy development (Donovan et al., 2012). The nursing role not being recognised in legislation such as the Act can be multifactorial in societal hierarchical structures. Nurses hold a distinct role within the healthcare team and need to be acknowledged as partners in patient care, alongside, rather than below that of doctors (Elsous et al., 2017).

Doctor-nurse collaboration is crucial and has been highlighted in different contexts including cooperation in work, sharing responsibilities for solving problems, and making decisions to formulate and carry out plans for patient care (Elsous et al., 2017; Sollami et al., 2015). Doctor-nurse collaboration can improve patient outcomes, maintain patient safety, lower healthcare

cost, and lead to increased job satisfaction (El Sayed & Sleem, 2011). It is considered a primary part of information flow in healthcare, whereas poor communication between doctors and nurses can create a conflict between their roles, increasing medical errors, leading to worse patient outcomes (Cypress, 2011). However, within the Act there is no mention of the role of the nurse in the collaboration of care for the patient who makes a request for an assisted death, despite nurse's significant role in supporting the decision making process in chronically ill patients (Killackey et al., 2020). Prior to this research, it was unclear how this would impact upon the implementation and the shared responsibilities in patient care, and nursing practice and policy.

The nursing voice is crucial for defining and evaluating ethically safe practices, and shaping policies that prioritise patients' rights to make decisions, while helping to prevent old and new forms of neglect when they face death (Monteverde, 2017). Neglect can range from not acknowledging suffering, dismissing the felt loss of dignity, and failing to question the choices made by patients citing autonomy without discussing or educating about alternate means of care (Monteverde, 2017). This is significant for the assisted dying discourse where from the current legislation there is no legal obligation to involve nurses at any part of the process (Tsai & Menkes, 2020). It is well known that many initial assisted dying requests are made to nurses, and nurses are often the health professional with most frequent contact in patients with advanced illness (Killackey et al., 2020; Van Bruchem-Van De Scheur, 2008; Wilson et al., 2020a). Nurses need to be provided the right education to respond when a request is made, assess for care needs such as whether the request is a declaration of suffering or a genuine request and be able to continue to support the patient in care (Pesut et al., 2019; Wilson et al., 2020b). As a nurse in the field of end-of-life care reading the legislation and related documents, there was ambiguity around the roles nurses would hold, and the professional responsibilities as part of the duty of care to patients.

Nurses in NZ are governed by the both Māori and Western principles as a part of their ethical responsibility under the NZNO (2019) code of ethics. When it comes to assisted dying a patients' right to autonomy is most frequently cited, for nursing practice this is described as nurses' duty to:

Support clients to make informed decisions, individually or collectively
(NZNO, 2019)

The duty of health professionals supporting autonomy and informed choice is discussed extensively within the assisted dying literature. Gómez-Vírveda et al., (2020) described that autonomy is a complex phenomenon especially in end-of-life care where individualistic model of autonomy in decisions at end-of-life is highly valued. This shift from healthcare being paternalistic, to a more liberal individualistic approach, has led to miss-interpretations of

autonomy as the right to non-interference, dismissing the duty of responsibility that health professionals have (Kouwenhoven et al., 2019). Without fully defining and understanding autonomy, we are at risk of other means of neglect (Monteverde, 2017). As said by medical novelist Atul Gawande:

Everyone dies. Death is not an inherent failure. Neglect, however, is
(Gawande, 2016, p.267-269).

In modern medicine, these means of neglect can manifest in different ways such as pursuing futile treatment, or not questioning choices and offering alternate options through a fear that we may be interfering in the patient's autonomous decision making process (Gawande, 2014; Gómez-Vírseda et al., 2020).

As health professionals, we are in a position where we understand the ways in which diseases progress, the associated symptoms and the outcomes of interventions in great depth. Decisions are commonly placed on the patient and family due to a shift to hyper-respecting autonomy, whereas recommendations can be provided, without undermining the patient's autonomy (Gómez-Vírseda et al., 2020; Walter & Ross, 2014; White et al., 2010). Nurses are trained to improve the well-being of patients and their families, with ethical knowledge and a relational and embodied perspective of care (Gómez-Vírseda et al., 2020). Nurses are closely involved in patient care and often have more time with patients, putting them in a privileged position to support autonomous decision making as assessors, information providers, supporters, and educators (Gómez-Vírseda et al., 2020). Despite nurses not legally being mentioned within the actual assisted dying legislation, they will have obligations within their scope of practice, nursing competencies and ethical guidelines to uphold their duty of care, and could be instrumental in supporting ethical practice and supporting with relational patient autonomy.

Water et al. (2017) reviewed several Health and Disability Commission inquiries in which nursing practice was examined, citing nurses' multiple obligations within their practice standards to better understand philosophies of care. They described nurses' personal accountability for the standards of care provided to patients, and their professional status being intrinsically tied to their responsibilities and liabilities in regards to their duty of care (Water et al., 2017). Within this study they found that a nurse's duty of care is regulated by legal, ethical and professional obligations and this includes a moral commitment to not only give care, but to care. These findings suggest duty to care, lies at the heart of nursing practice. If nurses are duty bound to care, then this raises the issue that not preparing and resourcing nurses to be able to care about a patient who makes a request for assisted death, puts nurses at risk of professional misconduct and moral distress. Pesut et al. (2020a) conducted a comprehensive review of ethical arguments examining euthanasia in relation to nursing practice including the moral ontology of nursing and identified insufficient quantities of recent literature. There was

literature both strongly for and against a hastened death as something that could violate the ontological morality of nurses, and could potentially lead an erosion of public trust, versus data that supported it as a means to relieve patients of suffering, support in their decision making, and give greater meaning to end-of-life nursing roles (Pesut et al., 2020a). However, much of the research was outdated. It is unclear if nurses in patient facing roles were prepared for assisted dying in NZ, and how it would make them reflect on the morality of their role in practice, or what policies would guide and protect them.

Wilson et al. (2020b) found Australian nurses had a variety of intentions if met with a request for assisted dying, including refer and support, object to, or deflect the request, engage and explore the request, or assess needs and provide information. Many people making a request for assisted death are making this request at time critical point in their illness (Wilson et al., 2020a). Thus, these responses do not necessarily correspond with the nurse's professional obligations to the patient. A concern when assisted dying was introduced in Victoria, Australia was the legal implications for nurses citing the gaps in nurse's legal knowledge (Hewitt et al., 2020). To ensure nurses' conduct falls within the law relating to assisted dying, it is imperative that healthcare services provide education and create clear policies, and guidelines that accurately reflect the law (Hewitt et al., 2020). However, international literature shows that assisted dying policy and guidelines including those created by specialist committees often do not translate to quality implementation, adequate training or equitable access to assisted dying in practice (Pesut et al., 2020b; Philip et al., 2020). The MOH was responsible for implementing the Act, making regulations, and developing policy and guidance for health providers for the implementation of assisted dying in practice in NZ. A governance group for implementation was established in NZ, and an implementation programme was commenced by the MOH including establishing Support and Consultation for End-of-life in NZ and End Life Review Committee (MOH, 2021a). They are responsible for service design and planning as well as planning for workforce training and guidance. Within the Information MOH website which is the key source for information, the document *Information for Health Professionals* it states

This document contains general information about assisted dying. It is not legal or professional advice of any kind (MOH, 2021b).

This is limited in terms of supporting nurses with assisted dying services, leaving it unclear as to what other guidelines would be created that could legally support nurses practice.

As with involvement in end-of-life care, involvement in assisted dying requires significant personal and professional moral work (Pesut et al., 2020b; Elmore et al., 2016). Key issues faced by nurses involved in assisted dying internationally included the absence of clear professional and legal guidelines, role ambiguity, and lack of professional collaboration (Fujioka et al., 2018). Prior to assisted dying law being officially passed in the Netherlands in

2002, the practice of euthanasia was not specifically legal however their laws specified physicians would not be judged guilty for their involvement (Muller et al., 1997). During this time, there were cases of nurses having legal action taken against them for their involvement even alongside a physician as the law did not specify the nurse's role (Muller et al., 1997). However, through later policy development it was suggested that nurses should be included in guidelines as the involvement of nurses in the decision making process in cases of assisted death is desirable, because of their specific expertise and daily involvement in patient care (Muller et al., 1997). Later data in the Netherlands from Van Bruchem-Van De Scheur et al. (2008) showed that despite law stating only physicians could administer the fatal medicine, nurses were still involved in this practice. The management of medications at the end-of-life have been predominantly in the realm of nursing practice, so, although legislation did not include nurses' ability to administer medication, nurses commonly did this supporting doctors, as well as delivering a significant amount of the education of what will occur at the time of administration (Van Bruchem-Van De Scheur et al., 2008). For quality implementation of assisted dying services to occur, it is paramount that the current end-of-life practices and the role of the nurse in end-of-life care settings are understood, so guidelines and policy accurately represent and align with the roles of these nurses. As evidenced by past literature, assisted dying is a significant change to the practice and policy for nurses, however, there is currently significant ambiguity around what is, and what is not, a nurse's role within the Act, and nurses' professional responsibilities (Pesut et al., 2019). These roles can vary in different care settings, thus a deeper view of nurse's wider roles in advanced illness is explored.

2.3.1 Nurses role in advanced illness

Nurses have a prominent role in caring for patients in advanced illness managing symptoms and maintaining supportive clinical relationships with patients and their families to educate and empower them, across multiple practice settings, and provide health education, research and health promotion (Andersson et al., 2016; Douglas et al., 2018; Heath et al., 2021; Matzo & Sherman, 2019; Tully, 2015). In clinical roles, the nurse is often the immediate health professional available to the patient and their family, and acts as a conduit between these parties and multiple disciplines (Raines, 2012). Nurses have a role in patient assessment, continuity of care, communication and end-of-life conversations, and have the ability to empathise, along with understanding that care will not just include the patient, but their wider family and community (Tully, 2015). Despite nurse's growing roles in NZ, society often still views nurses in the infancy of nursing practice (Borbasi et al., 2010). Not all nurses working in end-of-life care settings have specific training in the speciality of palliative care, and are usually supported by specialist palliative care services. There is a growing role of nurses, such as prescribing advice or prescribing rights, which is planned to expand to meet population needs (NZNO, 2018). As such, nurse's roles in different settings are explored to better understand the different

challenges across care settings with the implementation of assisted dying and the impact upon practice and policy.

2.3.2 Care across care settings

During 2018 in NZ almost 20,000 people died supported by hospice services (HNZ, 2018). Hospice's statistics of death are relevant to assisted dying as those referred to hospice are usually people experiencing suffering related to a life-limiting condition with a shortened prognosis, therefore, will likely be the population eligible for assisted dying. Of those who died, 14% died in hospital, 36% died in a private residence such as their own home, 22% died in an inpatient hospice facility and 26% died in residential aged care (HNZ, 2018). Hospice involvement and the specialty palliative care services they provide, is a key indicator in positive family and patient experiences of end-of-life care (Frey et al., 2020). Hospice New Zealand (2017) issued a position statement, that on an organisational level they did not support assisted dying citing the WHO, that the intent of palliative care is not to hasten death (HNZ, 2017). Palliative Care Nurses NZ Society held the same view in their position statement that assisted dying is incongruent with the ethos of palliative care (Palliative Care Nurses NZ Society, 2012). Hospice New Zealand (2017), however acknowledged that they would still support a patient considering assisted dying, and the family of that patient, suggesting that patients who chose assisted dying would have support until and after assisted dying, but imply they will not be the administrators of this service

Unlike the district health boards, the Hospices can choose to opt in, or opt out of providing support with assisted dying, and although HNZ took a conscientious objection against assisted dying, individual hospices could choose to support this. Tōtara Hospice in South Auckland, NZ for example, was one of a few hospices that did not conscientiously object to assisted dying, and now host assisted dying services for those patients in their care who wish to access it (Tōtara HNZ, 2021). Hospices globally, however are usually involved in the care of people who make a request for an assisted death. Internationally, hospice nurses generally do not support hospice as a place for an assisted death to occur, however, are in support of providing support with people's ongoing palliative care needs (Freeman et al., 2020; Miller et al., 2004). Although older research, Miller et al. (2004) is often cited when referencing hospice nurse involvement in assisted dying services. Miller et al. (2004) sent a questionnaire to hospice nurses, and social workers to assess their attitudes about assisted dying following legalisation in 1997 as at the time of the research 86% of the people who had died by assisted dying were enrolled with hospices. Almost 70% of respondents reported that at least one patient had discussed assisted dying as a potential option in the past year, and 22% were not comfortable discussing assisted dying with patients. Hospices in NZ provide a large majority of the end-of-life education across multiple community care settings. Later studies of Hospice nurses show mixed support for an assisted death based upon factors such as religiosity (Barnett et al., 2020). It is not known how

individual Hospices involvement or non-involvement will impact on the role of nurses working in hospices that choose to either opt in or opt out as yet, or nurse confidence in discussing assisted dying as they usually would discuss other end of life choices that people make.

The medical model of dying still largely dominates the end-of-life landscape with many people dying in hospitals, even though dying at home is assumed to be a priority (Gott et al., 2017a; Walter, 2017). Despite many people still dying in hospital, information related to patients and families experience of palliative care in a hospital setting remains limited (Robinson et al., 2015). Within hospital settings, there are often specialist palliative care services that support in the specialist advice for managing complex symptoms of advanced illness, and end-of-life care. However, in NZ hospital settings, many of these are consult services providing advice during business hours only (Counties Manukau District Health Board, 2021; Waikato District Health Board, 2016; Waitematā District Health Board, 2021). For this reason, a significant amount of the care is left with either with the primary teams who usually see a patient once per day, and/or treatment is predominately implemented and managed by nurses who are with patients 24 hours per day (Waikato District Health Board, 2016). Nurses confidence providing end-of-life care in the hospital setting varies significantly depending on years of experience, previous hospice or palliative nursing experience or training, care setting with differences in ICU, medical-surgical, or oncology settings (Gagnon & Duggleby, 2014; Fridh, 2014; Hendricks-Ferguson et al., 2015; Moir et al., 2015). Nurse's roles providing end-of-life care in the hospital setting are complex and include inter-disciplinary collaboration, communication, transitions from cure to comfort care, advocacy, education, patient support and support to bereaved family members (Gagnon & Duggleby, 2014; Fridh, 2014).

Many hospital nurses report low levels of knowledge in overall palliative care and end-of-life care, with the most confidence in pain and symptom management, but least confidence in managing complex conversations, goals of care discussions and providing education to the patient and family (Kim et al., 2020). When nurses are knowledgeable, skilled, and confident providing end-of-life care, whether to those imminently dying or in the final stages of advanced disease, this can improve the quality of life and satisfaction of patients and their families in hospital settings (Moir et al., 2015). Nurses in oncology settings are often more confident in providing end-of-life care than other settings, and nurses in non-oncology settings were more confident providing end-of-life care to oncology patients, compared to those with other chronic diseases (Choi et al., 2012). This is reflected in patient satisfaction where family members of deceased persons with cancer report higher satisfaction with the care, compared to those dying of non-malignant diseases (O'Sullivan et al., 2018). Previous studies suggest managerial and organisational support, policy, and education are fundamental to facilitate high-quality palliative and end-of-life care, and further programmes were needed to increase nurse's knowledge and confidence in these areas (Kim et al., 2020; Reed et al., 2018; Gagnon & Duggleby, 2014).

It has been shown that nurses in acute hospital settings experience moral distress providing end-of-life care, due to lack of experience, education, staffing, time, performing care they found to be futile, and euthanasia (Borhani et al., 2015; Rice et al., 2008). Moral distress caring for end-of-life patients is not only experienced by nurses involved in direct patient care, but also nurse managers (Nikbakht-Nasrabadi et al., 2018). Thus, if there is ambiguity around the roles of registered nurses in assisted dying, nurse managers will likely be faced with the questions from their staff, and this may cause moral distress if they are unprepared to support their staff. There is a lack of clear policy for nurses, thus it is unclear what the role of the nurse would be in assisted dying in the acute hospital setting, however, it is likely they will receive requests for an assisted death, be involved in initial communication with patients and family, and possibly be involved in supporting interventions such as inserting IV lines or managing infusion sets or enteral feeding equipment, and possibly for the post death care of the deceased, and bereavement support to family. It is unclear the preparation that has been given to nurses and nurse managers in these settings, or the awareness nurses in these settings have of their mandatory requirements as nurses within their professional practice to respond to requests or involvement in interventions supporting the administration of the lethal medication, and if adequate training and education is being provided. As evidenced by the inadequate training on palliative care (Borhani et al., 2015; Rice et al., 2008), it is unlikely the education provided on assisted dying will be any better, which is likely to put nurses and nurse managers at risk, and negatively impact on patient care. This may be of even greater significance in community settings where nurses have less access to support.

New Zealand has one of the highest rates of rest home residency and deaths per capita in aged residential care in the world, with over 30,000 people living in aged residential care and 38% of all national deaths occurring in aged residential care facilities relating to NZ's largely migrant population (Connolly et al., 2014; Swarbrick, 2018). These numbers are growing with the aging population, with many facilities providing a large portion of NZ's palliative care (Connolly et al., 2014). Therefore, it is more than likely that assisted dying will be brought up by residents, and subsequently impact on the nurses providing care in these aged residential care settings, however, there is a lack of clear national policy including the responsibility to prepare nurses in these settings for assisted dying. Older age alone does not mean these patients qualify for assisted dying, however, some of the patients in aged residential care will qualify due to advanced chronic disease. Long-stay residents will have built up relationships with staff over a number of years, and may have been offered opportunities to discuss preferences for end-of-life care, and often consider that setting as home (Connolly et al., 2014). It is possible assisted dying may be able to be administered in some aged residential care facilities, and therefore the nurses in these facilities that have relationships with these patients will undoubtedly be involved in supporting patient and families. They will also be responsible for the post death care of the patient, as well as support to other residents. Often the doctor routinely visits the facility once

per week and routinely visits individual patients sometimes once every three months, unless an acute review is required thus, majority of the care administration is up to the nurses (Connolly et al., 2014). As one nurse can be responsible for up to 30 patients, there is often not an alternative nurse to perform the duties that may be required to care for a patient who chooses assisted dying. Literature has shown a significant number of nurses working in aged residential care already get requests from patients to hasten death (Cheung et al., 2017). There is no current policy identifying responsibility of aged residential care providers to give support to nurses, or what nurses roles will be in relation to assisted dying in these settings.

Many international nurses coming to NZ work in these facilities, while gaining experience to then shift to better paid areas with more growth opportunity such as hospitals. This means that in these areas, there is not a large investment in training, poor retention of staff and culturally nurses are new to NZ and the end-of-life practices (Frey et al., 2016). In a 2021 report of aged residential care sector in NZ, 39% of the registered nurses in aged residential care settings were on international work visas suggesting not only were they a large migrant workforce but also relatively new to the country if not yet residents (NZ Aged Care Association, 2021). It is already known that these nurses struggle with the cultural changes and a lack of support while adjusting to life in a new country (Jenkins & Huntington, 2016). Assisted dying although becoming more acceptable from a Western view, for many of these nurses are from countries with strong religious faiths, countries such as India, and Philippines, with faiths as Hindi, Muslim, Christian and Catholic and religiosity is known to be a factor in views against assisted dying (Barnett et al., 2020; Jenkins & Huntington, 2016). Nurses may feel challenged and morally conflicted by assisted dying, if a request for assisted dying was made or it is carried out on site, it is hard to know the impact this may have on nurses in this setting, not only from their clinical practice but the morality of their nursing practice. These nurses, as new to the country may be vulnerable or feel uncomfortable to decline participation, even though this goes against their moral views, thus policy is needed to protect them and their nursing practice. Covid-19 has changed some of the recruitment into these facilities and with national staffing shortages these areas are struggling to recruit and retain staff (NZ Aged Care Association, 2021). It is unknown the impact assisted dying will have on staff satisfaction and retention in these areas.

Frey et al. (2016) found that there were low levels of satisfaction with end-of-life care in aged residential care, suggesting that symptoms and suffering are higher and people perceive the death is not a good death. Available evidence, suggests that some residential aged care residents at the end-of-life receive suboptimal palliative care, inadequate symptom control, and high rates of acute hospitalisation, but low rates of hospice referral (Frey et al., 2020). Due to a majority of aged residential care facilities being privately owned, pay is often poorer than state run hospitals, with less training opportunities (Frey et al., 2020). In a survey of aged residential care nurses and health care assistants, 65% had received some form of palliative care education. This was

most often delivered by the local hospice. As stated earlier Hospices said that they would continue to deliver their business as usual palliative care services, however would not be administrators of assisted dying. As community hospices are the main providers of end-of-life care education and in these facilities, only 14.2% of the palliative care education was delivered by the aged residential care facility (Frey et al., 2020). Most staff, reported wanting further palliative care education for aged residential care facilities. Thus if end-of-life care education is provided by hospices, and hospices are not going to be involved in assisted dying then it is unclear where nurses in these setting will acquire education about this new type of death.

Increased specialist palliative care support in residential aged care facilities has been shown to reduce hospitalisations, and to provide more comfort for the residents and their families. The lack of training, helps to explain why these nurses may feel out of depth with complex end-of-life discussions, and providing palliative care (Frey et al., 2020) let alone providing assisted dying services. If symptoms are poorly managed in patients with advanced disease, this has potential to make a patient more likely to request an assisted death, as unmanaged pain and psychosocial distress are already reported as a factor in death wishes amongst people living in aged residential care in NZ (Cheung et al., 2017). Many nurses in these setting still feel unprepared for managing complex symptoms and end-of-life care, and advanced care planning discussions (Frey et al., 2020). Adding the complexity of assisted dying potentially puts these nurses in a vulnerable position if training is not adequate to support them, complicated by the high turnover of nurses in these areas. Retention in these areas is already difficult and has been worsened significantly through the Covid-19 pandemic with critical staff shortages and burn out is high (NZ Aged Care Association, 2021). This may further burden the nurses working in these facilities. Outside of the hospital setting and aged residential care settings, nursing is also provided in homes and people are supported by nurses in different roles.

District nurses have a skilled role in supporting patients to live well and achieve quality of life, with both malignant, and non-malignant chronic disease at home (Reed et al., 2017; Skelton, 2005). They also support in end-of-life care at home, something that increasing numbers of people are opting for (Midlöv & Lindberg, 2020). In rural communities, where other health services are limited, district nurses have complex knowledge of the people in their community, and the available resources. They form caring therapeutic relationships, and advocate, utilising emotional skill and moral agency (Reed et al., 2017). These roles can be both emotionally rewarding and demanding, and district nurses describe a lack of resource including access to specialised palliative care teams (Midlöv & Lindberg, 2020). The complex role of the district nurse is often poorly understood, in part due to the large scope of practice that they have, and the differences depending on locality (MOH, 2011). The poor understanding of district nursing, and their roles, could suggest that their roles in assisted dying may be misunderstood.

The specific care provided by district nurses varies in NZ, in urban compared to rural settings (MOH, 2011), and this also varies internationally (Midlöv & Lindberg, 2020). The *District Nursing Service Development in New Zealand* report showed the significant role of district nurses in provision of palliative care services (MOH, 2011). Key figures included that 98% of the district nurses reported providing symptom management and support to patients with malignancies; 100% were involved in subcutaneous or intramuscular medication administration; 94% supporting with enteral feeding such as nasogastric feeding or PEG feeding; 85% in IV medication administration. These figures on community medication management are significant in the assisted dying discourse as they indicate that it is highly likely, nurses, more so than general physicians would be routinely involved in these medication management activities services such as those required for administering the lethal medication for assisted dying (MOH, 2011). Also 90% of district nurses provided palliative care, with some as sole providers in the community, with remote support from their region's hospice specialist palliative care team services (MOH, 2011). For nurses in areas with little or no other palliative services available, the district nurses had developed significantly advanced skills and knowledge to meet all presenting needs. With most services providing after hours and overnight support for acute, essential, palliative care needs. When considering specialist palliative care services, usually the role of hospices, and hospital specialist palliative care teams are recognised, whereas district nurses are not considered specialist and rather generalist providers of palliative care despite their evidently significant, and continuously growing role in this sector, consequently, they may also not be the focus of assisted dying education, despite their significant role with patients who may request this mode of death (MOH, 2017). Policy would also be required to support district nurses and their roles in communities.

There was little international data on district nurse involvement in assisted dying. Most studies were focused on nurse attitudes including a study from France where euthanasia is not yet legal practice, finding that many district nurses were in support of assisted dying (Bendiane et al., 2007). Another study in the UK where euthanasia is not legal the author described that in patients with motor neuron disease they often initiate discussions about euthanasia with the district nurse however, once they are made aware of effective palliative care then this is often not raised again (Skelton, 2005). It was found in the UK that district nurses often have a significant role in decisions around end-of-life and advanced care plans, including decisions around resuscitation for multiple patients with chronic diseases to help prevent hospitalisations, and improve patient lead care (Griffith, 2014) thus, will likely also have a role in assisted dying conversations. In the Netherlands there were differences in involvement of nurses in different care settings including decision making around euthanasia. Nurses are frequently involved in hospital or aged residential care facilities. Whereas, in general practice or community settings this was closer to 50% suggesting better communication was needed in community settings (Muller et al., 1997; Van Bruchem-Van De Scheur et al., 2007).

After the law on euthanasia came into force in the Netherlands in 2002, there were issues concerning the legislation with respect to the nurses' role in assisted dying, thus in 2003 Minister of Health commissioned a study into the role of nurses in end-of-life decision making, and the subsequent care of people requesting an assisted death (Van Bruchem-Van De Scheur et al., 2007). In this seminal study, about 22.3% of patients spoke with a district nurse first when inquiring about euthanasia. After the requests were made whether these requests were made to the district nurse or not, some form of consultation between GPs and district nurses during the decision-making process took place in 41.2% of cases. For the actual administration of the lethal drugs 48.9% of GPs did not inform the district nurse when the medication would be administered, despite their extensive involvement in patient care. In at least 79.8% of the analysed cases, patients and or the family informed the district nurses when the lethal drugs would be administered. In two cases, district nurses had gone to patients' homes to find that the death had already occurred which they found disturbing and annoying (Van Bruchem-Van De Scheur et al., 2007). In NZ, there could be a greater chance of this information not being communicated to other health services such as district nurses or hospices that are involved in patient care in the community, as this may be a doctor from the SCENZ group who has had no input with these other nursing services, it is unknown the impact this may have on nurses who have had prolonged professional relationships with patients and families. Policy would help clearly define roles and responsibilities of those supporting people to access assisted dying, and ensuring the responsibility of the health professional orchestrating the assisted death, to notify all practitioners involved in patient care, not only the doctors but nurses and wider multidisciplinary teams.

Van Bruchem-Van De Scheur et al. (2007) found district nurse presence during actual administration of the lethal medication occurred in 13.3% of cases, and this was mainly for supporting the patient and family. District nurses' role in administration included handing the lethal medication including drawing this up, checking this with the doctor, managing the infusion pump themselves or teaching the physician to do this, or injecting lethal drugs via a gastrostomy drip-feed. As above, the role of community medication management including infusion pumps and gastric feeding is usually managed by district nurses in NZ (MOH, 2011). Of the cases analysed 80.3% of district nurses were involved in aftercare following euthanasia this was predominantly as a home visit for a personal talk (Van Bruchem-Van De Scheur et al., 2007). From this study, it was suggested that better collaboration was needed between GPs and district nurses, and that this could help with future policy development internationally. District nurses have a significant role in patient care in people with advanced illness, this includes end-of-life decision making, management of disease and related symptoms, terminal care of the patient, and post bereavement support to families (Van Bruchem-Van De Scheur et al., 2007; MOH, 2011). Nurses are at risk of both distress from arriving for a routine visit to a patient and finding out assisted dying has been undertaken, or lack of supporting legislation for nurses

meaning they are possibly at risk of breaching law through their role being undefined within legislation or guidelines, however possibly participating to support patient, family, or the physician. It is evident from past literature that assisted dying implementation will be a significant practice change in which likely requires corresponding policy to protect and enable nurses to practice safely. It is unclear the provision of support provided to district nurses in NZ since the Act was passed in the implementation of assisted dying.

Other nursing services involved in management of patients with advanced illness care in NZ include nurse specialists from different sub-specialties such as renal, haematology, respiratory, cardiology and oncology (MOH, 2017). Nurses at Māori and Pacific health providers and general practice settings also play a significant role in managing patients with advanced illness, especially as these services are becoming increasingly overwhelmed with the aging population and aging workforce (MOH, 2017). There is evidence that non-specialist palliative care providers often feel ill-equipped to manage patients' palliative care needs. Research has also indicated a failure among non-palliative care health professionals to discuss prognosis and engage patients and their families in end-of-life decision-making, both of which are essential to effective palliative care delivery (Keane et al., 2017). There is evidence in international literature, of the fragmented relationship between generalist and specialist palliative care providers (Keane et al., 2017). With an increased shift from end-of-life care in hospitals to communities there is a need for better coordination between these services (Keane et al., 2017). GPs and special palliative care providers often work alongside each other, but also often have conflicting views. Practice nurses, although often involved with patients receiving end-of-life care, expressed that they had little specific palliative care training. They recognised that GPs at their practices may have had specific training but time to deliver palliative care to patients and families was often a barrier. Where available, if there was a local hospice practice nurses and GPs usually referred patients to them (Raphael et al., 2014). It is planned that nurses will manage people living with chronic conditions including as case managers in nurse lead clinics as the first point of call for the management of health care (NZNO, 2018). However, these roles remain poorly understood, as evidenced by the lack of acknowledgement of the nurse as being a key person involved in patient care in legislation such as the Act, and subsequent policy. Stronger policy that acknowledges nursing roles will likely help wider teams to better understanding what a nurse is, and does, and place responsibility on policy makers to ensure adequate education and resource is in place for a change to practice and policy as significant as assisted dying.

2.3.3 Cultural considerations, nursing and assisted dying

Cultural safety and adherence to Te Tiriti o Waitangi is integral to health care and nursing practice in NZ (MOH, 2017; NZNO, 2018). Te Tiriti o Waitangi has significantly influenced how healthcare has developed in NZ (MOH, 2017). New Zealand is a bicultural country with

people who hold a range of different beliefs, customs and values that influence their ways of life, as well as their end-of-life practices. Providing end-of-life care to culturally diverse patients and their families requires nurses to have an awareness and understanding of cultural differences about death and dying (NZNO, 2018). This is significant not only to patients but also nurses and other health practitioners especially those from minority cultural groups. The Māori nurse role and assisted dying is a significant topic which has been explored by Manson (2021). Manson (2021) found that Māori nurses already experience tension as Māori nurses caused by the history of colonisation, marginalisation, racism, bullying, bias, and dominant white nurse culture that impacts their nursing identity, cultural identity and cultural safety of being Māori as a nurse. With the assisted dying it was anticipated that there would be burdens associated with assisted dying, and the patient's journey to the spiritual world, supporting the patient and their whānau (family) in this, and Māori nurses ongoing significant responsibilities that they carry as Māori nurses in the ongoing care of Māori patient and their families fighting institutional barriers to deliver equitable care (Manson, 2021). Significant effort has not been made to address cultural issues for Māori or obligations under Te Tiriti o Waitangi for implementation of assisted dying (Carrucan, 2020; The House of Representatives, 2019) and was not addressed as a specific requirement within the Act.

Gott et al., (2017b) recognised that most palliative care research in both NZ, and internationally remains predicated upon a specific cultural understanding of the good death, firmly rooted in a Western world view, where autonomy is valued highly. In many cultures' death is viewed as a spiritual process where elders are called upon for prayer and song and care is at home and surrounded by family and death is not a final state but a transition (Moeke-Maxwell et al., 2019b; Terpstra et al., 2021; O'Brien et al., 2013). Malpas et al. (2017) interviewed Kaumātua (elders) and sought their views towards assisted dying. For those in support of assisted dying, they drew on their experience of death the associated suffering at end-of-life. This included their beliefs that to end suffering through assisted dying could be culturally acceptable. Some Kaumātua were strongly against assisted dying and felt that it denies the tikanga (protocol/custom) and mana (honour) of both the whānau and of the dying person. Carrucan's (2020) views reciprocated some of the Kaumātua, that assisted dying violated the mauri (life force or essence), that mauri should be protected and enhanced. He believed assisted dying would mean the mauri is being actively destroyed. Other views included that it denied the taonga (treasure) of life (The House of Representatives, 2019).

Carrucan (2020) also raised concerns about how family would be protected if their family member chose assisted dying and how any whakamā (shame) would be addressed. Shame was also a theme in international literature. Roest et al. (2019) reviewed 66 studies involving family perceptions of assisted dying in the Netherlands. Most family experiences of assisted dying were positive. However, certain themes of shame were found. Andriessen et al. (2020)

conducted a review of literature regarding grief associated with bereavement following assisted dying including studies from Switzerland, Netherlands, and the USA. The findings of this review suggest that the psychosocial aftermath of this type of death is not worse than that of other types of death. However, a difference highlighted was in the social perception of assisted dying and with moral and relational issues within the family caused by the choice for assisted dying. As such, it is evident the choice for assisted dying could cause tensions to arise within Māori families, nurses will likely have a role in helping family to navigate these, that role, and what cultural support services will be available is yet to be defined in the Act. From Manson (2021), it was found that a lot of this responsibility to manage complex situations or complex bereavement for Māori patient often falls on Māori nurses despite them not being provided any additional resource to support these people.

Māori patients and families are less likely to engage with hospice and palliative care services than non-Māori due to the unjust health systems that provide inequitable access to care and are focused on Western values thus it is likely a similar disparity will continue with assisted dying (Gott et al., 2017b; MOH, 2019; Moeke-Maxwell et al., 2019a). Kidd et al. (2018) explored the experiences of Māori in palliative care and found that several barriers existed in the current system of engaging Māori in palliative care including a lack of cultural health literacy of health care professionals. Meaning that they do not understand how to deliver health care and provide information in a way that meets a Māori world view. In the first instance during initial visits, health professionals may approach sensitive topics without understanding the importance of taking time to get to know someone, their family and showing respect for them as a whole person before starting to discuss their diagnosis, and their suffering (Kidd et al., 2018). Moeke-Maxwell et al. (2020) found that a monocultural system of palliative care can make it difficult for Māori to carry out their cultural and spiritual customs at the end-of-life. A lack of cultural health literacy leads to disengagement with palliative care services and risks marginalising Māori from receiving the high-quality care they are entitled to (Kidd et al., 2018; Moeke-Maxwell et al., 2020). It is unclear how this reduced access to quality palliative care to reduce suffering in advanced illness will impact on requests for assisted death based upon unmanaged suffering or whether there will also be disparities in access to assisted dying through it being viewed as a taboo or shameful death, or that people need to first know about assisted dying being available to be eligible to access it (The Act, 2019). For Māori nurses being seen as role models for delivering care to Māori can cause fatigue from resistance met when advocating for Māori clients and the fight to improve services when their cultural contributions undermined by colleagues or wider organisations (Simon, 2006; Hunter, 2019).

Hospice and associated palliative care services are also under-utilised and commonly misunderstood among many minority cultures in NZ including Pacific populations in NZ (Foliaki et al., 2020). The Pacific individual is seen as one component of a collective that is

critical in major decisions in end-of-life that the wider family is involved (Foliaki et al., 2020). For many indigenous people, death is viewed as a spiritual process and is not considered a final state rather, a transition or journey from this life to the afterlife (Terpstra et al., 2021). In countries such as Australia, the United States and Canada there are indigenous populations with cultural practices that differ from Western end-of-life practices for example, in Canada, indigenous populations regard dying as a spiritual process, and have practices that are often disregarded in hospital settings (O'Brien et al., 2013). Terpstra et al. (2021) identified that health practitioners often have limited understanding of how to meet the cultural needs of aboriginal Canadians. In review of assisted dying legislation in Canada their select committee recommended that support and services, including culturally and spiritually appropriate end-of-life care services for Indigenous patients, should be improved to ensure that requests are based on free choice, particularly for vulnerable people however, Indigenous spiritual practices are not regularly addressed in modern health care systems (O'Brien et al., 2013)

Despite these recommendations in Canada, they noted that Indigenous organisations and communities had not been involved in discussions relating to assisted dying. Of the 68 safeguards for assisted dying identified in Victoria, Australia there are none specific to culture identified and no recommendation for seeking cultural consultation (Victoria State Government, 2017). Cultural safety is mentioned in the Victoria State Government, assisted dying guidelines in that Health practitioners should be aware of cultural and religious issues that may affect the decision making of patients and families at this time advising that in some situations, health practitioners may find it helpful to seek culturally appropriate assistance in talking to patients about end-of-life concerns and options (Victoria State Government, 2017, 2019). The need for cultural consultation was highlighted frequently in NZ literature about creating assisted dying guidelines and in working with those who chose assisted dying however, the lack of multicultural input remained a contentious issue throughout assisted dying debate (Carrucan, 2020) Again, this is not only significant to patients of minority cultures but also to nurses from minority cultures that may be challenged by the introduction of assisted dying.

2.4 Conclusion

Throughout this literature review it is clear that assisted dying is a complex social issue understood within the sociology of dying and is not purely a legislative change. This is a change to the dying process and a significant practice and policy change for nurses. Despite this being acknowledged from past literature, the role of the nurse remained undefined in NZ legislation and poorly defined within guidelines. Nurses are central to instigating and enacting change in health settings, however, evidentially minimal research had been undertaken in NZ into how this change may impact upon nursing practice. It is clear nurses have significant roles in patient care, especially in patients with advanced illness who would likely be eligible for assisted

dying. Past literature explored some issues in relation to practice and policy implications for nurses however, there was limited literature specific to the NZ health context and after the Act was passed. Throughout this research, I hope to bridge the gap in knowledge of the practice and policy implications for nurses with the introduction of assisted dying.

Chapter 3 Methodology

In this chapter, the steps taken to carry out this research are outlined including the development of the research question, aims and objectives. The methodological approaches are described. The ethical considerations, recruitment processes, data collection, analysis process, and themes are identified. This chapter formulates the framework for the subsequent findings and discussion chapters.

3.1 Research question development:

The development of an answerable research question is challenging, and initially, I planned research engaging with bereaved family members, to better understand their experiences of end-of-life care and suffering when there was access to specialist palliative care in the home. Given this experience, I hoped to understand their views towards assisted dying with a focus on Māori families and their views through a Kaupapa Māori methodology. I also intended to do two interviews with Māori specialists in the field of end-of-life care and assisted dying to better understand the relationship between the Act, policy, actual care, and the dying experience from a Tikanga Māori perspective to help guide those delivering care to meet the needs of Māori.

However, during the process of consultation with academic leaders in Kaupapa Māori research, a number of gaps were identified in my knowledge and experience that could potentially put this population at risk. As a masters' student I am new to research, and new to Kaupapa Māori methodologies. Although I have Māori ancestry my world views are largely influenced by my Western upbringing. Those that I sought consultation from were gatekeepers of Māori research, and have a role in protecting Māori knowledge and those that it can impact upon. Gatekeepers might see researchers as unsuitable because of gender, age, experience, cultural background or lack of trustworthiness (Holloway & Galvin, 2017). In this instance, it was a combination of my lack of experience and that although I am Māori I am also Western. It was identified that a more Māori nurse potentially could do that research. It was raised that I could do a disservice to the families, and the stories that I hoped to share. Instead of uplifting and providing insight to guide practice in the area of supporting families through assisted dying, I was encouraged to reflect that there was risk I would apply a Western lens to the research that may disrupt the meaning of the individual family narratives. As I wanted to ensure the strong, significant spiritual, and cultural importance of these stories were maintained, and shared by the right person, I made the decision with the support of my supervisor to change the direction of the research.

Something of equal significance to me as supporting and uplifting patients and family, is the protection and growth of nurses. Throughout my career I have always been passionate about nurse education and nurse's experience of nursing. How to see nurses succeed, grow, remain in

nursing, and find meaning in the work they do. As a nurse now working as a clinical nurse specialist in palliative care within a tertiary hospital, part of my role has been supporting other nurses. I have a strong interest in the nursing contribution to the health workforce. I witnessed within my workplaces, that assisted dying would be highly impactful for nurses, specifically in a number of settings where end-of-life care is provided, including community roles such as hospices and aged residential care facilities. In this current role I have been approached by both ward nurses, and nurse managers seeking information about assisted dying and concerns about how to respond to requests. Since the start of this research, there has been one thesis completed on Māori end-of-life nurses' views towards assisted dying however interviews were conducted prior to the Act passing. Therefore, there was a clear need for furthering the information. Nurses working in end-of-life care are a less vulnerable participant group than bereaved family, and I recognised that the practice and policy implications for these nurses was poorly understood therefore, leading to the shift of the research focus.

3.1.1 Research Question:

With this context in mind, the research question developed was: What do nurses perceive as practice and policy implications of assisted dying based on their experience in end-of-life care?

3.2 Aims and objective:

After significant consideration, and development of the final research question, the aim of this research was to contribute to the assisted dying discourse, and bring forward a nursing voice into the discussion of the impact of assisted dying in the end-of-life care setting. Interviews were undertaken after the End-of-life Choice Act passed but two months prior to November 2021 where it was enacted, during the planning and implementation phase. The objective was to better understand what nurses experienced during this implementation, and what they anticipated to be the policy and practice implications going forward working with patients and families who may request assisted dying, and how these translate to actual patient care.

3.3 Methodological underpinnings:

3.3.1 Qualitative research

Qualitative research is a form of inquiry commonly used within the social sciences and frequently used in nursing research (Parahoo, 2014). Social constructivism and qualitative research are naturally compatible through mutual acknowledgement of the complexities of the human experience, and the researcher's distinct role in exploring this (Kim, 2014). This form of data collection allows the researcher to endeavour to understand perspectives of participants through means of exploration, learning from others, their cultures and their experiences (Parahoo, 2014). Qualitative research is concerned with making sense of, understanding and

interpreting meanings people make of their experiences in the world, rather than purely producing statistical data from which to draw exact conclusions (Silverman, 2015). Qualitative researchers develop person centred, and holistic perspectives, to help develop an understanding of human experiences. This is important for health professionals who focus on caring, communication, and interaction, allowing for exploration of emotions, perceptions, and actions (Holloway & Galvin, 2017).

These factors make qualitative approaches appropriate for this specific research, where the true impact of assisted dying could not be understood in numbers and percentages. It is better articulated through stories that hold meaning. A qualitative design allows flexible and interactive means of data gathering that is holistic (Parahoo, 2014). It provided a flexible framework to draw upon in this study, and assisted with bringing visibility to a poorly understood phenomenon. This is relevant to this subject matter where there is little pre-existing knowledge or research within NZ pertaining to practice and policy implications of assisted dying for nurses. Approaches to social inquiry consist of the procedures of sampling, data collection and analysis, but are also intertwined with particular ideas about the world and how knowledge is constructed (Holloway & Galvin, 2017). There are multiple methodological approaches that can be employed within qualitative research which highlights the diversity required to understand the different disciplines (Holloway & Galvin, 2017). This qualitative study is situated within a social constructivist paradigm, as nursing and nurses have an interest in questions and issues of human subjectivity and developing holistic understandings of people and their experiences (Borbasi et al., 2010). For this reason, nurse researchers often embrace qualitative methods where they can explore and draw meaning from real life experiences therefore, narrative inquiry will be used to explore key issues of assisted dying as reported by nurses and specific to the nursing profession.

3.3.2 Ontology and epistemology

Ontology forms part of the sociological debate between structure and agency and the influence attributed to each, in shaping our social realities such as the social changes that have led towards legislation of assisted death (Bryman, 2016). It concerns the nature of reality, that can be seen as a continuum corresponding to the research paradigms from positivism to constructionism (Bryman, 2016). For this study, as earlier described, I drew upon a social constructivist paradigm accepting that individuals construct meaning, assuming that meaning and knowledge is constructed rather than discovered (Gergen, 2015). Epistemology considers the nature of the relationship between the knower, the knowledge that is sought and the validity of the knowledge (Bryman, 2016). The socio-historical context of this research being that we are at a time in history where there is an awareness of death, and value of autonomy, allowing for such a change to occur. Within the social constructivist paradigm, the researcher plays an active role in acquiring and creating knowledge, as it is accepted that they bring their experiences to the

research (Bryman, 2016). Thus, knowledge is always subjective because it is constructed and understood through their worldview (Bryman, 2016). As the researcher, through my worldview I am neither strongly for, nor against the practice of assisted dying however, as a nurse I was concerned with the impact of this societal and legislative change on nursing practice and policy.

3.3.3 Establishing trustworthiness:

Trustworthiness is achieved through thorough planning and recording of the research process, using a systematic approach and in the engagement with experts in all stages of this research including in analysis of data (Cypress, 2017). Trustworthiness is commonly used in qualitative research to describe means of methodological soundness. To allow for trustworthiness and reliability, qualitative research needs to be transparent. Reliability is linked to replicability and auditability. Within qualitative research, the research can never be wholly replicable (Holloway & Galvin, 2017). This research can be replicated in terms of process, but not the actual stories given different participants and researcher. Future studies can be accurate, reflect the words of participants, and may produce similar results in related settings and contexts. I have provided detail of all the methodological underpinnings, and step by step detail of how the research was carried out including through analysis and ensuring validity.

Rigor and validity are achieved through transparency, thoughtfulness, methodological congruence (Braun & Clarke, 2016). Rigor has more commonplace in quantitative research due to its connotations with measurement and objectivity (Holloway & Galvin, 2017). There is controversy surrounding rigor in qualitative research however, it is generally accepted that rigor must be maintained throughout the research process. Rigor is achieved through the use of discipline, attention to detail and accuracy, including in the recording of processes and decision making, as without the stiff boundaries within qualitative research, establishing trustworthiness is important. I followed structured recording processes, a five step process from study conception, design, conduction, analysis and following completion I plan to use the study to contribute to evidence based practice (Borbasi et al., 2010).

Credibility involves ensuring that the conclusions of the research were seen as truthful and the findings are compatible with the perceptions of the people under the study. To achieve credibility in this study several steps were taken. I used well-established research methods, as in nursing narrative inquiry is known to be a method useful to uncover nuance and detail of experiences, acknowledging that nursing practices are dynamic processes characterised by the continuous interaction of human thought and behaviour (Wang & Geale, 2015). Credibility is achieved through prolonged engagement, persistent observation and triangulation (Korstjens & Moser, 2018). When engaging in the interviews I made sure there was sufficient dedicated time to both build rapport, trust and familiarity to get to know participants as the holders of data and knowledge that would ultimately become the findings. Persistent observation was achieved

through establishing alongside my supervisor and true to narrative inquiry prompts to guide the interviews, identifying elements that are most relevant to the problem while also allowing the participants through their narratives to guide what is of greatest relevance to them. For data triangulation, I recruited a range of participants of different demographic backgrounds and different nursing experience and different rural and urban settings across New Zealand for insight into whether there was cross-site consistency in the data and while conducting interviews I took field notes as well as recorded my own reflections of the experience of engaging in the interview directly after the interview and during interviews clarified meaning with participants.

Reflexivity locates the researcher inside the research project, examining the researchers own conceptual lens, assumptions, preconceptions and values including the impact of these on research decisions, in all phases of qualitative studies. This is the process wherein the researcher engages in explicit, self- analysis of their own role (Holloway & Galvin, 2017). It is a conscious attempt of the researcher to acknowledge their own involvement in the study. To constantly locate and relocate themselves within their work (Gillam & Guillemin, 2018). The main shared cultural group in this study was end-of-life nurses. As I belong to this cultural group it was important for me to maintain self-awareness. Kassan et al. (2020) found that the cultural background of researchers influenced the interview interactions and including the depth of data that can be gained through participant's ability to feel open and share their honest stories. As a nurse researcher, engaging in research with nurses, instead of methodological concern with power imbalances studying up or down I acknowledged the set of concerns in relation to producing empirical material when 'studying sideways' (Plesner, 2011). Prior to engaging in my first interview I was guided both by my supervisor and I sought consultation from an experienced interviewer and journalist and reviewed literature for strategies for studying sideways. I did this to build specific skills for engaging in narrative interviews and not placing my own story within the story or participants. This raised the importance of allowing periods of silence, not asking leading questions also on building rapport when remotely interviewing. Strategies when studying sideways include creating objections with interpretations during interviews to deepen understanding through participants defence against the interviewer's misinterpretations rather than agreeance (Plesner, 2011).

Reflexivity when studying sideways is questioned by Plesner, (2011), of the researches reflexivity versus the inherent reflexivity of participants and giving reflexivity back to the participants, acknowledging that their accounts are intrinsically reflexive. Focusing on participant's reflexivity has the potential to get closer to the participants and to be more interesting than merely applying self-examination to enhance the validity of the interviewers' research practices (Plesner, 2011). Throughout the interviews I sought to challenge and question participants' views rather than accepting my own understandings of what they were narrating

based on my clinical understandings as a nurse. To aid with self-awareness after each interview I reflected on my experience of the interview maintaining reflective journaling. This helped with identifying my own beliefs and assumptions, as well as how the stories impacted upon me. Throughout the analysis process, I also frequently engaged with my supervisor and jointly discussed the impact of the stories on myself as the researcher and on the findings.

Validity in qualitative studies is achieved through making the researchers own assumptions and research decisions visible. As with many qualitative methodologies, the means of analysis are scrutinised for their validity. Within thematic analysis, some of this lies within novice accounts of themes simply emerging from the data without thought or articulation, potentially rendering the methodology as questionable (Braun et al., 2019). Failure to account for how themes have emerged can be...

...Misinterpreted to mean that themes 'reside' in the data, and if we just look hard enough they will 'emerge' like Venus on the half shell. If themes 'reside' anywhere, they reside in our heads from our thinking about our data and creating links as we understand them (Ely et al., 1997, p205-206).

However, it is more true to say through thinking about the data and creating links we begin to understand them (Braun & Clarke, 2016). Thematic analysis is congruent with the theoretical framework of a social constructivist paradigm, and narrative inquiry. Within thematic analysis, knowledge is accepted as co-produced between the researcher and participant. In thematic analysis the researcher requires credibility and reflexivity, including awareness of their own role in shaping the research. The research processes were carefully planned out and there was thoughtfulness, and reflection in all stages of the research process. The steps taken will be detailed within the following sections.

3.3.4 Narrative inquiry

Narrative inquiry emerged as a discipline within qualitative research as a means to understand life experiences (Riessman, 2008). Narratives are oral or written accounts of daily life, reports of events, stories, gossip in past, present and future times which become the data that provide a deeper understanding of cultural and historical identity, and life (Daiute, 2014). A key point of this approach is understanding, not only the story, but the way in which it has been told. This includes observing emphasis in parts of a story, facial expressions or emotion evoked throughout the story telling process. The participant's narratives are considered their representations and interpretations of the world. What they remember or share of events and the way these are applied to the current situation is what is of significance (Muylaert et al., 2014). The narratives are expressions of their truth of a point of view in a particular time, space and socio-historic context. The significant context in this research being the introduction of assisted dying into the practice of end-of-life nurses. However, this is impacted upon by external factors

such as the global pandemic of Covid-19 which in itself shaped some of the design, recruitment and engagement of this research.

Narrative research allows the stories to be maintained from the story teller's perspective, compared to other methods concerned with interpreting what a person's experience is like rather than allowing the participant to define the experience. In narrative interviews, questions are generated to help elicit the stories rather than structure a guided interview (Allen, 2017). Narrative inquiry is a method wherein the relationship between the participants is a narrator-listener relationship instead of an interviewer- interviewee relationship (Riessman, 2008). This allows the researcher opportunity to better understand the participant, their individual meanings, and their lived experiences (Bold, 2012). The focus is on few in-depth narratives that go beyond simple descriptions so a large sample size is not of great importance, the depth achieved is of greater significance (Muylaert et al., 2014). This was taken into consideration with recruiting a maximum of ten participants. As with many qualitative approaches it does not have clearly structured processes regarding the means through which data is collected and analysed (Richards, 2015). The stories can be viewed as a window into a reality and be analysed using concepts derived from theory. In this research, nurses are placed of the experts of their experience, hearing their stories and how they tell them is important in understanding the meaning this holds for them as nurses rather than trying to deconstruct the stories. In narrative inquiry, researchers need to plan for meaningful data reduction without losing the core ideas and meaning of the subject matter, thematic analysis was the chosen as the method of analysis in this study (Richards, 2015).

3.3.5 Thematic analysis:

Meaning was derived from the stories of participants through thematic analysis. In thematic analysis, themes across each participant's stories are identified so that the data can be understood and sense can be made from them (Riessman, 2008). Thematic analysis is commonly used to understand narrative research because it allows greater depth and description in the analysis. Ideas are kept whole, often integrating participants own words in the reporting, compared to other methods of qualitative research analysis that deconstructs ideas (Braun & Clarke, 2006, 2016; Polit & Beck, 2021). Thematic analysis can be applied to multiple types of data and can generate case studies of individuals, groups and typologies. Themes capture the essence and spread of meanings and unite data that may otherwise appear incongruent (Braun & Clarke, 2016). The themes are malleable and based on the information gathered. Working with the nurses on this topic where there is limited prior knowledge, it was important not to deconstruct their ideas and potentially alter the meaning of their stories. Rather keep ideas whole, but find shared meaning in the stories. A key aspect of thematic analysis is calling on subjective accounts and valuing insider knowledge such as the knowledge held by the nurses in this study.

3.3.6 Ethical considerations:

Ethics approval was applied for and granted through the AUT Ethics Committee reference number 21/179 (Appendix A). Within the context of NZ, the ethical and professional values and principles relevant to researchers include obligations under the Te Tiriti o Waitangi and principles of free enquiry, an open society and human and civil rights (National Ethics Advisory Committee, 2019). This includes respectful and rights-based knowledge discovery between researchers, participants, and communities with the goal to advance science, technology and the humanities in NZ, and recognise the potential impacts on communities, including their intergenerational interests (National Ethics Advisory Committee, 2019). The goal of this research was to contribute to nursing practice, and thus, contribute to engagement with patients and their families. Key components include professionalism, integrity, care, and diligence by appropriately knowledgeable people. I followed the AUT code of conduct for research (2019), as a registered nurse engaging in nursing research, I also followed the code of conduct for registered nurses and code of ethics (NZNO, 2019; NCNZ, 2012). I was guided through consultation with Māori experts shown in the changing of the research focus away from bereaved family, to instead engaging with nurses to protect a potentially vulnerable participant population. After changing the research question I also consulted with AUT Mātauranga Māori committee and took their considerations on in the design of the research to make it accessible to Māori including identifying myself as Māori in the participant recruitment information.

3.4 Research process:

3.4.1 Sampling:

Sample size in qualitative studies have less to do with the actual number of participants and are more closely linked to the quality and depth of the information elicited throughout the research process (Holloway & Galvin, 2017). After thorough discussion with my supervisor and an AUT the research ethics advisor, and staying true to the methodological recommendations, it was decided that the goal would be for six to ten participants. I used purposeful sampling aiming to make sure the sample characteristics resemble the nursing population as closely as possible so the samples represent the population (Borbasi et al., 2010). I recruited nurses from a number of different end-of-life practice settings, as I recognised that they would likely be impacted upon by this change and it would be relevant in their practice areas. At the conclusion of the recruitment process a total of ten participants were interviewed.

3.4.2 Recruitment:

In the development and planning phase of this research, I had planned to recruit from local hospices, aged residential care facilities, and district health boards, with face to face explanation of the research, and flyers about the research. This method was chosen as face to face

recruitment is often the most effective in recruiting health professionals (Bruneau et al., 2021). However, there were a number of factors that caused reconsideration of this process. Due to Covid-19 and the risk of future lockdowns, face to face recruitment could have been disrupted. Some of the interviews ended up occurring during a level 4 lockdown in NZ so virtual, non-contact consultations were the only means possible (Department of the Prime Minister and Cabinet, 2020). I took into consideration the time it would take to both physically arrange recruitment, and the possibility of needing to apply for locality ethics approval especially in the current health setting where Covid-19 response remains the priority for District Health Boards (Department of the Prime Minister and Cabinet, 2020). Recruitment time was a priority due to assisted dying becoming legal in November 2021. My plan was to have all interviews completed prior to the Act coming into force for consistency of data, independent of issues following the date of implementation, which I achieved. As there is a small distinct network of nurses working in end-of-life care, some with high profiles at their workplaces, recruiting nationally allowed for a wider layer of confidentiality (Petrova et al., 2016). I also wanted to make research participation accessible to Māori and Pacific nurses so that the research represented a NZ health context. After consultation with a Māori nurse researcher, she reported that she found she was able to recruit a wider number of Māori nurses when requests were disseminated nationally allowing for virtual interviews. Recruitment was through contacting professional organisations including NZNO and their subsidiaries, and Hospice formal education or professional channels. Initial emails were sent introducing the research and requesting that the information be dispersed within their networks. Attached to this email was the participant information sheet and researcher contact details (Appendix B).

3.4.3 Inclusion/ exclusion criteria

Inclusion criteria for this study included that participants were nurses, working permanently in end-of-life care settings, both specialist and generalist palliative care settings. This included areas such as hospices, aged residential care, district nursing, hospital wards and specialist palliative care nurses. Exclusion criteria included individuals who I had a social or current working relationship with, or nurses that had worked in end-of-life care for less than one year. The response to recruitment was positive and recruitment was swift with responses within days of initial requests for participants and all recruitment complete within four weeks.

3.4.4 Participants

Ten nurses in total participated from all over NZ. They were diverse in gender, culture, practice setting, and experience. Most had completed some postgraduate education either certificate diploma or masters. Experience ranged from ten to forty plus years (Table 2).

Table 3 Participant demographics

Gender		Self-reported Ethnic group		Nursing role		Years of Nursing experience	
Male	1	Māori	1	District nursing	2	<10	0
Female	9	Pacific	1	Hospice (inpatient)	1	10-20	2
		Asian	1	Hospice (community)	2	20-30	2
		European (NZ)	3	Palliative care education	1	30-40	2
		European (UK)	2	Hospital palliative care	1	>40	4
		European (USA)	1	Nurse practitioner	1		
				Aged residential care support	2		

I did not get any responses from nurses working directly in hospital wards or in generalist nursing roles in aged care facilities where nurses frequently provide end-of-life care. A factor in this may have been the recruitment being virtual and through professional bodies and education channels, as face to face recruitment is often the most effective in recruiting health professionals including nurses in research however as outlined above remote recruitment methods were chosen due to Covid-19 and for an additional layer of confidentiality (Bruneau et al., 2021; Petrova et al., 2016). I did have nurses supporting hospital wards and aged care facilities that have regular interactions with these nurses, so it provided and insight into some of their chief concerns that may be present for these nurse groups not specifically included.

3.4.5 Interaction with participants

Participants were provided with participant information sheets (Appendix B) with interview prompts attached (Appendix C) and consent forms (Appendix D) so that they had all of the necessary information to make an informed decision about whether they would like to participate, and who to contact if they chose to withdraw. Participants were able to withdraw from the research at any point during, or after the interview, prior to analysis commencing. If participants chose to withdraw, they were offered the choice of having identifiable data removed, or allowing it to continue to be used. However, none chose to withdraw. They were informed that they could access three free sessions of counselling through AUT for any emotional harm caused by participating in the research. They were also reminded that they could engage with their workplace free counselling services if recalling events from practice evoked an emotional or traumatic response (National Ethics Advisory Committee, 2019).

Interaction prior, and following interviews occurred via email. I discussed confidentiality, their roles and responsibilities, potential risk, all steps taken to remove identification however anonymity was not guaranteed due to the small palliative care community. Participants were made aware that if any involvement in illegal activities were identified then I may be obliged to report this. However, no actions were required. At the start of the interviews I gained informed consent. For the face to face interview a printed consent was signed. For the zoom interviews I had a specific verbal consent protocol and verbal consents were obtained.

Qualitative researchers understand that the context of participant's lives or work effect their behaviour, and acknowledge that the participants are grounded in their history and temporality (Holloway & Galvin, 2017). Of the ten interviews, one took place face to face, the other nine were via Zoom. Many of the nurses had families and many work shifts, or were involved in other commitments outside of work, thus, being flexible to allow a time and place and being able to conduct interviews virtually was in part of understanding the participant group I was interviewing. Zoom allowed flexibility for participants from different cities across NZ and were able to be conducted around work rostered times. The duration of each interview was approximately one hour.

Allowing an added layer of confidentiality in recruiting online as well as having the choice for participants to interview virtually in a place where they felt safe was important (Petrova et al., 2016). For the face to face interview this was conducted at AUT in a private room, at a time convenient to the participant and for Zoom interviews most participants completed this from a room at home or in a private room at work. The interviews started with thanks for their participation, and a small period of introductions and an explanation of the importance of hearing their stories and views with them leading the narrative rather than me acting as interviewer and them as interviewee. Karakia (a blessing often offered at the start and closing of a meeting) was given by the Pacifica and Māori nurse. I provided a gift card as a thank you for all participants' participation.

3.4.6 Interview prompts in narrative interviews

The interview prompts (Appendix B) were used to encourage the sharing of narratives of different matters relating to assisted dying and how these contribute to the views held by the nurses. They were a means to gain an understanding of experiences. I encouraged participants to explore what influenced the views they hold. This included their past experiences personally and professionally, their culture, upbringing, religious beliefs, education or anything else they felt was important to them and informs their views and nursing practice as well as policy implications. They were not read directly but rather used to place the narrative in the context of the research.

3.5 Transcription:

Data was transcribed verbatim by a paid transcriber that was recommended by my supervisor. Prior to the interviews being sent for transcription they were cut to separate the verbal consent from the interview to allow additional confidentiality. A confidentiality agreement (Appendix D) was signed by the transcriber that detailed their duty to maintain confidentiality and agreed by the transcriber that no copies were to be kept once transcription was completed. This topic was sensitive including topics around assisted dying and nurse's experiences working with people at the end-of-life. Due to the sensitivity of the topic, there was potential for this topic to be triggering of emotive for the transcriber. Before the transcriber agreed to transcribe, and before sending the first recording, I informed her of the topic, and ensured that she was able to withdraw from her role at any point and that support was available if she was affected by any of the topics covered or stories shared in the recordings. To ensure accuracy of transcriptions I listened to the interviews while reading the transcriptions and making additions or changes where needed to ensure they were accurate as is detailed within meaningful analysis when doing thematic analysis (Braun & Clarke, 2016).

3.6 Data analysis

Initially, I had planned to attach pseudonyms to each participant and introduce each participant individually. However, throughout the stories it became evident that the nurses would likely be recognisable if each participant was singled out and each story told individually. Recognising that participants could be identifiable, I had an ethical responsibility to adapt the research to ensure confidentiality was maintained (Petrova et al., 2016; Borbasi et al., 2010). The issues around confidentiality have been described in focus group (Sim & Waterfield, 2019) and participatory research (Petrova et al., 2016) however I could find little past literature about this issue specific to nursing narrative inquiry research specific to NZ where there is a relatively small end-of-life nursing community. It was clear many of the nurses they held views they felt uncomfortable to share openly, including with their friends, families and workplaces so protecting their identities was incredibly important. Thus, rather than speaking about each individual with a pseudonym and putting the person behind the story identifying them with differentiating factors such as the gender, culture, religion, specific work area I have instead placed them all as what they are in this research, as nurses. Nurses, that bring a diverse background with them into the work that they do, and whose careers have taken different paths, but who all, in their own way, are impacted by this new legislation.

Prior to commencing the data analysis, I attended a thematic analysis workshop hosted by Gareth Terry at AUT to gain skills in thematic analysis, as I previously had limited understanding of this process. I followed the six steps of thematic analysis including familiarisation, coding, generating themes, reviewing themes, defining and naming themes and

writing up (Braun et al., 2019). Following the initial review of recordings and transcripts for accuracy, I immersed myself in simultaneously re-listening to the interviews and re-reading through transcriptions. I highlighted quotes while taking small notes. I then broke this down line by line and phrase by phrase drawing maps to visually organise the data, my early thematic maps are referenced in Appendix F. Thematic maps can be used to visualise how codes fit together, tell the overall story of the data, and generate themes (Braun et al., 2019). The codes were taken directly from the narratives using the terminology used. Codes in the data were identified and where necessary rephrased. At this stage maintaining openness to all possibilities of themes is important in developing the themes (Braun et al., 2019). The analysis was then moved into coding tables to start to categorise the codes. Through this, the themes were then developed by finding links between the codes and understanding in the meaning of that code while allowing the stories to hold their meaning.

Through applying the skills learnt in the thematic analysis workshop I was able to find relationships between the codes and ask questions of the data. I was able to identify what was happening and find how codes related to other codes when recoding and analysing. I learnt that through the process if codes are not picked up initially, that when realising data they became more relevant and the relevance deepened when they were compared to other interviews and data (Braun et al., 2019). The interviews were recoded and analysed and compared three times initially to fully understand the codes and develop the themes that represented the narratives of the nurses and how they told a deeper story, I then looked back on the transcripts after themes were established to better understand the narratives when compared alongside the themes. Some of the meanings became deeper when comparisons were drawn between different interviews and the complexities faced by each participant. The following themes provided a framework to explore the more in-depth discussion of the issues.

Table 4 Themes

Overarching theme: Assisted dying challenges the professional identity of end-of-life care nurses		
Own world: <i>Being human makes a nurse</i>	Patient and family world: <i>We are here for them</i>	Professional world: <i>I feel very unheard</i>

At first, the process of establishing themes felt overwhelming. However, the thematic maps (Appendix F) allowed for visual representation of the data, although likely illegible to the outsider is where the ideas began to fit together. Through stepping away from the data, ensuring I always had a pen and paper in hand whether once in bed at night, or out for a walk, allowing time for thoughts to have space to grow and connections to be made. Multiple possible themes were being made apparent in the initial analytical process. Through writing, thinking, stepping away, discussion and reflection, the overarching theme: *Assisted dying challenges the*

professional identity of end-of-life care nurses was established through this constant tone that nurses felt conflicted and challenged holistically. Assisted dying was something similar to their work, and a lot of their usual work would continue alongside it, but it was different, they felt a strong duty of care professionally and personally to act or react or prepare but were at a loss with how to do this and had in many cases had tried to no avail and there was frustration, desperation, loss and anticipation. The three subthemes were an organisation of the key elements of the different worlds of nurses and established from the narratives and how they interact to form or deform their professional identities.

3.6.1 Conclusion:

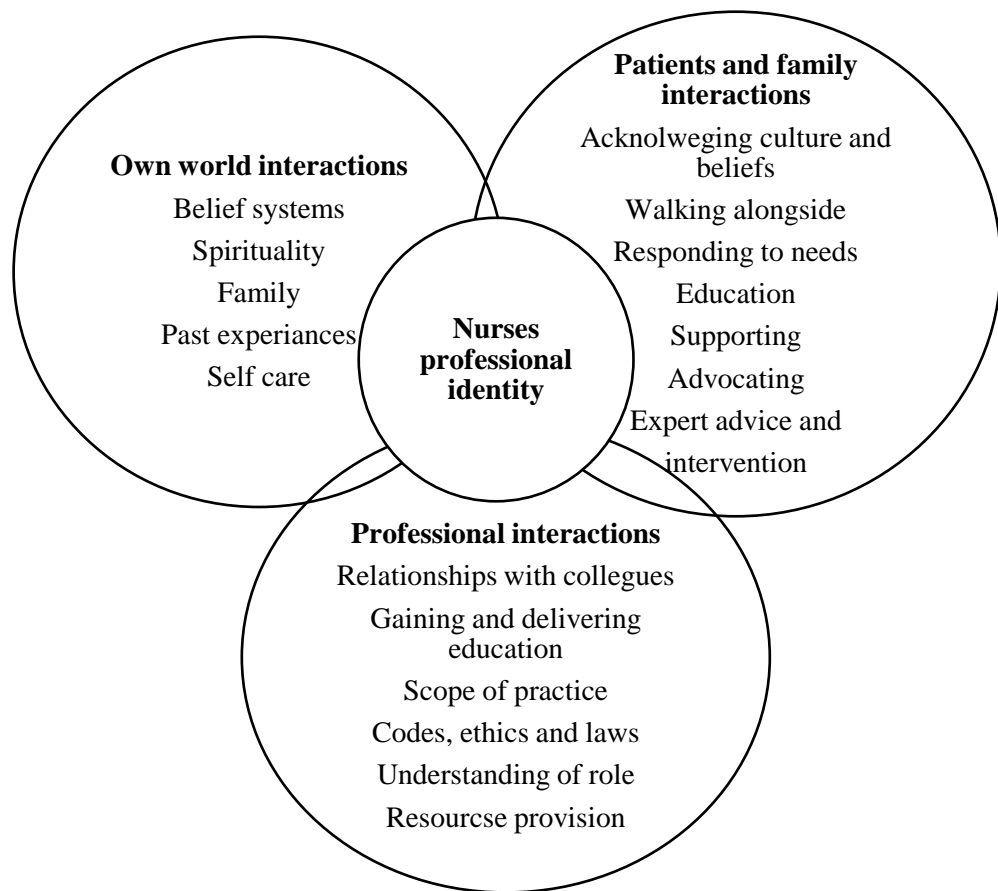
I undertook this research because I saw this as a meaningful and impactful topic. The process of establishing the research question and basis for the methodological underpinnings chosen were described in this chapter, including their appropriateness for this research question. This was presented in a transparent and coherent manner to ensure rigor and validity were maintained. Replication of results will be exposed to subjectivity of the researcher as well as being set in a specific historical and social context. The consultation process, barriers and adaptations that were made, were explained with justification provided for the changes made to the research design. The process of analysis was described with themes listed. The findings will be presented in the next chapter.

Chapter 4 Findings

This chapter pertains to presentation of the research findings. Understanding the significance of this conversation of assisted dying is important for nurses who are at the front of holistic, end-of-life patient care (Evangelista et al., 2021). This is founded by past understanding that assisted dying challenges nurses both personally on their own moral values and professionally (Pesut et al., 2019). It is also central for the guidance of policy makers in better supporting nurses to advance in their roles supporting patient, and family care (Manning & Kriebel, 2020). The nursing voice has not been sufficiently heard in the assisted dying discourse in NZ, and is often missing internationally when implementing policy that impacts patient care (Royal College of Nursing, 2020; Tsai & Menkes, 2020). The overarching theme was: ‘Assisted dying challenges professional identity of end-of-life care nurses’ with the three subthemes: Own world: Being human makes a nurse; Patient and family world: We are here for them and; Professional world: I feel very unheard. These will be individually presented in this chapter.

4.1 Overarching theme: *Assisted dying challenges the professional identity of end-of-life care nurses*

The overarching theme ‘assisted dying challenges professional identity of end-of-life care nurses’ was founded on the premise that nurses in this study described when discussing assisted dying and the holistic implications on their practice. The lack of clear transparent guidelines and expectations of nurses in practice regarding the new legislation and specifically how this challenged nurse’s professional identity was evident throughout all of the nurse’s narratives. Table 5 is a depiction of the factors that nurses described that influenced their professional identity and their overall experience of being a nurse in an end-of-life care setting.

Table 5 Nurses Professional Identity

The above diagram depicts what nurses described central to them and their nursing practice being identified as their professional identity. They described implications of assisted dying being present leading up to the legislation passing, current during implementation and expected in relation to their own world, patient and family world, and professional world interactions.

4.2 Theme one: *Own world: Being human makes a nurse*

The first theme of '*Own world: Being human makes a nurse*' nurses described what makes their nursing role meaningful, what gives them the ability to stay in an area of practice where they are frequently exposed to death, how they maintain self-care and where assisted dying sits within this. Initially, I thought the start of the interviews would be about building rapport before exploring the core of the nurses expected practice and policy implications of assisted dying. However, I realised this was the foundation for the research. Seeing the nurses as individual people with their own core values in a shared situation was important to the story, and for beginning to understand the implications of assisted dying on their practice.

4.2.1 Nurses and nursing as a calling

Nurses were from a range of backgrounds but some had shared stories. The first point of note, however, was them having a family member that was a nurse was common.

I wanted to be a nurse is because my grandmother was a nurse...she's always, always wanted one of her children or grandkids to be a nurse... had one Māori friend, one Tongan so it was a very small group of us minority and other Asians... I failed my first date and then I had to wait six months... But I thought nah I can do this, I'm sure there's a purpose in life for me to be a nurse given that my nana was a nurse. So yeah I carried on I, finally became a registered nurse thank God! (p7)

For this participant, becoming a nurse was something that they were proud of and was a part of their purpose in life however they described overcoming adversities to achieve this. Another participant spoke about coming from a family of nurses and how they had early exposure to death. This helped them to accept death as a normal part of life.

I grew up very early on, yeah being exposed to nursing, going to all these funerals... having the deceased brought home... It was sort of very similar to Māori culture in some way... very much ah grew up know, knowing that death and dying, it happens. It, it happens to us all and yeah so I do, consider it normal (p8)

However, not only having a family member as a nurse was notable, nurse's spirituality or religion was closely intertwined with their choice of career and its level of meaning to them personally.

I remember talking to my mum about this role and she said... I think you should go for it and she reminded me of my baptism... I would work in that area of compassion so I was like okay well, I should go for this role and then I got it... being a palliative care nurse... it is a huge privilege (p9)

For other participants, they had worked in a number of clinical areas before the end-of-life care settings. All of the nurses agreed that end-of-life nursing is meaningful, with several of the nurses talking about what influenced nurses to changing the course of their nursing career into end of life care. This example is of nurse that made this change, due being present with a friend as they were dying and how this experience was meaningful and lead to them making this change in the course of their career.

It was just an incredible experience... I got so much out of being with him... we prayed and meditated while he was, he was kind of drifting in and out of consciousness... I felt like he was doing so much, inner work in that last few days that he was alive, that last bit that he was alive and I just felt like it was such... a gift and a privilege to be able to be with him. And I thought oh okay well you know I'll do hospice nursing one day...and then I don't know it just kind of stuck with me and ...I just was inspired to... change tracks and... become a hospice nurse then (p10)

The discourse of how assisted dying aligned or did not align with nurse's personal core values was common amongst several of the participants. There were nurses that had strong views either for or against the practice of assisted dying and some nurse's views fluctuated. A nurse who was strongly against assisted dying described trying to separate their personal views and professional role as a nurse to support people choosing assisted dying.

I certainly have religious objections for it. I don't think it's right to end suffering by ending the life of the person um. I cert [sic], I don't have any problem at all with using whatever means necessary we have to alleviate distress and, and sometimes that will be palliative sedation um. But I do have a problem with actively giving someone something with the intention of ending their life. (p3)

For some nurses, assisted dying did not fit into acceptable ethical practice in the same way alleviating symptoms and withdrawing burdensome treatment did. A nurse spoke about how their views towards assisted dying have changed over time they initially felt assisted dying discredited the work they did and reflected on how their views changed to recognising what might drive people to want assisted dying.

I also felt a personal attack on what I did... as a nurse that for people it wasn't good enough... I don't think a lot of people would understand that but it is kind of like saying well your job isn't good. You know you're not doing a good enough job... I was really against it and then, it went through. I had to get over it. Because it, that's what people chose and the more I've thought about it since then is the fact I think people did it because they want a choice. Not so much for the outcome. And they want to make that choice and I was thinking about it before I was thinking do you know what? If I was in that situation, I would want a choice, as well (p6)

With another nurse describing trying to separate their personal views from their professional views towards assisted dying and how they felt conflicted and how this challenged them holistically- like they were being asked to separate who they were as a person and their professional hat as a nurse when the coexistence of these is what adds value to their role and deepens the pride and value of their role.

I read the ah referendum and all that around assisted dying and I honestly felt really um, I tried to separate my professional hat as a nurse and my personal view but there was no way I could do that because, it's just it almost felt like just taking the whole mana out of me. You know park it and be this nobody! (p7)

4.2.2 Nursing support

For a nurse that was open to the practice of assisted dying, they did not like sharing their views in public or within their family because they are known as a palliative care nurse in a small community and did not want it to be a barrier in the way they were perceived.

Personal views, I don't tend to say them in public ever. Even if I'm with family because it's, if I'm looking after someone or if I'm with friends I don't want it getting out that I'm for or against or whatever that's not what I'm about in my role and my role is you know, well known because I've been doing it for a long time (p4)

After the Act passed, nurses discussed a period of silence where people did not talk about it and it was the 'elephant in the room' in their workplaces. This is an example of what they described.

I thought it's going to happen, it's going to happen but then it did happen and I was just so depressed! Um and then everything I feel like everything went deadly quiet it's like it passed and no one talked about it for ages after that. (p5)

For many nurses their means of self-care was through regular debriefing, supervision or counselling provided through their organisation that would need to continue or the need may increase. This nurse described that debriefing would be needed with assisted dying coming in.

At the moment obviously we got the EAP [employee assistance programme] and supervision... Some time we might have specific debriefing yeah. And I think when that, end-of-life choice Bill come out and I will imagine and I will ask for, ah we will definitely keep kind of a record, but also to get our team, multidiscipline team to do more regularly debriefing and I think it's a learning process for every one of us. (p1)

In areas such as hospital wards, aged residential care, district nursing and practice nursing many nurses do not have access to supervision or regular debriefing. Nurses supporting aged residential care setting or hospital ward nurses described nurses not having access or time for any regular mindfulness.

Not many people access EAP purely because of that, you have your three session and that's it you have to pay for the fourth session. It's being promoted but nobody has time but there's also mindfulness. But no, no nurses have time to get off the ward to attend those mindfulness. It, it's really sad. (p7)

For nurses that did not have supervision they relied upon their nursing colleagues for shared support. A number of nurses spoke about support within their teams; however, this was more common in smaller or rural teams.

We're a really close knit, super supportive team for each other and, and we do talk over things, we debrief... we help each other current emotionally with the palliative care and we understand that it's important to do that. (p10)

Despite trying to get access to supervision in areas such as district nursing where they provide palliative care two nurses described that this was not provided due to their role not being fully understood.

They were looking at trying to um bring in some kind of peer supervision but she didn't really see, that it isn't, actually as district nurses... our role in palliative care isn't very well understood or recognised. (p5)

However, even in areas with access to supervision a nurse mentioned the concern that this was new for everyone, and supervisors may not know how to respond. The nurse described a situation where a supervisor became tearful when discussing assisted dying.

I went and talked to my supervisor about it the other day just sort of saying oh this is going to be a big thing. She cried. She wanted, she's had some traumatic deaths and she would do it in a heartbeat and she would have done it for them if she could of at the time. And when I talked to her a little bit, there's supposed to be my counselling session remember I, I actually pulled back because I was thinking hang on a minute this is, this is going pear shaped here, you know crossing the boundaries. (p4)

4.3 Theme two: Patient and family world: *We are here for them*

Nurse's roles working with patients at the end-of-life was explored and built on the stories already shared regarding how participants perceived their role with patients and families with the introduction of assisted dying. Nurses reflected on their role as 'walking beside a patient and their family,' with a role as advocates, to empower them, and provide education and support. Nurses shared stories of their role and experiences caring for people at the end-of-life and how assisted dying was incorporated into this.

4.3.1 Decision making in advanced illness

All of the nurses had experienced some sort of a request to hasten death even prior to assisted dying being a legal service in NZ, whether offhand or more serious.

I remember sitting in a patient's room and he looked at me and he goes I'll give you 50 grand to put a bag over my head right now ... it was kind of go ha, ha, ha you know I'd love the money but no!... I mean if I could have a dollar every time a family member has said to me I wouldn't put an animal through this (p6)

It was common for nurses to experience someone changing their mind about wanting death to be hastened compared to someone that had fixed views and how the two situations differed. A nurse described a comparison of these scenarios.

I've had a guy who genuinely wanted euthanasia and he was quite depressed... his wife stopped him taking a heap of tablets and called us in a flap and I went round there and the mailman happened to come it was so damn lucky and his grandson had written to him... said, you know granddad you are my role model I found it really hard but you've always kept going and you do all these things and he just sat there with tears pouring down his face and that was the last time he talked about euthanasia... nearly a year later... when he died... his family said we, he had the best he had the best few months after that kind of watershed moment. But I had another guy and

he had a bowel cancer... he chosen not to have treatment but then he kind of occluded and he said my dad had bowel cancer and if I could have avoided his death I would have... he had really good symptom control... good family support, he wasn't a burden. He had none of the things that you can 'fix', he'd made a clear informed decision and he was someone that I would think yeah okay you're not doing it because there's no alternative, you're doing it because this is your genuine wish. (p4)

For a number of the nurses there was differentiation between patients that they felt were making informed choices versus those that were acutely distressed or suffering and that suffering can sometimes be difficult to recognise. This nurse described a patient early in their hospice career that had not been engaging with hospice services, and not being willing to have their symptoms managed despite significant physical symptoms. However, they made a breakthrough in finding the cause of this through spending time, and allowing silence, they reported the importance of the nurse role in recognising unrecognised suffering

We were in this awkward place for I, it seemed like an eternity I don't know how long it was, it was probably only 5 minutes but it seemed like it was forever ...because he was so uncomfortable he said, you know why I'm afraid of dying? And I said no. And he said well it's because I saw my mother be cremated and her, ah, the, the roller got stuck. And she didn't, she didn't go all the way into the oven. And it was really, it was really horrible to see that, her head burn, while they were struggling to get the body in. And I don't know what's going to happen to my body, I'm really freaked out... I don't want to be cremated... I said oh okay well you know our social worker is really great with helping you work out, you know there's other options there's you know there's natural funerals you can be buried in a plain box, you can just be buried in a shroud, there's a natural um, ah graveyard near here. And instantly he was like really? ... that was the breakthrough that he rang his sister, and his, his sister came and stayed with him... he got much more on top of his pain medications, he was much more at ease with the whole concept of dying... that was a big lesson for me, a big like, how powerful silence can be and just like spending time with people (p10)

When discussions are needed or when patients and families are at transition points in their health, family meetings are a common way to bring people together to not only support patients but also families.

Healthcare professionals are there, for the person, for the patient.... we're there for them, we have to advocate for them. We have to advocate for them and having conversations... getting to know them early you know what's important for them... are you aware that this is your father's wish? It is his final wish. Getting them to come to terms, this is what he wanted. There's a lot of work that needs to go on, over time to prepare families.... if there's still disagreement or ah difference of opinion within a family... that absolutely has to be addressed, the family meetings and recurring family meetings (p8)

Nurses regularly discuss end-of-life and the care choices people have. This often is initiated during advanced care planning however nurses anticipated this may change with assisted dying.

I feel like the conversation about their advanced care planning becomes almost don't want to have it. Because, when that's an option, quality of life isn't good... you're sort of, pushing someone along to, to consider those options. (p5)

The conversation about prognostication and how this was measured was also significant.

It's like looking into a crystal ball... with cancer it's you know it's, it's way more straightforward than it is for you know say heart failure or organ failure any other kind of organ failure... But still even, even so it's, you know, how many people have you taken care of that you know that their doctor told them to go home they'd be dead in three months and here we are a year and a half later... That doctor sure got that wrong (p10)

4.3.2 Cultural considerations

For communities such as the Pasifika community that current palliative care does not service well, assisted dying was raised as a concern that would further distort people's views of palliative care

It's bad enough trying to sell palliative care and hospice care and then this blimen [sic], Bill came out ... It will just create another, layer of... Complexity of to their understanding... it's just the hospice word itself but if they have to add assisted dying, this hospice providing that, that would just put people off. I, I've been trying so hard for our people to connect with hospice... the fear that these people perceive when I say these people, our Pasifika community, perceiving palliative, hospice, end-of-life care, what's the other one, terminal care gosh. It's like a, life sentence for them (p7)

Causing a premature death through assisted dying would possibly be associated with the place such as the hospice building or hospital. If hospices were providing assisted dying they felt this would discourage people from minority cultures, such as Pasifika people engaging in palliative care services due to their association of assisted dying with that place

Despite blessing the room their spirit will be lingering because it's a premature death it's not a natural process... I think it's very important that the rooms for dying people natural dying is blessed.... Assisted dying... you'll always get suspicious that there's a lingered spirit and you can tell when you enter room and you can feel goose bumps through your spine oh somebody died in this room... I think they should have um some sort of communication with ah from a cultural advisors from Pasifika or Māori in terms of what that process looks like if in a Pasifika, Māori community... creating one size fits all it doesn't align with um, the values... moral values, spiritual values (p7)

The issue of trying to engage people in palliative care was raised by a number of nurses, especially how assisted dying may impact on engagement and understanding of services

We've got to be very, very careful... Pacific, Māori that may be very much against assisted dying and what if they have a relative that actually wants it but it doesn't fit well with them... and you know we're on the one hand

encouraging people to come in [to Hospice] yes, you some people die here but most of our work is around supportive palliative care, relieving suffering... then if we were to move, to provide a space within, the grounds [at hospice] that, either teams can come in, how is that going to be accepted, perceived... We've got to get it right, we've got to involve the right key stakeholders, including you know Māori, Pacific... Asian, everything in the mix, everybody needs a voice and an opportunity to say oh this is what my community needs (p8)

They felt that within their care setting, key cultural stakeholders had not been involved. This was raised that the nurses from minority cultures are looked to as the ones who have the answers when that is not the case

The tricky things too is, with um you know being a Māori nurse and, and I guess people think that I, I know.. I guess it's so hard to know where it, it fits in, in te ao Māori because it, we could say it doesn't, but then could say it does and, and um, and, the world you know, te ao Māori is, is changing you know they say te ao hurihuri so you know Māori are, are changing not, not full on changing tikanga and whatnot but just, you know evolving with um, with the changes in the world so yeah so that's tricky because I guess you know, I, I do, I have been asked that like well what's, does it, is it, you know is that something that would go against Māori culture and or Māori worldviews and I'm just like well I, I don't know be you know because um, there are so many differing opinions (p9)

4.3.3 Supporting families

Just as nurses described their own religion or spiritual experience's, they also described the spirituality or the sacredness of the process of dying.

I was looking after this, Māori man and he'd been unresponsive and he was just lingering and lingering and lingering and then they got... Kaumātua from somewhere local and he came in and this man had been unresponsive for days and this man and this woman they started doing karakia together and I swear, I was in the room and this man's mouth started moving, mouthing the words with them and then he died there's so many amazing things I've seen Everything that people go through and work through with people in those last few days of life, people are going to be working through it in a different way, in a quicker way in a more synthetic way ... we need to, have the knowledge and tools and the education... we've never done this [assisted dying] before... we need to know how to work through that as well. Because I think it's going to be very different (p6)

Sometimes the nurses were asked by families to be present in the final hours of a person's life and they questioned how this would change with assisted dying.

I think the presence of a nurse um, for many might be comforting... the practical stuff of doing something or getting the telephone or, just that practical element but, but also that being with... look I'm here. This is the toughest thing you're going through, but I do care... that will be really important that they know that... but also, as a nurse well for myself, supporting that doctor. Look I would be there for him or her, too. Or the

nurse practitioner. It takes, it takes a team to provide palliative care, it sure needs a team to... do this [assisted dying] as well. (p8)

One of the nurses had worked in a country previously where assisted dying was legal and a patient they had been involved in through their work with hospice chose to have assisted dying. The family called to ask them to be present, but they were off work so missed the call and did not find out until after it was already done. They were grateful that they had not taken the call however, still reflected on whether they would have been able to say no to being present despite knowing it was against their personal views.

I wouldn't of wanted to be present even though I had a, a great relationship with that woman and her family it's not something that I would of wanted to be and I might have felt pressured to... so just the whole after that it's like, no I'm really clear I don't want to do that... for my own, safety my own emotional safety, I need to be really clear about what my professional boundary is and, and it's to not participate. I'll support people you know to get the help that they need but I don't want to be part of it... I had some bereavement follow up with, with her daughters. They all felt like it was one of the most beautiful things... they all had, they all drank some wine and toasted her and sit around there was candles and there was music playing and she took it and she died peacefully, shortly thereafter. And they, thought that it was the most beautiful experience they'd ever been through and were completely at peace with it. More so than I was! (p10)

Saying no to being present was something that nurses felt uncomfortable about.

If I was working and someone who was going to go you know who went down that pathway and I, and I kind of had to opt out or not respond oh yes I'd be really torn.... I couldn't be involved but I'd also feel very, I'd probably feel quite guilty at saying I don't, this isn't right to me I don't want to give them my values ...I'm not judging them ...it just makes me quite churned up (p5)

Nurses also had concerns about complex bereavement for families but also for staff.

Supporting you know supporting receptionists... they need support... the cleaners... they get to know families as well. And the volunteers... it's important that we look after them... it's a massive change. You know education, ongoing support. The language we use when we come to that situation. How, how what's the impact going to be on the nurse, on the healthcare assistant, on the doctor, on the specialist delivering assisted dying medication? How is that going to impact not just the healthcare professionals, but the families with their grief and bereavement? (p8)

The bereavement was also a concern in regards to culturally not involving the family in a request for an assisted death as nurses in end-of-life care settings do not only care for the patient but also support families. Bereavement issues were raised by most of the nurses.

Bereavement's complicated enough when someone dies naturally but if you've hastened that death and you've been party to hastening that death,

how are they going to feel you know oh I wonder how long mum would have lived if we didn't have euthanasia and did we do the right thing or didn't we? I can just see lots of complex grieving. Um yeah and it's not like you can go back and undo it, when it's done it's done. (p3)

This included both family locally and those that nurses talk to and provide updates to virtually which has been increased with Covid-19, or those that the patient may not inform and the responsibilities nurses feel to those families.

...particular now Covid... they, they can't have family overseas to come and visit ... how are we going to say that actually New Zealand is not going to be the famous ah assisted dying country to let migrant die here without telling the families... from a nurse oh from healthcare professional here, we do care not just for the patient, we care for a whānau . And so for someone that actually care for and is alone in this country, and have all the valid reason to go through this process, and how we are going to look after the family overseas. And, and I this is the part that I find it more scary (p1)

4.3.4 Coercion and advocacy

Several nurses had witnessed coercion in different settings but some described that coercion can be hard to see

I don't think I would recognise I mean I think it's so subtle sometimes you know I've often later found out something about a family I had no clue about you know it's not easy see even when you're going into a home (p5)

A migrant nurse added a point about language as a barrier where nurses or doctors working with people may otherwise more easily be able to identify coercion

How can we be surely to say the person you care for speaking other language than you, that you are confidence that they are not being coerced by family member... being a person speaking English as my second language, I always challenge this Bill... if any client we look after they're speaking other language than us, and how nurses or care professional will be sure that they're asking um not because of coerced by other (p1)

In terms of coercion, some talk about the financial burden of care, especially aged residential care for those who didn't qualify for full funding and the coercion of being a burden

There's huge financial costs involved in being in residential care you know they have, either they have to pay privately which is sort of \$1100 a week plus... you're talking quite significant amounts of money that the families are paying out even if they're subsidised. (p3)

Another spoke about that for some people providing care is a time burden especially for families who are already struggling and that is unavoidable.

A lot of people the primary reason is they don't want to be a burden ... "I don't want them to have the grief of watching me die"... "it's too hard

they're away from home" her view was protecting her family and her way of showing love is protecting her family, they didn't necessarily want to be protected. There will be other families where they feel like a burden and they will be a burden because you know the daughter's short of money and she's got to work whether she likes to or not and she's got three children and one of them's got Type 1 diabetes or something... and the mum's like actually we can't, my family can't do any more than they're doing (p4)

Several nurses raised concerns about the legislation and compared it to other countries in terms of the medicalisation of picking a date in advance and feeling coercion of feeling a burden by changing their mind

I interpret the Act... that, the patient needs to schedule the... time that it's going to happen. And if they, decide not to then they've got to go start all over again and reschedule another time... I think that disincentives people to be able to change their mind or even to step back for a little bit more considered well maybe I'll do it next week ... "the timing doesn't feel right today, I don't want to do it today" ...they might think well, you know I made the appointment, I can't let the doctor down... it just seems kind of weird to me... it makes it so sort of institutionalised or medicalised or I don't know it just seems weird. (p10)

4.4 Theme three: Professional world: *I feel very unheard*

Nurses were asked about their professional roles, policy and implementation. Nurses in this study were from a variety of care settings with varying roles and responsibilities. Their professional concerns were surrounding the implementation processes, their inter-professional relationships, the care provision and service access, and ensuring equitable access across their different health care settings.

4.4.1 Impact of assisted dying for nurses

During the planning within their workplaces, nurses felt unheard. Nurses were often not invited to participate in the discussions around implementation.

It was all done with the board, with the medical team...it's not being passed down to us. It will just be implemented. That's what will happen. It will all be sorted and implemented without any, kōrero with us whatsoever you know... I feel, very unheard... personal and professional viewpoints have been just disregarded and disrespected and. And that, that's, it's very upsetting actually you know. (p2)

A number of the nurses reported that their role in patient care was not well understood and in regards to assisted dying they felt their professional opinion was not taken seriously. It was felt that energy of the implementation was focused solely on prescribers rather than the wider teams involved in that patient's care.

Yeah more effort, when you look at the Ministry of Health seems to be on the prescribers and the ones who will be doing it and or not doing it and you

know how to refer but there's not a lot of thought being put into you know the cleaner who happens to be on when something happens or the volunteers or the nurses or even admin staff in places might be really uncomfortable with it. (p4)

Participants felt online learning would not be sufficient to prepare them for assisted dying in practice.

Shocking... what is the main stuff that you need to learn? It's how to, you know, get the information that you need... it's all about communication you can't learn to communicate with somebody online... it has to be, face to face you know there's got to be this kind of, collegial discussion ...for a lot of people they don't learn that way [virtually] you know. (p2)

They also did not know if it was a conversation they were allowed to have with the introduction of this new legislation.

If we are asked, is it a straight referral? But then it just seems so weird like someone saying to you oh I want to have assisted dying and then I'm like okay this is who you need to contact. It kind of, doesn't really flow nicely. Because as a nurse you're caring and you want to kind of find out a bit more but we're not finding out a bit more. (p9)

Feeling unsure or unprepared to respond to a request for assisted dying was common amongst a lot of nurses. A nurse had concerns that a scripted response compromised authenticity and thus the genuine rapport and respect shared with patients.

I guess it's like every other conversation that you know we have with someone... who has a terminal disease... People they, they know because they're at the rawest of their life and anything fake you know anything that's not natural or actually genuine, they know... so you can't have a script you're going to be reading from (p6)

It is important to note the context of this study occurring during the Covid-19 pandemic. These interviews taken partially during a level four lockdown in NZ. Covid-19 was a factor in all areas that was described as a factor that has shifted some of the focus of resources for preparing for assisted dying implementation.

I've been asking the nurses is there any word on euthanasia and what will happen here [in aged residential care] and they're all saying no so, I, whether they're going to scramble and suddenly work out what their stance is or not I don't know. I think the focus has been taken off it with Covid (p3)

Even for nurses who were for assisted dying, they had concerns about experienced nurses leaving that area because they do not want to be around it.

I think it would be really sad the fact if they did leave because I think the ones I know who are they're very experienced older palliative care nurses who we need around it's, all those with such strong viewpoints it

challenges them on so many aspects of their own being, and that's not you know and you can't, you can't force you know you've got to accept people's feelings when it comes to that. (p6)

There was also the concern around recruitment for aged residential care an area that already has a high turnover.

Whether that will make it harder to recruit nurses for aged care I don't know, it may well do. They're already losing huge amounts of staff to hospital ah hotel quarantine and vaccination hubs... if they can get those jobs, are going to them... there's no new staff coming into the country so, um, you know it's a difficult time for staffing so you're going to be having euthanasia coming in right at the end of all that.(p3)

One of the nurses talked about how they will consider resigning depending how it is implemented.

I actually felt... when the Act passed that I, I would consider resigning. When this yeah depending on how this is implemented yeah (p5)

Having presented the findings, it was clear these nurses had a wealth of knowledge within their nursing field of end-of-life care. Many felt deeply about the implementation of assisted dying. Some were frustrated and angry however this was often due to issues with implementation rather than the Act itself.

4.4.2 Palliative care, access and duty of care

Professionally, many of the nurses who worked in end-of-life care settings were in specialist palliative care fields of nursing, all of them assisted either directly or indirectly in provided palliative care. A number of nurses mentioned when introducing palliative, care making the differentiation that this does not hasten death has always helped when explaining palliative care to patients.

I've always liked the, um, the fact that you know we can tell people palliative care we don't unduly prolong life but we don't shorten life either. So it's about allowing a natural death when the time comes with as little distress as possible so um. You know that, that's quite at odds with, having assisted dying. (p3)

Several nurses mentioned feeling that palliative care need to support people seeking assisted dying as the people resourced to support people at end-of-life.

Palliative care cannot turn their back on this and this is what I'm really scared of (p6)

This included concerns about patients and families access to information if this was not provided by palliative care services and that there is not anywhere else that is skilled or resourced in discussing end-of-life care

Where the hell are people going to get their education, and how is this process going to work, if the people who are providing the main you know, education in the field of end-of-life care, are saying well we're not having anything to fucking [sic] do with it. (p2)

There was palpable frustration from several of the nurses in both the implementation processes and how future support would be offered to patients and families. In their roles in palliative care they still expected to continue to support people up until their death.

I'd not change my care for them... because I still want to give them the best care they can until they yeah until they die (p9)

The conversation of where assisted dying fits in within the professional world of palliative care was important and mentioned by several participants both for and against assisted dying, and the involvement in palliative care services in this process.

The original philosophy of palliative care you know we honour, living dignified dying. So there's nothing in palliative care definitions that, say anything around, um, you know ending life. Basically ah life, there's sanctity in life, it's important, means different things to different cultures, beliefs. So and I think in the future there needs to be perhaps another addition to the palliative care definition around the other option which is assisted dying I think perhaps New Zealand need to look at that (p8)

This included the actual definitions of palliative care as they were important in defining nurses' practice

I also wonder, will you know with time, will, will it change and eventually it will become something that hospice provides... but then you know they'll have to rewrite the, you know the WHO will have to rewrite their definition (p9)

Other nurses working in areas where they had not had much information when requesting information and stating they did not want to be involved due to inequalities in access to palliative care services

We refused to participate, facilitate or support the practice of euthanasia in our community. While of course continuing to deliver palliative care without discrimination so quite a long letter about our reasons you know entrenching already serious inequalities... I got a response yeah kind of um saying that, acknowledging our concerns... we'll be monitoring developments in this space as health practitioners under the Act you are under no obligation to assist any person who wishes to exercise the option of receiving assisted dying. (p5)

Some nurses described their concerns regarding access to specialist palliative care versus the access that will be provided to assisted dying.

Everything about euthanasia is free, they're going to bring it to you if you can't access it, that's how good it's going to be. How the hell do you get palliative care to stand up and do what it can really do if you don't have the resources and access that you have... for euthanasia, it's going to be the default position.... we don't have sitters that can go overnight and give an elderly wife a rest or a stressed out mother we just don't have it... if they want to do a fair go at the End-of-life Choice Act, then actually put some good solid supports in behind the people that are trying to manage at home. (p4)

The nurse's role itself was poorly understood not only at a higher government level but also within their organisations and they felt that this impacted on their ability to provide quality palliative care as it was not resourced to provide the holistic care that was often needed by patients and families, whereas assisted dying was an easier and cheaper option for the government to fund and resource.

It's really so hard to like okay well you're going to see three patients today and you've got an hour to see each patient and you know it's like well, you can't really say that.... management that, that come from a not, palliative care background, that want to see kind of performance metrics... it doesn't work that way. You know and if you want to give holistic care you, you kind of can't really quantify it like that. It takes time, it takes time and resources to provide really good holistic care you, you know those, those kind of metrics are really meaningless. Get different metrics if you're wanting to measure your nurses performance (p10)

Access to palliative care was described as something that could potentially lead to people choosing euthanasia as an option especially in areas where access is limited such as some rural communities with larger Māori populations

You know it looks like some of the places where there's mostly Māori which is East Coast and up, up North think that's where the chunk of Māori are, up North is just really terrible access to good palliative care and that's one of the reasons why I did worry about assisted dying because of course if you're not going to have good access to palliative care and you don't know any better and you're suffering of course you're going to want to die (p9)

Some of the nurses reported concerns round how assisted dying would impact upon their funding for palliative care services which would subsequently impact upon their resource and patient care.

There was a hospice that put out that they were going to um you know object, be conscientious objectors, and apparently they were vilified on social media and in the paper and a whole lot of their funding has dried up because people are like you know if you're not, then I don't support you. (p4)

For nurses that were open to participating they were unsure if this would be allowed by their organisations.

I personally would have no issue with being involved in the process.... that's probably bit controversial and I recognise that that's not going to happen in my workplace! (p2)

4.4.3 Responsibility for wider health care teams:

A nurse recognised the difficulties for nurses new to NZ trying to adapt culturally with the added stress of assisted dying.

As a migrant nurse... if I'm looking at them they are all still ah trying to find their life, settle their life... so a lot of, mental space, emotional space, how much they actually got people to help them to prepare or how much they're going to reflect on and to find meaning from the experience and this is the part that I'm actually quite concerned (p1)

Nurses commonly have clinical roles that are not only with patients, but also roles in supporting wider teams, so their concerns extended to the support that would be available for the wider health care team. They also had concern for the support team such as counsellors and spiritual carers

Our palliative support team are like that too they're like gosh what does that [assisted dying] mean for us? How's that going to be? And like what if you've got a divided family? And half of them are like okay and the other half are furious (p4)

Many of the nurses that worked with aged residential nurses felt the nurses either did not know at all about the assisted dying legislation or knew very little because the facilities they work at had not discussed with them the importance of this.

I had a month ago, about 10 nurses from aged residential care facilities... I raised the topic with them. And, all of them, not aware of the legislation that's coming... I was quite shocked. So, yeah I encouraged them to you know this is, it is coming, you will have families, you might have residents in your care, that you've known, nursed for years, and they might ask you, they, they have a right because it will be law. So there's a significant amount of education that needs to go there and often these nurses... have English as their second language, different cultures... whose responsibility is that, the facility? Supported by? I think the community nurses are too stretched as they are. We need to build a workforce. (p8)

There was concern that nurses working in aged residential care would face more distressed families, that do not understand the legislation and feel the staff are being obstructive by not providing assisted dying when patients may not qualify. They felt this could lead to verbally abusive behaviour towards staff, which they described is an issue that already exists.

The residential aged care has to ask for support... Not just about person asking for assisted dying and then we have person die. Because not necessarily die that we need extra debriefing. I will see that we will have more challenges to face. The EPOA, family member they will make attack the healthcare team... I will see that's another part come out from because of the Bill happening (p1)

4.5 Conclusion:

The presentation of findings in this section were taken from the narratives of nurses showing similar accounts and concerns across care settings to tell the overall story of assisted dying implementation and the practice and policy implications for nurses. Engaging in this research and hearing the nurses' stories my interest and recognition of the need for this research grew deeper. Prior to the discussion chapter, I first reflect on the nurses' narratives.

Chapter 5 Reflection:

When I initially undertook this research I recognised a gap existed in the literature. However, after I started to receive responses the significance of this assisted dying for nurses became more evident. In nurses' initial responses to the invitation to participate, some of the nurses shared stories of their career and what made them interested and willing to participate. Some of the email requests were highly emotive. This responsiveness showed the demand for research in this field, and also showed that these nurses wanted to have their views and voices heard. This was something that they had otherwise not been given a chance to do. Although these email responses were not formally a part of the narrative, they also told a story. I was incredibly thankful to the nurses for choosing and agreeing to participate, as without them I would not have been able to produce this research. I was humbled as a lot of the nurses were incredibly thankful for the chance to be able to speak and share their stories. There was also comradeship, many of the nurses mentioned that seeing I was a nurse, they were willing to participate to help out a fellow nurse. Recruitment was a part of the story that I did not expect to be so meaningful but was a significant part of setting the scene for their narratives.

Reflecting on the depth of what the nurses shared in their narratives, it was clear that the end-of-life care nurse role is complex and the care they provide is not quantifiable. It is a distinct profession, requiring advanced clinical knowledge and skill. It is also an art form involving morality, spiritual awareness and genuine compassion. Poetry can be a means of recognising the existence of truths within attitudes, feelings, or ideas (Harmon, 2011) and in qualitative research this can illuminate these truths in the mind and heart of readers (Brown; 2018). This is an ode to nurses who have, do, and will walk alongside people through some of the hardest moments of their lives, as the strength, perspicuity and wisdom people need during the greatest moments of uncertainty. However, these nurses are currently going through uncertainty in their practice, with little consideration of the impacts upon them as individuals. Within every line lies a story, a memory, a meaning. It is also a perspective for those who are unaware of these truths that may to us, as nurses seem obvious.

5.1 An ode to the end-of-life care nurse

Sees, feels, listens, hears
 Of utmost importance truly cares
 A shoulder of warmth in a cold ward
 A knower a guide leading forward
 Teaching and sharing to prepare successors
 Here there is no second chance to right any errors
 Ensures the practicalities are seen to
 So later distress does not ensue
 Recognising spirituality and religion are sacred
 While ensuring physiological suffering is negated
 A voice on the phone when no one else knows
 A certainty as uncertainty grows
 Allows silence the sacred space
 As within lies truth beyond a brave face
 The changes that would otherwise be missed
 From others before, knows what this is
 A process, a passing, a departing chance
 Not afforded to many, it is the last dance
 These months these moments of learning
 Reconciling, remembering, laughter returning
 Within the darkest moments of life
 Showing where to find light, is the passing's midwife
 Though you may say it is tantamount to
 A hastened death is something new
 With every change requires preparation
 Inclusion, reflection and education
 If there was understanding of what they provide
 I am certain you would not cast them aside
 As when this song has been sung
 It will be them picking up what has been left undone

Chapter 6 Discussion:

The participants' narratives presented in the previous chapter, uncovered deeper meaning than anticipated to the expected practice and policy implications of assisted dying in NZ for nurses. The overarching theme, and subthemes were established from the data. It was clear from the nurse's narratives that assisted dying challenged participants overall professional identity. This will be further analysed within this chapter to better understand the practice and policy implications of assisted dying for nurses in NZ. As a nurse working in an end-of-life setting, and with values embedded within both Western world and Māori world views, my interpretations of the narratives contributed to this analysis, and the holistic understanding of the role of the nurses. Within social constructivist theory, and in narrative research, the researcher cannot be isolated from the research (Riessman, 2008; Gergen, 2015). Participants and their narratives impacted upon me as I did upon them, setting the foundation for these discussions. Assisted dying within a social constructivist paradigm will be explored to set the scene for further discussion for this change to practice, policy and professional identity of nurses. As this is a fledging field of research, it was not always possible to find literature that specifically supported my findings, however in these cases I have drawn upon other similar studies and literature to help provide meaning.

6.1 Assisted dying within a social constructivist paradigm

It was evident in the participant narratives, that their individual beliefs about assisted dying, could not be isolated from the practice and policy implications. The approaching implementation of assisted dying was meaningful on a deeply personal level for the nurses. Exploring this from a social constructivist paradigm parallels can be drawn with Vygotsky's (1978) social constructivist theory that there is nothing in the mind that is not first in society. Later explained by Giddens

Human beings produce society, but they do so as historically located actors,
and not under conditions of their own choosing (1993, p.186).

The nurses' views were situated within their socio-historical context, and held meaning based on this. As earlier explored, death is a complex social construct that is deeply embedded in societal and culture norms through time (Martineau, 1838; Ariès, 1974). Social constructs and the interaction of meanings, norms, power, work, goals, desires, history, and quality of life without human beings and their interpretations, mean nothing (Mohan, 2021). Clandinin (2013) suggests that we bring all of our personal life experiences into our professional life. It was clear that the participants constructed meaning on how assisted dying would impact their nursing practice based on events and experiences from their lived worlds such as coming from a family of nurses, early exposure to death prior to nursing, spirituality and experiences of different

patient's deaths from their nursing practice. In the narratives, while speaking aloud, participants were also in the process of making meaning and externally self-debating their own thoughts, often contemplating throughout their narratives the factors that meant that assisted dying would fit, or would not fit within their accepted nursing practice, and within their role as a nurse. Additional to this, it was uncovered that nurses' early reflective thinking and conversations about death prior to entering into nursing also influenced their views towards assisted dying within their professional worlds and the making meaning was a continuous and reflective process. This is consistent with past literature that has identified that nurses' social standpoints are associated with views towards assisted dying and are also influenced by their area of nursing practice (Elmore et al., 2016; Barnett et al., 2020; Hains & Hulbert-Williams, 2013).

Asking the nurses about their past experiences and what led them into their current roles was initially planned as rapport building, before discussing how the new legislation affected their practice and policy. However, it became evident that this was the foundation for the research. Participants' stories of what led them into nursing were linked to the specific field of end-of-life care and also their views for or against assisted dying. If being a nurse was not an individual experience that was meaningful, then this research would not have been needed. But, being human, the ability to empathise and show compassion, recognise existential distress, to draw on their own world, and professional experiences, is what makes a nurse. This is supported in past literature, that human factors drive nurses' ability to empathise and are associated with improved patient perceptions of care (Allahyari-Bouzanjani et al., 2021; Dehghani et al., 2015). The ability to show compassion is cultivated by values that existed before nurses become nurses, and is further grown within their roles contributing to their overall professional identity (Kristoffersen, 2021). Being human is equally what makes such a fundamental change to the process of dying meaningful and impactful for nurses' practice and policy (Elmore et al., 2016).

6.2 Supportive mechanisms

Some of the nurses in this study felt they may be pushed to leave or had colleagues that were considering leaving their roles depending on what nurses' professional expectations would look like, and how the implementation of assisted dying was carried out. Factors that can influence a person to enter the profession, and factors that make a profession meaningful, if compromised can equally influence leaving the role (Gergen, 2015). Internationally, leadership and organisation level strategies were viewed as essential to create a climate that supports nurses who encounter ethical dilemmas in clinical practice during assisted dying implementation (Jannette et al., 2013; Lemiengre et al., 2014; Pavlish et al., 2015; Suva et al., 2019). It is evident internationally, that nurses have a significant role in patient care leading up to, and after an assisted death, and report profound personal, moral, and professional challenges with assisted dying that fundamentally challenge how they view themselves and their role as a nurse in the

end-of-life care setting (Pesut et al., 2019; Wilson et al., 2020a). This resides deep within the foundations of nursing practice, where nurses are duty-bound not only to give care but to care (Water et al., 2017). From this research, it was unclear if some of the nurses' apprehension about assisted dying and the feeling of being pushed to leave their roles would dissipate after it came into force, however regardless it was clear the deficit of resource allocated to nurses in this practice and policy change to prepare nurses impacted deeply upon them in their roles. Assisted dying challenged participants' experience of being nurses' and thus, also confronted their professional identity as end-of-life care nurses' whether they were for, against, or neutral on the practice of assisted dying.

The participants did not feel they were resourced to cope with the change, and they felt their services were not sufficiently prepared, which challenged their confidence in their roles. With any practice change in nursing, it is a shared responsibility between the organisation to provide resource and education, and the nurse to engage in learning, and ensure they are practicing using evidence-based practice (Grol & Wensing, 2020). At the time of this research, there were initial training modules available online as well as webinar sessions (MOH 2021a, 2021b, 2021c). Many of the nurses were unaware that these were available, and had not been provided any information on this by their employers. For the nurses aware they were available, they had not been given any time within work to access and complete these. Two nurses had taken time outside of work to watch the webinars. Many participants felt face-to-face training would be required in addition to online learning, to build confidence in having conversations, respond to assisted dying requests, and that overall there was a significant shortage of information. The education needs of participants in this study far exceeded what they were provided as education by their workplaces aligning with past literature and likely impacting on the professional identities of nurses through feeling unprepared for this change, and their roles and expectations as a nurse with the implementation of assisted dying (Beuthin et al., 2018; Pesut et al., 2019; Van Der Cingel & Brouwer, 2021).

Participants described the ways in which assisted dying would create a greater need for self-care, and challenged some of their usual means of self-care. It was clear from the participant's narratives they had a significant amount of compassion for patients and the families they supported. Having compassion is essential, especially in the end-of-life care settings but the risk of burnout and subsequent compassion fatigue is well known (Cross, 2019; Drury et al., 2014; Frey et al., 2018; Harris & Griffin, 2015; Todaro-Franceschi, 2019). Consedine and Fernando (2019) described that rather than traditional ideas that health professionals somehow run out of compassion, the systemic issues such as causes of burnout, encouraging rest and mindfulness need to be addressed to support the longevity of the health workforce. When the causes of burnout are addressed, this leads to improved staff retention and patient outcomes whereas, if not managed can impact job satisfaction, patient outcomes, and can lead to nurses leaving a

profession where there are already significant staffing shortages (Hellyar et al., 2019; Harris & Griffin, 2015). Internationally, support groups were formed for doctors who participated in assisted dying with the same planned for doctors directly involved in assisted dying in NZ (MOH, 2021c). However, nothing similar was available for nurses that would be involved in the care of patients going through the process of assisted dying in the NZ context.

Access to means of self-care was an issue that participants reported, including a participant describing that their professional supervisor broke down crying during a session where they raised assisted dying. Often nurses hold supportive roles such as clinical supervisors, for those in supporting roles, I could not find any literature about whether these professionals require their own forms of support to be able to help the professionals in patient-facing roles with new type of death, however, there is literature outlining the need for nurses to be supported through assisted dying implementation (Pesut et al., 2019). It was found that a variety of methods is needed for engaging in self-care as people have different levels of comfort with different methods such as some people may feel too vulnerable or uncomfortable to share emotions in a group debriefing session (Milne et al., 2016). Beuthin et al (2018), described varied experiences of nurses and self-care practices after involvement in assisted dying in Canada, including a nurse manager supporting impromptu debriefing on the ward, with tea and biscuits involving the family, which for nurses and doctors was ultimately a very positive experience, where other nurses described fears of involvement in assisted dying due to scaremongering during the legislative change create a negative culture around assisted dying and thus it was a taboo topic that was not discussed or reflected on in their workplace. This aligned with participants' stories of assisted dying as the elephant in the room. The need for means of self-care is an organisational responsibility, and it is likely new methods of support will be needed with the introduction of assisted dying (Drury et al., 2014; Edwards & Goussios, 2021; Frey et al., 2018). Kelly et al. (2020) found that even for physicians, internationally there is lack of professional advice and support to help them in dealing with the emotional response generated by requests for assisted dying and subsequently coping with the impact. With this change, nurses will require support however from nurses' narratives, their roles in assisted dying were not acknowledged thus, support for them was not considered a priority, this is not only for nurses in patient facing roles, but for nurse mentors and nurse managers that support other nurses. Elmore et al. (2016) suggested that when nurses' perspectives are not respected or considered by other members of the multidisciplinary team when caring for patients requesting assisted dying, their experience in care is negatively affected.

Many of the nurses spoke about assisted dying creating a divide or tension within their workplaces and a taboo topic that they could not discuss impacting on their collegial relationships. The participants had not been guided in how to support each other and their teams. A nurse spoke about the cohesion between views in their small rural team, and fears

about how new staff would fit in with this as well as fears about how assisted dying would work within their small community team if there were conflicting views and practices between staff. It is widely accepted that assisted dying is a social issue, and thus, people can hold polarising views for or against the service, which could be amplified or cause tension in small teams (Dierickx et al., 2018; Van Brussel & Carpentier, 2012). It has been long understood that comradery is important in the healthcare setting for coping with stress, and improving pleasure at work and the growth and professionalism of nursing (Davidhizar & Bowen, 1992; Koff, 2016; Lee, 2008). Resilience in nursing can be improved through relationships with colleagues, and can help make nurses feel grounded, and supported in their roles, and offers a valuable avenue for coping with stress and increasing the pleasure experienced at work (Miles et al., 2021). It is important to recognise that a change as significant as assisted dying does not only impact upon the institutional care, it has a greater impact for those providing and subsequently those receiving care (Pesut et al., 2019). Looking at social constructivism and nursing practice, it has been theorised that individualistic approaches to nurses practice may make nurses feel as though they are the only one that is struggling in situations where they are exposed to suffering or challenges within their workplaces (Aburn et al., 2020). It was important in this research to recognise nurse's different views, placing them as the experts of their own experience, and identifying them as individuals in a shared situation, to deepen the understanding of this change for them, and their experiences of being a nurse.

Some of the study participants described their fears about expressing their views towards assisted dying due to the stigma associated with it. This was particularly prominent in nurses supporting smaller communities. The stigma around the choices for assisted dying is evident both for those choosing assisted dying, and in health practitioners that support people with this process (Wardle, 2016; Winnington & MacLeod, 2020). Another nurse also described previous avoidance of social gatherings when providing end-of-life care for well-known people within a small rural community to avoid people inquiring or causing discomfort for any relatives or close friends of the patient that may be there. This was not a hindrance, but rather an accepted part of their role. Other rural nurses described similar situations of social and professional crossover in current or past roles working in small communities. The overlapping relationships for health professionals in rural communities have been acknowledged in past ethics literature including that they may simultaneously be providing care to multiple family members, or know them socially outside of work (Crowden, 2010). Rural compared to non-rural healthcare workers report that they have more interaction with patients, and less awkwardness in relationships with their patients outside of work, however patients often expressed more concern about knowing them in both personal and professional roles, had more concerns over confidentiality, and experienced more embarrassment concerning stigmatising illnesses (Crowden, 2010; Nelson et al., 2007; Warner et al., 2005). This issue is specifically poignant to NZ with a small population, and many nurses having roles where they care for people that may be known to them within

their wider social circles outside of work. Assisted dying may be seen by patients as a stigmatising issue that could affect their comfort discussing this in a rural setting. Participants raised the concern of specific issues relevant to rural nursing in NZ which had not been addressed in any of the education modules for assisted dying. The implementation and ongoing access to assisted dying is likely to have different issues in rural settings for both those accessing, but also those supporting, such as rural nurses with long held relationships with patients and their families.

6.3 Nurses were not identified as stakeholders in this practice and policy change

Nurses described that involvement in a hastened death was previously a very firm line in the sand that end-of-life care nurses did not cross, but overnight would become something that they would have to face. This aligns with past literature of the challenges health professionals working in end-of-life care settings face in that assisted dying conflicts with definitions of palliative care to neither hasten nor postpone death (Bernheim et al., 2008; Haining & Keogh, 2021). This is a change to the way in which people die, in what is seen as an acceptable or good death, as understood within the end-of-life care context (Cohen, 2020; Van Brussel & Carpentier, 2012). As earlier discussed, within wider assisted dying literature the meaning of a good death has been extensively explored within the context of growing societal value of autonomy and in awareness of death within the palliative care movement (Buchbinder, 2018; Spelten et al., 2019; Van Brussel & Carpentier, 2012). A good death is something that the participants had constructed meaning about since their own childhoods, throughout their careers and entering into an end-of-life care setting. For some of the participants assisted dying created a new way for patients to have a good death, seeing it as a way patient's could minimise suffering and have control over the setting of their death. For other participants it starkly challenged their views of a good death as a spiritual or natural process, as an unnatural phenomenon. These challenges for nurses caused them to reflect on their roles despite not being acknowledged as stakeholders of this change.

Participants in this study described assisted dying as a “*huge*” change to practice and policy in the end-of-life care setting however, described assisted dying as something that would just happen and they would be expected to pick up the pieces without any extra resource to do so. They felt everything happened at a board and executive management level with little input from nurses in patient facing roles. All of the participants have been nursing for greater than ten years some with greater than 40 years of nursing experience. Many of the nurses had been, or were actively involved in research, professional bodies, and nursing professional organisations. However, within their own teams they were not recognised as people with value to add to this discourse or in the national implementation processes, which it has been reported to reflect a

lack of value placed on nursing roles in healthcare organisations (Grol & Wensing, 2020). Hospital boards are involved in strategic decision making, so having nurses on boards is crucial as they are strong patient advocates and have expert knowledge of how to best achieve high-quality, safe care (Hassmiller, 2013). However, nurse underrepresentation on boards thought to be due to nurses being viewed as implementers of care, rather than decision makers of care (Hassmiller, 2013). Yet many nurses, such as the participants in this research, are highly educated, hold several degrees, and have held leadership positions in the hospital setting and community (Walton et al., 2014). This exclusion of nurses in practice and policy change locally, and at a national level, is interwoven in government and societal perceptions of nurses, restricted by hierarchies, time, management support, gender-bias, as well as nursing professional issues (Hajizadeh et al., 2021; Juma et al., 2014; Manning & Kriebel, 2020). As such, many nurses actively sought feedback on the change process including any issues that were raised and what was being done to address these. A nurse described contacting the district health board and receiving a generic response that did not address their concerns raised. Despite attempts to seek information within their workplaces, the nurses were not acknowledged in their requests or invited to be a part of the implementation processes due to these previously understood phenomena of perceptions around the lack of value placed on nursing roles. This lack of role recognition ultimately impacts upon nurses own perceived value of their roles, nurses' professional identity and thus nurses' subsequent practice (Van Der Cingel & Brouwer, 2021).

Some of the participants had contributed initially to the assisted dying discourse through participation in submissions during the submission period of The End of Life Choice Bill (2019) alongside their professional bodies. Their willingness to participate in this research is an indicator that they were further willing to contribute their time and knowledge, to improving the implementation of assisted dying and the safety measures around it, both for patients and nursing. However, they felt unheard within their care settings. The theory and implementation of practice change in health care settings has been extensively researched, focusing on approaches to build meaningful quality improvement implementation strategies, that engage those impacted by the change (Grol & Wensing, 2020; Shea et al., 2016; Von Thiele Schwarz et al., 2021). Despite raising, and showing concern, the nurses that sought to be involved were not invited to partake in any implementation meetings, or be involved in local implementation processes overlooking the significance of this fundamental change for these nurses. Participants in this study felt that their views and opinions were not valued within the assisted dying implementation. In wider nursing research, nurses being heard within their organisations is essential for better patient care, increased safety and better staff satisfaction (Garon, 2012). Nurses bring a unique patient centred and caring approach to healthcare change bringing "the bedside to the boardroom" (Walton et al., 2014). The impacts of assisted dying for nurses once implemented in practice has been well studied in past literature, and it is evident that it is

important to involve nurses at a patient facing level during assisted dying implementation (Elmore et al., 2016; Hewitt et al., 2020; Pesut et al., 2019). Nurses were not widely involved in assisted dying implementation in NZ, causing a lack of input in practice and policy development and implementation.

Participants felt the general policy, implementation processes and education lacked a nursing focus. Both local health providers and national policy makers, have a responsibility in ensuring dedicated time and resource for nurses providing direct care to patients are engaged in change throughout practice change initiatives (Arsenault-Knudsen et al., 2021; Mitchell & Waterworth, 2012; Raines, 2012). This is crucial to the adoption, implementation and ongoing incorporation of change into health practice (Mitchell & Waterworth, 2012). This ongoing need for nurse involvement, adequate preparation, and policy for nurses is consistent within assisted dying implementation literature (Pesut et al., 2019; Suva et al., 2019). Nurses are involved in multiple stages of assisted dying, thus, are key stakeholders in this change (Beuthin et al., 2018). However, for these participants they were not identified as key stakeholders thus, these practice change objectives were clearly not achieved within these nurses' workplace building on past literature that nurses are key stakeholders in assisted dying however often not recognised (Pesut et al., 2019). This adds to NZ literature, and for other countries implementing assisted dying that nurses need to be recognised as key stakeholders in this change including nurse managers and nurses in patient facing roles if nurses are expected to have ownership or be engaged in this change, and subsequently provide support to patients, families and other health professionals.

Many participants were unsurprised that registered nurses were not mentioned in the legislation feeling that their roles are poorly understood. In both NZ and in most international assisted dying legislation the nurse's role is not defined aside from the nurse practitioner (Suva et al., 2019). Public 'health professional literacy' around the functions of health practitioners may influence the nurse role being undefined in this legislation as the public often do not value nursing roles in the same way as doctors (Offiecer & McBride-Henry, 2021; Van Der Cingel & Brouwer, 2021). Nurses are essential, dynamic contributors to population health outcomes in NZ and globally, however their dynamic roles are often poorly understood by the public, by other health professionals, and by government which impacts upon the way government shapes policy and organisations and managers implement change (NZNO, 2018; Peach, 2001; Van Der Cingel & Brouwer, 2021). They provide knowledge and skills to many third-sector organisations and are often the subject experts in their field, working autonomously or in a very small team and over a wide geographical area (NZNO, 2018). This was evident with the nurses' narratives in this study that described their significant role providing palliative care in rural communities. The fact that nurses may be the primary health provider involved in a patients' care, was not recognised within the assisted dying legislation or the subsequent implementation process impacting on the practice and policy for nurses.

One of the key issues consistent throughout the nurse's narratives was that they did not know what their role would involve, and therefore felt unprepared and concerned that this would negatively impact upon the care they could provide. Inghelbrecht et al. (2010) found that nurses were occasionally involved in administering the euthanasia medication, including to people who lacked capacity, despite Belgian law requiring a patient to have decision-making capacity and authorises only physicians to administer the lethal medication. Similarly, a quarter of nurses surveyed in the Netherlands were unsure if they were permitted to administer the fatal medications for euthanasia, suggesting a lack of awareness of legislation on their practice (Francke et al., 2016). Many of the participants had not had access to any formal training about assisted dying, either face to face or virtually, thus were unprepared to respond to requests or provide support at any point through the assisted dying process, and were also at risk of professional misconduct through being unaware what they could or could-not say or do in the care of a patient requesting an assisted death. This is a significant practice and policy issue for nurses that unknowingly they could be breaching law. Hewitt et al. (2020) previously identified nurses do not commonly have significant legal knowledge thus, there is an responsibility of healthcare organisations to provide adequate training and policy that supports and protects nurses practice, especially in a change as significant as assisted dying.

Covid-19 was raised by participants as a factor which played a role in disrupting the implementation of assisted dying in NZ. Many nurses described the multifactorial impacts of Covid-19 in their workplaces, and the impact this likely had on assisted dying implementation. This was especially significant for those supporting nurses in aged residential care settings. Internationally, Covid-19 has brought unprecedented pressures to health care systems, and continues to impact directly on nursing care, and capacity of the health services as well as the ability to recruit nurses (Labrague et al., 2021; Yip, 2021). In NZ, much of the focus of health resource at the time of this research was on pandemic preparedness, and ongoing response (Department of the Prime Minister and Cabinet, 2020). Covid-19 brought changes to the way services interacted with patients, with a greater number of virtual consultations and in the way information was delivered to staff, with a significant increase in online learning and virtual seminars (Jones et al., 2020). In some ways this remote way of sharing information made some information more accessible, however, many nurses in this study felt that they had not been provided sufficient access to the available information and training. Regardless of Covid-19, there was consistency in the concerns from the nurses in this study corresponding with international literature that there is a lack of nursing education and consideration of the nursing role (Hewitt et al., 2020; Pesut et al., 2019). Although Covid-19 likely played a part in some of the access to education, and shifting some focus and resource from education about assisted dying, it cannot be wholly responsible. Without the disruption caused by the Covid-19 pandemic, it is unclear whether significantly more resource would have been allocated at a government level based upon the lack of preparedness for assisted dying of nurses

internationally (Beuthin et al., 2018; Pesut et al., 2019). The lack of preparedness, and resource that was nursing focused impacted on nurses' ability to feel confident and fulfil their roles.

6.4 Professional identity and resource provision

Many participants spoke about often being told "I don't know how you do that job." For these nurses dying was regarded as a normal process. Meaning was derived through helping patients and families come to terms with death, guiding them to a place of acceptance, ensuring symptoms were managed and practicalities were addressed to allow for quality time together. Participants were the holders of 'tribal knowledge' specific to their practice areas. The factors in end-of-life care nursing of alleviating physical, psychosocial, and spiritual suffering, and being expert communicators are incredibly rewarding as described by the nurses, and as acknowledged in past literature (Moir et al., 2015; Raphael et al., 2014; Thurston & Waterworth, 2012). Participants drew on their cultural backgrounds, their upbringings, and their years of nursing practice and specialist training and skill. However, they described that the lead up to a hastened death will be different quicker and more synthetic thus needed the tools to know how to discuss this new way of dying with people (Friesen, 2020). The responsibility to support and protect nurses' practice is seen as a wider role not only organisationally but in the way government shapes policy, codes and ethical guidelines (Edwards & Goussios, 2021). The lack of recognition of nurses as key stakeholders in this change led to a lack of resource to prepare nurses and thus a lack of confidence to carry out their role as acknowledged from other countries and jurisdictions where assisted dying has been implemented (Hewitt et al., 2020; Pesut et al., 2019).

A number of nurses also spoke about the spiritual support for patients and families and how that would happen with an assisted death. Nurses had not been provided the education and support to know how to respond to requests for assisted dying and fully support patients, or families both in their requests, and in the ongoing care in the lead up to this new sort of death. Usually when people are approaching end-of-life, nurses are used to recognising changes in condition, and signs of dying, and communicating these changes to family to alleviate distress to help people accept these end-of-life changes, and death, as a normal part of life (Gagnon & Duggleby, 2014; Lowey, 2015; Reed et al., 2018). This positive self-image and feeling of doing good within their role is important in professional pride, and enhancing professional identity and job satisfaction (Jeon et al., 2020; Van der Cingel & Brouwer, 2021). Assisted dying challenges these perceptions of their role through the exclusion of nurses, and assisted dying brings one of the most profound changes occurring in end-of-life care settings in recent history. Regardless of whether they were for, against, or neutral on assisted dying, all participants in this study were challenged especially by the way assisted dying was implemented putting nurses at risk of moral issues after implementation (Pesut et al., 2019).

Some participants in this study were told by their employers to state they could not support people with their request, but not how to do this in a way that recognises the significance of a patient is making a request for assisted dying. While others described feeling pushed to protect themselves, and their professional practice by shutting down patient and family questions about assisted dying because they felt unprepared if assisted dying came up due to unclear or inconsistent messages about the response they could give. Past literature showing nurses have mixed intentions when responding to requests for assisted dying (Wilson et al., 2020b). Most nurses saw responding to requests as part of their role, and part of their nursing assessment and management or care. Many nurses support patients in end-of-life decision making (Adams, et al. 2011) and it is often nurses that receive initial informal requests for assisted dying (Bernheim et al., 2008; Dierickx et al., 2018; Wilson et al., 2020a). These requests can come when time for patients is limited, the request may be genuine or a declaration of unresolved suffering (Young, 2020). Nurses were not prepared for how to respond in a way that allows a safe space to inquire, and ask further questions, to identify the nature of the request, and to address any existing issues the patient may be experiencing in that moment.

Participants described the importance of ‘being present,’ allowing silence, and being able to recognise suffering, to then address it. These were crucial parts of their roles and required the ability to be genuine and connect with patients. They reported that patients nearing end of life are in some of their most raw conditions of their lives, thus can recognise when someone is not genuine, being able to be genuine was a part of building real connections where patients and families could connect and trust nurses on a deeper level to allow them to understand and address deeper existential distress. They described the specific skill of being able to allow space for participants to be able to open up, beyond the surface level questions. They felt unprepared to do the ‘digging deeper,’ and fully connecting with people when they made requests for assisted death, while also conflicted as recognising and addressing suffering was such a vital part of their role. It is well reported that health practitioners responding to requests should understand that nuances in requests exist, and be able to openly explore discussions and enquires about assisted dying. From past literature, an expression of a wish to hasten death may not be a literal request but an attestation of unresolved suffering, wanting choice or due to fear of a bad death for others this is a persistent wish (Young, 2020). Neglect can include not acknowledging suffering, dismissing the felt loss of dignity, and failing to question the choices made by patients citing autonomy without discussing or educating about alternate means of care (Monteverde, 2017). In this research, participants unanimously described a lack of education for nurses and a feeling of unpreparedness to respond to requests, which puts them in a position where new forms of patient neglect and not meeting their duty of care to patients arises, through a lack of preparedness to respond to a request and fully explore this with the patients (Wilson et al., 2020a).

Nurses described the discomfort in ‘saying no.’ Nurses like helping to facilitate care however generating a response to assisted dying requests can challenge nurses morally if they do not support this, leading to reduced fulfilment and satisfaction in their role (Elmore et al., 2016). There was the thought of a discomfort of saying no to being involved or present due to their beliefs despite many nurses having had previously been asked to be present by patients or family members in the final days and hours of life. This was something they often did in their roles to help guide and people, but it was also something different. Past literature questions the implication holding a conscientious objection would have on health professional’s therapeutic relationships with patients, with many health professionals feeling an obligation to be involved in some aspects of assisted dying process (Haining & Keogh, 2021; Pesut et al., 2020c). Pesut et al. (2020a) reviewed literature from Canada, Belgium, and the Netherlands of the ethical, policy, and practice implications for nurses working with assisted dying. They recognised an absence of clear professional and legal guidelines. The lack of clarity or firm guidelines for nurses can leave nurses with moral distress as they feel the decision is on them individually rather than a policy driven requirement and can also have implications on patient outcomes (Wilson et al., 2020a). The choice of supporting or not supporting a request for assisted dying is not a binary decision and is shaped by sociocultural factors (Pesut et al., 2020c) and these was seen within the participant’s narratives. It was clear the responding to requests was something nurses felt unprepared for and thus more resource is needed to support nurses in responding to requests.

Some participants felt that their institutions that held organisational conscientious objections against assisted dying may be against their involvement, even if they themselves would be willing to support a person through the process, be present to offer support to the patient and family at the time, and in the immediate post bereavement care. For the nurse who had previously worked in a jurisdiction where assisted dying was legal, they described still reflecting on the event of a near-miss where they missed a call from a family asking them to be present and the relief that they had missed that call, as they would not have wanted to be there, but would have not known how to respond. Drawing back on the social cognitivist paradigm, Haidt (2012) suggests moral intuitions can drive decision making but are rarely challenged unless there is significant reason as these safeguard internal balance and in harmony with our peers. In a morally conflicting situation, we are pushed to question our rationale for our moral intuition and it is more likely to be changed where there is significant social interaction around a phenomenon, such as that existing with assisted dying (Haidt, 2012). It cannot be suggested that nurses reason their way through the rightness or wrongness of assisted dying based on set principles, and determine their willingness to participate. Rather, nurses need to engage both in a critical reflective process of reasoning, and in conversations with others about how they are making sense of their moral positioning in regards to assisted dying, as when interacting with human situations, decision making is not simple and linear (Pesut et al., 2020c). With Pesut et

al. (2020c) posing the example of a nurse with a long held therapeutic relationship with home-care patient requesting an assisted death, in light of that relationship, the patient asks the nurse to assist in planning and by being present throughout the process. Is the response one of immediate agreement and feeling honoured that they were asked to support? Or does it cause discomfort and a sense of wanting to withdraw internally as it goes against their long held moral standpoints? Or are they somewhere in the middle and unsure? This same narrative came through in the nurses interviewed for this research. Nurses need to be prepared not only themselves, but in ongoing discourse with their colleagues. Engaging in active reflection with both those whose views align, and do not align with their own supports active learning through the differing views, and levels of participation more can be learnt of the potential impact of assisted dying with diversity, allowing us to strategically engage this new moral landscape, all the while observing the consequences of our choice (Pesut et al., 2020c). Suggesting safe space for reflection with colleagues about actual or anticipated experiences with assisted dying should be encouraged in workplaces.

For nurses supporting aged residential care facilities, they raised concerns that many of the nurses in aged residential care settings had little, to no knowledge of the assisted dying legislation with many completely unaware of this legislative change. If these nurses are not even aware the legislation exists, they will be unable to respond to a request or provide any additional education or information. Nurse's role in responding to requests is significant as their response can have an effect on a patient's outcome at a point in an illness where time is critical (Wilson et al., 2020a). Internationally, if not involved in the ongoing process of assisted dying nurses were required to alert a physician of the request or provide information to start the formal request process and that nurses who supported assisted dying would perform information sharing activities, more so than clinical procedures such as intravenous line insertion (Wilson et al., 2020a; Oliver et al., 2017). Participants were confused about what was actually required from them within their role. In past literature nurses not fully understanding their roles and responsibilities was raised frequently, however, I did not find any sources of nurses being completely unaware of the actual legislation existing and assisted death being legal in jurisdictions where assisted dying legislation had been passed (Hewitt et al., 2020; Inghelbrecht et al., 2010). This shows in itself a significant issue with implementation processes, if this information had not reached nurses in these roles and they were completely aware that this legislation had been passed and was soon to be enacted and accessible.

Many of the nurses spoke about the importance of providing a safe space for patients and their family to share their fears and ask questions. They questioned how they would support this when their organisations were not preparing them for assisted dying. The participants described a sense of responsibility, and a deep sense of caring for the outcomes of their patients and the families, describing death as something that has ongoing effect on those left behind. Research

indicated that nurses experienced a profound sense of responsibility for patients, families, and other members of the health care team (Pesut et al., 2020b). Participating in assisted dying is impactful for nurses and required significant personal and professional moral work (Pesut et al., 2020b). While nurse's value autonomy and the ability to make decisions in their practice, they also value clear guidance of their roles and scope of their practice. Nurses felt there was a lack of clarity on supports that would be available to patients and their family's when requesting an assisted death, and described the likelihood of them being left to pick up the pieces where psychosocial needs had not been fully addressed, something they expressed already happened especially in more rural areas with limited access to multidisciplinary psychosocial support services. This suggests not only clarity on nursing roles is needed, but also that of the wider teams involved in patient care and bereavement follow up.

The participants had a variety of roles whether they themselves were involved directly in patient care, or they supported nurses in community settings with some roles covering direct patient care as well as education and support to aged residential care settings, Māori health providers and general practice. A significant number of nurses in aged care settings are immigrant nurses that already experience a substantial amount of cultural change working in NZ. Senior nurse roles are poorly understood however they have complex roles including being experts within their field, staff and patient education, consultation with multidisciplinary teams, developing nursing practice and research (Jokiniemi & Miettinen, 2020; Mohr & Coke, 2018). The nurses in this study felt unprepared to answer questions and provide support to the wider teams they support, whether other nurses, health assistants, administrative staff and wider multidisciplinary teams. There was concern and this is a significant issue raised that nurses are often involved in disseminating education and support multidisciplinary teams across care settings, but they were unprepared for the implementation of this legislation, thus assisted dying would likely not only impact their practice, but that of other health professionals who looked to them to support them, and ultimately on patient care.

Nurses in this study were distressed by factors that could be perceived as not within the direct scope of their role, such as donations to their hospices being cut due to the hospice either objecting or being open to assisted dying. Concerns such as these about funding and resource access, is impactful because nurses work directly alongside patients and families and when resources to provide care are cut or reduced, this directly affects the quality of care they can provide. Nurses have a significant role as advocates for patient care. Nurses have a legal obligation to use their expertise and influence to promote the health and wellbeing of health consumers and communities (NCNZ, 2012). This is important as the determinants that can lead a person to request an assisted death include different forms of suffering that can be physical, existential, fatigue, anorexia, dry mouth, psychological and social determinants (Bos et al., 2021). Nurses felt that with ongoing restricted palliative care resources, and their inability to

respond to patients needs in a timely manner, there is potential it could lead to patients choosing this mode of death over palliative care, and they felt a duty of care to advocate for better access to palliative care services for these populations. This is beyond direct care with patients but on a wider scale of advocating for equitable access and quality care. From MOH documented engagement with nursing stakeholders, issues with implementation and policy of assisted dying were similar to those raised by participants and in nurses in international literature including care access, palliative care services, safe guards, policy, education and implementation processes (Office of the Minister of Health, n.d.; Pesut et al., 2020a). This suggests, that going forward, the inequities in palliative care access need to be addressed not only for patients but for nurses' ability to fulfil their role in a meaningful way.

Several nurses described circumstances where a person had spoken about a wish for a hastened death due to access of care in home, or because the provision of care that met their specialist needs was just not available. Participants gave several examples from practice where the burden of care became too great for the family, or a patient, and assisted dying could be perceived as an easier or cheaper choice than funding in home care, or going into aged residential care. Nurses reported that inpatient hospice was limited usually with stays a maximum of two weeks for either end-of-life care, or acute symptom management. They described a concern for institutional coercion due to lack of resource. What they reported was significant in rural communities and parts of NZ with larger Māori populations and limited access to health care services.

Based on legislation, nurses described a provider of assisted dying would be flown to the patients' door in far reaching rural communities, however, they struggled to get a palliative specialist to review patients face to face because of stretched resource. Shaw et al. (2021) found that people that were living in poverty, or who worked with marginalised people did not feel this would drive them to consider an assisted death. However, it is well known that dying and advanced disease threatens a person's independence. While many people intend to maintain independence and control at the end of their lives, loss of autonomy and independence in the latter stages of a deteriorating illness is common, and associated with perceived suffering, and opting for either an assisted death, or suicide (Black & Csikai, 2015). The nurses would be working directly alongside people that may have lack of care options available. They did not know how to advocate for increased resource if they felt this contributed to a decision for an assisted death. The role of advocate and promoting health and wellbeing services, is a significant part of the nurse's role, and nurses would also require greater information on how to combat acute deficits in access to palliative care not only that directly influence requests for assisted death but in general to continue to fulfil nurse's practice and policy responsibilities.

6.5 Cultural safety

A number of nurses raised the question about responding to requests for culturally and linguistically diverse patients. For myself as a nurse and within a Māori world view, I recognise dying as a process that is not only a physical process, but something of strong cultural, spiritual, emotional and social significance, this was also recognised by several of the nurses. The Act is a very biomedical approach to health, without the need to necessarily involve wider cultural leaders and acknowledge the spiritual significance of death (The House of Representatives, 2019). Holistic models of care are embedded in nursing training however, some wider health providers and policy makers do not acknowledge some of the key principals of holistic care (NZNO, 2018). In NZ, promoting access to services which meet the needs of Māori health consumers, and integrating Māori models of health into care, is a legal and ethical responsibility (NCNZ, 2012). Due to the lack of preparedness and engagement for wider nursing in providing education into how to support culturally diverse patient's requesting an assisted death, nurses felt unprepared to provide support to patients and their family.

The participant's perceived that being unprepared for assisted dying would limit their ability to provide culturally safe practice, not only for patients but organisationally and for themselves as individuals. Cultural awareness and subsequent cultural safety is linked with establishing a strong professional identity and important in safe, effective nursing care, patient safety, and ethical inclusive practice (Doutrich et al., 2014; Hampton et al., 2010). Nurses from culturally and linguistically diverse groups also raised concerns that they may be seen as experts or the knowers of what to do within their workplaces when a patient of their culture made a request for an assisted death. A number of nurses talked about building culturally appropriate frameworks that would better serve communities from collaborative cultures and support the nurses. Concerns were raised about the support available to patients, their families and the health professionals supporting them that currently were not culturally and linguistically inclusive. It is well known that current end-of-life services both in NZ and internationally are Western focused and often do not meet the needs of indigenous cultures (Hampton et al., 2010; Kidd et al., 2018; O'Brien et al., 2013). These findings are similar to those reported from places such as Canada and Australia where despite recommendations of a culturally safe approach, legislation and related training did not provide adequate cultural support in supporting those from indigenous communities (O'Brien, et al 2013; Victoria State Government, 2017). Distinct in this study is that nurses from minority cultures also require access to cultural support as they are often looked to as the experts but had not been prepared themselves. Similarly, this had been raised by Penman et al. (2022) who found that culturally and linguistically diverse nurses should be considered in the development in educational programmes for assisted dying to meet the needs of nurses from different cultural backgrounds.

In NZ, assisted dying can only be requested by NZ permanent residents or citizens, however given the large migrant population it is likely the patient may be isolated from their family with was intensified with Covid-19 border closures and delayed visa processing (MOH, 2021a). The participants described complexities of collaborative cultures or for families where members were overseas and unaware of what was happening, nurses talk to and provide updates to families virtually which has been increased with Covid-19. They voiced concerns about the distress this would cause if the patient chose not to tell the family overseas and how this would work in their roles with rapport or support they may have been providing to this family. Nurses have a significant role in building connections and educating about health services in diverse communities (Hampton et al., 2010). A nurse raised the concern that it would be near to impossible to recognise coercion in patients that speak another language as someone with English as a second language. Although recognising coercion is not defined as a nurse's role under the Act, participants continuously spoke as strong advocates for their patients and disclosed past experiences where there were situations that had been difficult to navigate or abuse or neglect had not been recognised due to language barriers and they felt this would be no different. The lack of support or access to means to mitigate these issues therefore, impacted on the ability to provide culturally safe care. Nurses felt unprepared to support culturally and linguistically diverse patients and overcome challenges which subsequently impacted on their professional confidence supporting these patients, their perceived organisation wide cultural safety, and thus their professional identity was challenged. Assisted dying can also challenge their nurse's holistic views and beliefs (Penman et al., 2022).

Nurses identified Māori and Pacific people as generally less engaged in palliative care services due services not being designed to meet the needs of these people, and subsequent fears around palliative care. Nurses described some patients and families had fears about palliative care due to falsely held beliefs that palliative care was about hastening death. Similar to both Australian and Canadian indigenous populations, these groups are under supported palliative care services and have a sense of cultural isolation when accessing mainstream services that are not culturally appropriate (Hampton et al., 2010; O'Brien et al., 2013). It is unclear how assisted dying would impact upon people from these cultures, whether they may seek an assisted death as suffering at end of life was not addressed, or whether their access to this would be restricted as the legislation required literacy of biomedical health systems, and the specific legislation wherein the person must first know assisted dying is accessible to be able to access it (Stephens, 2019). Nurses had concerns about this, as they felt they would need to address confusion about palliative care in their practice as assisted dying blurred the lines and causes greater confusion about palliative care. With internationally, even health professionals assume that palliative care would be the orchestrators of assisted dying despite palliative care generally wanting to remain separate from it (Philip et al., 2020). Thus, it is likely this will also obscure patients and

families' views about what palliative care is, and does, impacting the practice of nurses in these settings.

Several participants voiced concerns specific to implementation of assisted dying for Māori patients and families as well as that of Māori nurses. Kidd et al. (2018) explained that there is a lack of cultural health literacy of health care professionals in palliative care leading to a lack of understanding of how to deliver health care and provide information in a way that meets a Māori world view. This adds pressures to the roles of Māori nurses and creates additional workload as they are looked to as the experts or “all things Māori” (Manson 2021). Participants felt that they had not been resourced with how to meet the needs of Māori patients or their family who request this mode of death. Most palliative care research in both NZ and internationally is focused on Western world views (Gott et al., 2017b). For Māori nurses they can feel more responsible for the care of Māori patients as Māori nurses (Hunter, 2019; Simon, 2006). Māori nurses commonly are seen as role models for delivering care to Māori however can be fatigued from resistance met when advocating for Māori clients and the fight to improve services when their cultural contributions undermined by colleagues or wider organisations (Hunter, 2019; Simon, 2006). A nurse participant described ‘te ao Māori’ changing ‘te ao hurihuri’ (the Maori world view as changing and evolving with the advancements in the world). They stated Māori do not hold a single world view and their views grow and adapt overtime. This was shown in a study with Kaumātua views towards assisted dying where some were strongly against it on cultural and spiritual grounds, while others were in support of it as a means to end suffering citing it as an old concept only the means had changed (Malpas et al., 2017). Ideologies are not fixed however, and participants felt challenged in the way their services would be delivered in a culturally competent way, mostly on an organisational level and the pressures specific to Māori nurses and the expectations placed on them to know how to support Māori people making requests for assisted death, with no specific cultural support provisioned for them as nurses. Within assisted dying legislation there has been inadequate preparedness to wider cultural needs responding to requests for both nurses and from patients and families from a variety of cultures impacting the practice and policy of nurses.

6.6 Conclusion

In this chapter the findings were discussed, whilst previous research had explored nurses' views and their individual roles there was a significant gap in knowledge especially since the passing of the End-of-life Choice Act (2019) in NZ in November 2020. Throughout this chapter assisted dying was acknowledged as a deeply complex issue within the field of health care and especially in the field of end-of-life care. It is acknowledged as a complex socio-historical issue and something that health professionals can hold strong views about. Explanation of this was formed within a social constructivist paradigm, and the understanding that nurses are influenced

by their socio-historical contexts which shape their views and their subsequent professional identity.

It was found that practice change theory and implementation processes were not applied by government agencies and organisations responsible for implementation of this change, and nurses had not been recognised as key stakeholders. Covid-19 was acknowledged as a factor that may have disrupted usual trainings and implementation. However, it is unlikely this was exclusively responsible as internationally, implementation and nurse involvement has often been poor or varied. The lack of involvement in this practice change left nurses feeling uncertain of their roles and how to respond to requests for assisted dying and how to support patients or other staff.

Nurses described factors that were understood as the fabric of their professional identity and what makes up their roles as end-of-life care nurses. They described the lack of resource, including time, education, and access to self-care that challenged how they were able to understand what their role would look like and challenged their professional identity. The policy and practice implication of assisted dying lay within the way that the participant's professional identities were challenged. This impacted the overall meaningfulness in their role, their sense of value, their confidence to carry out their role and thus has direct impact on the care they are able to provide to patients and families. This also impacted upon the support nurses would be able to provide to other health professionals such as wider multidisciplinary teams, administrative staff, doctors, or their own nursing teams, thus, restricting their overall fulfilment and pride in their role.

Nurses described that their cultural safety was challenged. This was significant for nurses from culturally and linguistically diverse background as they were also personally challenged in the ways they would be able to support patients and families, while keeping themselves culturally safe. Many of the nurses described that key cultural stakeholders had not been engaged in the lead up to and implementation of assisted dying, thus services and policy was inadequate to support the nurses to provide culturally safe care in regards to assisted dying. They anticipated this would create more work for them, with no additional resource, as well as had potential to be destructive to work they had done such as building trust in their palliative care services and further marginalise populations such as Maori, Pasifika and Asian populations in NZ who are already disproportionately receive inequitable end-of-life care. Assisted dying could also create additional workload or the need for culturally specific access to self-care for nurses, when nurses from specific diverse cultures are placed as the experts of delivering care for patients and families with the similar cultural identity.

This research highlights that assisted dying legislation affects the practice and policy of nurses by disrupting the professional identity of nurses working in end-of-life care settings. This is

therefore a significant practice and policy issue that needs to be addressed for both patient outcomes and for the health workforce. Within this chapter the research question was answered, as based on their experiences in end of life care, nurses perceive the practice and policy implications of assisted dying are extensive. Assisted dying is a change to the way people can now die in NZ, thus, it is a fundamental change to nursing practices in end-of-life care and the subsequent policy. Nurses are individuals in a human profession, and hold their own views that make them who they are as individual nurses. Assisted dying goes against some of the fundamental definitions that guide their practice, and nurses need resource to understand how to adapt and grow their practice so they can continue to fulfil their professional nursing roles. This included supporting patients and families, so that they can meet their organisational requirements, and also so that they themselves can continue to find fulfilment and meaningfulness in their roles, engage in ongoing means of self-care, and provide ongoing support to their teams. Nurses need to be seen, and heard as key stakeholders impacted upon by this change to be resourced with the tools to fulfil their roles. Assisted dying needs cease to exist as a taboo topic that is kept behind closed doors reserved for doctors and board members, it needs to be discussed in the open, and nurses need to be recognised for what they are, equal members of the health team, with their own distinct profession, that have skills and knowledge, essential to the delivery of holistic patient care, with a valuable voice to add to the assisted dying discourse that require equitable access to resource to be able to deliver to care they endeavour to provide, ultimately, to improve ethical, and safe practice, support policy and patient care.

Chapter 7 Conclusion

The aim of this research was to fill a gap in knowledge of how assisted dying implementation impacts upon the practice and policy for nurses in NZ. Nurses in end-of-life care settings work closely alongside patients and families, and often have enduring professional relationships with them through the final stages of their illness. Therefore, I identified them as a group with significant knowledge to contribute to this discourse and as individuals likely impacted by the legislative change. Employing a qualitative approach through narrative inquiry provided the opportunity to bring visibility to a poorly understood issue (Parahoo, 2014). The participant stories in this study guided the inquiry process, and thus guided the knowledge that could be gained, allowing for discovery of the key issues central to nurses and their practice (Allen, 2017). It was clear assisted dying would pose challenges to the individual values and beliefs of nurses regardless of their specific views for, or against the practice of assisted dying based upon both published opinion in NZ, and past literature (Manson, 2021; Pesut et al., 2019; Hewitt et al., 2020; Wilson et al., 2020a). Prior to this thesis, there was limited research specific to NZ nurses and their experiences, or ideas around the assisted dying implementation. Cultural values and practices vary across different countries. As such, some of the past studies were not completely applicable to NZ and the bicultural frameworks that guide practice and policy within NZ, including organisational and nursing responsibilities in cultural safety. In this chapter the key findings will be summarised, strengths and limitations, areas for future practice, policy and education will be described and final reflections will be made.

7.1 Key findings:

Nurses in end-of-life care settings find deep meaning within their roles and many are grounded by this meaningfulness. Many nurses are led into these roles throughout experiences in their life outside of nursing. These past experiences incite their genuine compassion, the ability not only to provide care, but to care. The human factors of nurses, their spiritual, cultural and religious awareness are a part of who they are both as people and in their role as nurses. Being human is what makes this change to practice and policy meaningful for nurses and is part of what makes up their professional identity.

Nurses not only described the holistic challenges for themselves, but for their colleagues through anecdotes of workplaces tensions, and the taboo nature of conversations about assisted dying. Nurses themselves or colleagues had felt compelled to leave their roles based on the way assisted dying was implemented, and the inconsistencies in expectations in their roles. This was evident in both nurses for, and against assisted dying. This corresponded with the absence of a space to openly discuss the fears, concerns or moral distress that they had. Nurses were not given a chance to make meaning of this change and how they would adapt to practice going

forward with this new means of dying available. It was apparent that a lot of the apprehension of this change could have been alleviated through better preparation by organisations and in the way government shaped implementation for nurses, and clearer communication. There was not clear information about what would be available going forward such as debriefing, education, supervision or other support networks however, they felt this would be needed.

It was determined that the nurse's roles within end-of-life care setting are complex and poorly understood. This is multifactorial not only in the way nurses are perceived by society, but also relating to the nuances in the nursing services across different settings from tertiary hospitals and community roles. Nurses' roles in patient care in advanced illness include comprehensive assessment skills, extensive knowledge of pharmacological interventions including the titrations of these to manage symptoms. They require a bigger picture of practicalities of death and dying including both understanding of physiological changes with an approaching death, options for after death care such as when to call a doctor, local funeral directors and how to lay out a body. They recognise and manage physical, spiritual, emotional and psychosocial suffering and are tactful in their skill discussing matters that other health professionals may either not recognise or not have the confidence, or skill, or knowledge of local communities to discuss. Although these nurses are familiar with death and dying, this is a new type of death, hastened and more synthetic. The preparation for this type of death would be different in that it was hastened and more synthetic, however would require much of the same holistic support and input both leading up to, and after the death. However, nurses were unclear of their role in this, and what they were actually allowed to discuss or what their ongoing involvement in care would be.

Many nurses were unsure what they could and could not discuss with patients and families. Not only were they unprepared, they recognised nurses in non-specific end-of-life care settings such as the aged residential care sector where many nurses were completely unaware of the legislation coming in. The lack of preparedness has the risk of putting nurses in a position where they may be unknowingly breaching their professional responsibilities due to a lack of clear policy and guidelines, including education of how to apply these practically into practice.

Nurses are also responsible for providing support, delivering education and as a resource themselves across health settings for other nurses, doctors, members of the wider multidisciplinary team, and other accessory roles fundamental to health services including administrative staff, cleaners and volunteers. In end-of-life settings these nurses are the go-to people for end-of-life care. However, as they were not recognised as key stakeholders in this new legislation, thus they did not get provided the resource to prepare themselves, and would be unable to resource and prepare others they support. Nurses needed access to education, not only online learning but face to face training, cultural support, not only for patients and families, but for themselves and the teams they support. This also required the time and resource to take on

the additional work that would be required as a result of this change. However, they were not recognised as key stakeholders, thus, were not given a seat at the table in their workplaces to be better informed about this change and prepare themselves or others for the change.

The overall finding from this research was that nurses were not recognised as key stakeholders within the implementation of assisted dying in NZ thus they were not resourced to prepare for this practice and policy change, challenging their overall professional identity as a nurse in the end-of-life care setting.

7.2 Strengths and limitations:

- There were several strengths of this study. I was able to gather rich data from nurses who work directly in end-of-life care settings, on the practice and policy implications of assisted dying during the months prior to the date it came into force. There was limited previous empirical data specifically on the implications of assisted dying implementation for nurses, and none in the period after the End-of-life Choice Act, passed and prior to the date it was legalised in NZ. I was able to gain insight on the implementation processes independent of issues post implementation for nurses directly impacted by this change. This has only been possible through the nurse's participation in the study and is thus greatly appreciated.
- As the researcher, and as a nurse working in an end-of-life care setting, this research was relevant to me and my practice and thus I shared my cultural identity as a nurse with the participants. My views are grounded within both Western and Māori world views and I was able to use these to strengthen the holistic discussions of this research in a NZ health context. Within social constructivism and narrative research, the researcher cannot be individual from the research and will impact on the research as it impacts upon them.
- As a nurse interviewer I was able to connect with the nurses. The connection with participants and the mutual respect shared as nurses was a significant strength of the research adding depth to the knowledge gained as the nurses shared true and raw accounts on the impact this legislation had upon them personally and professionally which inevitably influenced the research findings.
- I had initially anticipated Covid-19 would be a limitation but it positively impacted on this study. Participants were used to engaging in virtual meetings allowing for easy recruitment across NZ, and thus more diverse participants rather than having only recruited locally. The participants were happy and comfortable to meet over Zoom.
- A limitation was the small size of the study. However, due to the nature of this as a master's study and the methodological approaches chosen, ten was an appropriate number of participants for this narrative inquiry study.

- A further limitation was that there was only one person undertaking the data analysis. However, I engaged in regular meetings with my supervisor and was guided through my methodological approaches in my analysis and attended a thematic analysis workshop to build competence in these academic processes ensuring rigor and validity were maintained.

7.3 Recommendations for future research:

Within this research, multiple areas were recognised where further research would be needed. This is not an extensive list and highlights some of the key areas where future research is recommended. As an early study in assisted dying in NZ since the passing of the Act, this discourse overall requires further scrutiny. It has now been seven months since assisted dying was enacted, so further research is needed post implementation. Some topics could be further explored including nurses' experiences of responding to requests, supporting staff, patients, and family.

There were several issues raised about assisted dying being an easier option when palliative care resource was limited, or care burden was excessive, and the impact of this for nurses. Further investigation into palliative care provision or care requirements as an indicator for people choosing to access assisted dying would be useful. Further research is also needed in non-specialised end-of-life care settings such as hospital wards, and aged residential care settings, including their knowledge of legislation, and the practice and policy requirements, as it was raised that there was a clear lack of focus in these settings and a lack of resource provided to these nurses to prepare for assisted dying in practice. Since assisted dying came into force, there have been 143 assisted deaths in the seven months, with 9.1% occurring in aged residential care facilities (MOH, 2022), while in this research nurses raised significant concerns about nurses in these settings being unprepared, and in some cases fully unaware of the legislation. Thus, research into the provision of assisted dying in the aged residential care setting would be useful, including whether palliative care services were involved in the care of patients and the support given to nurses.

From published data thus far, 79.5% of those that have received assisted dying are NZ European, while 4.8% are Māori, 2.3% are Asian, and 14.3% are Pacific or other (MOH, 2022). From this data, assisted dying is predominately accessed by NZ Europeans. Participants in this research had raised that access to assisted dying for culturally diverse groups may be altered due to the way it was implemented within a very biomedical framework, thus research into this is also needed.

7.4 Recommendations for practice and policy:

Policy and legislation is planned to be renewed three years post initial implementation of the assisted dying legislation in NZ. From this research it indicated that including the role of the nurse in the legislation would likely recognise that nurse's roles are significant in patient care in end-of-life care settings. This may give government and subsequently organisations greater responsibility for adequately preparing, and educating nurses to respond to requests and better fulfil their roles with patients and families in supporting them with assisted dying requests, and through the process and subsequent post bereavement care. Self-care was another key issue raised so identifying differing methods of supporting nurses in self-care through the ongoing assisted dying implementation and delivery would be useful, including support for culturally and linguistically diverse nurses. Participants were concerned about culturally and linguistically diverse patient groups and assisted dying, so making a culturally diverse model of assisted dying would be of benefit.

If there was a change to legislation or specific guidelines for nurses, it would need to be the responsibility of the healthcare provider that nurses' education was provided in a way that met their learning needs, with a combination of online and face to face learning. They would also need to ensure adequate support was in place for nurses morally challenged by assisted dying to make sure they could access means of self-care, and have a choice to be involved in ongoing patient care in a way that was acceptable to them. NCNZ has a responsibility to nurses working across all sectors of health care to support with the integration of this legislation and ensuring there is provision for adequate education and resources for nurses. It was clear the nurse's education needs exceeded the education that was provided to them. Standardised national education frameworks for nurses may help to guarantee consistency across practice settings. A standardisation in self-care policies across care settings would be beneficial in safeguarding nurses to have access to means of self-care. This includes debriefings and professionally, culturally and spiritually appropriate support for nurses.

Better support for culturally and linguistically diverse health professionals is needed as raised by participants to address ways this challenged them culturally within their workplaces, and professional worlds. A greater focus of future assisted dying research where dying is accepted as not only a biomedical phenomenon but as a culturally, spiritually and social phenomenon would help to build understanding for not only nursing, but approaches to assisted dying inclusive of patients, families, and the multidisciplinary support teams that walk alongside people in advanced illness.

In general, assisted dying is a major health change in NZ, and the Act was written by non-medical personal, and subsequently many aspects of the Act are reportedly impractical in practice, and also fail to recognise nurses as key members of health delivery. For future change

in healthcare, especially with growing demand on nurses' roles, with a push for nurses to practice more autonomously, nurses need to be recognised as equal partners in patient care through recognition of their roles in legislation and subsequent provision of resource and education.

7.5 Dissemination of findings

I intend to make results and findings available as soon as it is appropriate to do so and I am aiming to submit my findings to a journal following the marking of my thesis. I also aim to present them at a nursing conference.

7.6 Conclusion:

Hearing voices of end-of-life care nurses has been important in understanding the impact the introduction of assisted dying has on the practice of nurses and subsequent policy. Employers have a responsibility to provide adequate training, and resource to nurses to fulfil their roles so that they can support patients and families. This research raised the previously unexplored concern that assisted dying challenges the professional identity of end-of-life care nurses because it is a change to practice and policy. It is suggested that not only change to policy, but change to the support provided to nurses, the resource allocation and likely the actual legislation needed amending to recognise nurses as key stakeholders with complex roles in these settings. This is needed to put responsibility on their organisations to resource them to be able to continue to practice with this change.

7.7 Final thoughts:

It was clear assisted dying held deep sentiment for the nurses, something they cared about not only for themselves, but for their colleagues, patients and families, and the people they support within their daily practice. Engaging in this research was a deeply meaningful process for me as the researcher in my connection with the participants sharing, learning, and growing through their stories. Assisted dying is a change to death from the end-of-life care practices nurses had known and arguably, the largest change in end-of-life care settings in recent history in NZ. These nurses are people that walk alongside patients, families and other health professionals in some of the most difficult, strenuous, fearful, yet precious times of their lives. They are compassionate, and knowledgeable educators, empowers, and specialists within their field of end-of-life care. They were not given the tools to be able to continue to fulfil their often challenging, and highly essential roles in a meaningful way, which has left them with a diminished professional identity in the wake of this new means of dying in NZ. This research identifies that government, organisations and policy makers need to do better for nurses, so they can continue in their critical roles in this field.

Chapter 8 References

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Chapter 9 Appendices

Appendix A *Ethics Approval*



6 July 2021
Rhona Winnington
Faculty of Health and Environmental Sciences

Dear Rhona

Re Ethics Application: **21/179 Exploring the views of nurses who work in end of life care settings towards assisted dying: policy and practice implications**

Thank you for providing evidence as requested, which satisfies the points raised by the Auckland University of Technology Ethics Committee (AUTEC).

Your ethics application has been approved for three years until 6 July 2024.

Standard Conditions of Approval

1. The research is to be undertaken in accordance with the [Auckland University of Technology Code of Conduct for Research](#) and as approved by AUTEC in this application.
2. A progress report is due annually on the anniversary of the approval date, using the EA2 form.
3. A final report is due at the expiration of the approval period, or, upon completion of project, using the EA3 form.
4. Any amendments to the project must be approved by AUTEC prior to being implemented. Amendments can be requested using the EA2 form.
5. Any serious or unexpected adverse events must be reported to AUTEC Secretariat as a matter of priority.
6. Any unforeseen events that might affect continued ethical acceptability of the project should also be reported to the AUTEC Secretariat as a matter of priority.
7. It is your responsibility to ensure that the spelling and grammar of documents being provided to participants or external organisations is of a high standard and that all the dates on the documents are updated.

AUTEC grants ethical approval only. You are responsible for obtaining management approval for access for your research from any institution or organisation at which your research is being conducted 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.

Please quote the application number and title on all future correspondence related to this project.

For any enquiries please contact ethics@aut.ac.nz. The forms mentioned above are available online through <http://www.aut.ac.nz/research/researchethics>

(This is a computer-generated letter for which no signature is required)

The AUTEC Secretariat
Auckland University of Technology Ethics Committee

Cc: rosie.davis4@gmail.com

Appendix B Participant Information Sheet



Participant Information Sheet

Date Information Sheet Produced:

28/04/2021

Project Title

Exploring the views of nurses who work in frequent end of life care settings towards assisted dying: policy and practice implications

An Invitation

Tēnā koe, my name is Rosalie Davis. My iwi are Ngai Tahu and Ngati Kahungunu. I am a specialist palliative care nurse. I am doing a master's degree at AUT. My work in palliative care during the voting to legalise assisted dying has inspired me to study the views of nurses towards assisted dying including policy and practice implications. I would like to invite you to participate in this research.

What is the purpose of this research?

The End of Life Choices Act 2019 comes into force on 7 November 2021. Assisted dying will be legalised in New Zealand after the passing of the End of Life Choice Act (the Act). Under this law, people who have a prognosis of less than six months and have unbearable suffering may access assisted dying. Because many of these people will require nursing care to manage the disease progression and related symptoms, it will invariably have an impact on nursing practice and on your holistic role as a nurse. The aim of this research is to better understand policy and practice implications for nurses working with patients who request assisted dying. The findings of this research may be used for academic publications and presentations and to inform future policy.

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

You may have seen the advertisement to participate through your professional organisation or work education network. You have received this information sheet because you have responded as a nurse, working in end of life care, for a minimum of one year in your current work place as a permanent employee. As nurses who work in frequent end of life care settings the introduction of the Act is likely to have the greatest impact in your area of work. You will be participating as an end of life care nurse, not representing your place of work or nursing association. Unfortunately, if you have been working in end of life care for less than 12 months, are a locum or student or are currently working at Hospice West Auckland you will be unable to participate.

How do I agree to participate in this research?

Please get in touch with me via email if you are interested in participating. You will need to complete a consent form prior to the interview.

Your participation in this research is voluntary (it is your choice) and whether or not you choose to participate will neither advantage nor disadvantage you. You are able to withdraw from the study at any time. If you choose to withdraw from the study, then you



will be offered the choice between having any data that is identifiable as belonging to you removed or allowing it to continue to be used. However, once the findings have been produced, removal of your data may not be possible.

What will happen in this research?

I would like to sit with you for a 60 to 90 minute face to face narrative interview to better understand your role as a nurse in end of life care and your perceived practice and policy implications of assisted dying on practice. Please see attached the interview prompts for the discussion points for this interview. If more convenient, or in the case of another Covid-19 lockdown we can meet virtually via zoom. Interviews will be audio recorded and transcribed. Following this, the information gathered will be analysed to identify themes. You will have the opportunity to review transcripts.

What are the discomforts and risks?

Sometimes in the process of engaging in an interview, sensitive topics or personal experiences might be discussed which could cause emotional distress (similar to what you may experience in professional supervision). While this is uncommon, should you feel uncomfortable or distressed, you have the right and freedom to immediately end the interview. If you do not wish to respond to any of the interview prompts you may choose to ask to move on to the next area of discussion without any justification. Your name and consents will only be available to the researcher and supervisor. Your name will not be given to the transcriber or any third party.

How will these discomforts and risks be alleviated?

At any point you can decline to answer questions, without giving a reason, ask for the recorder to be turned off, remove anything you said if you change your mind (as long as analysis has not commenced) or you can stop the interview. You can also request to review the transcript of the interview, this may take one month to be returned to you and you will have two weeks to review this. If you disclose any illegal activity or professional misconduct I may be obliged to report this. If engaging in the interview or recalling experiences from practice causes any distress I encourage you to engage with your workplace employee assistance programme (EAP) counselling.

Furthermore 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 921 9998.
- let the receptionist know that you are a research participant, and provide the title of my research and my name and 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/student-support/counselling-and-mental-health>

What are the benefits?

While there may not be any immediate benefits to you as a participant, the findings of this study may be used to make recommendations in order to inform policy and direct areas where further education is needed for nurses. Your participation will support my Master of Health Science Research project at the Auckland University of Technology, supervised by Dr Rhona Winnington.

How will my privacy be protected?

The interview will be held away from your ward or facility in an AUT interview room or virtually via zoom. Your contact details will be stored in a secure location, separate from interview recordings and transcripts. Data will only be available to the AUT research team. Typists who transcribe the interviews will sign a confidentiality contract and identifying data will be deleted from transcripts. No personal information identifying you as a participant will be included in any academic publications. Pseudonyms will be utilised for any direct quotes used and identifying details will be omitted or altered to obscure your identity.

What are the costs of participating in this research?

If you choose to be interviewed for the study, there will be a 60 to 90 minute commitment for the interview. You will also need to allocate time for travel to and from the interview. If you cannot meet face to face we can arrange to meet via zoom. Travel costs such as petrol for local travel, bus fares and parking may be subsidised. This will be negotiated.

What opportunity do I have to consider this invitation?

You will have a minimum of one week from the date I send you this information sheet before I contact you to answer any questions you may have and confirm your interest in participating in an interview. If I do not hear a response within four weeks I will send one follow up email. If there is no response to this I will remove your contact details and assume you do not wish to participate.

Will I receive feedback on the results of this research?

Feedback, should you request it, will be provided in the form of a summary of the findings. Once these are available (about 12 months after your interview), the summary will be sent to you via the contact details you provide. If this research is published you will also be sent a link for the publication if you wish to receive this.

Funding declaration

I have received a health workforce NZ scholarship through Waitemata District Health Board for course costs of this research, I plan to apply for an AUT grant for costs such as transcribing. I am self-funding additional costs such as transport and printing.



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, *Dr Rhona Winnington*, rhona.winnington@aut.ac.nz, + 64 9 921 9999 ext 7123.

Concerns regarding the conduct of the research should be notified to the Executive Secretary of AUTECH, ethics@aut.ac.nz, (+649) 921 9999 ext 6038.

Whom do I contact for further information about this research?

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

RESEARCHER CONTACT DETAILS:

Rosalie Davis, email: rosie.research.ad@gmail.com 021 0826 9774

PROJECT SUPERVISOR CONTACT DETAILS:

Dr Rhona Winnington, rhona.winnington@aut.ac.nz, + 64 9 921 9999 ext 7123.

Approved by the Auckland University of Technology Ethics Committee on 06/07/2021
AUTECH Reference number 21/179 Note: The Participant should retain a copy of this form.
 Oral Consent Protocol

Appendix C Narrative Interview Prompts



Narrative interview prompts

During this meeting I am going to give you prompts to share your stories about different matters relating to assisted dying and how these contribute to the views you hold.

I will ask these as prompts but I want to hear your stories, and to gain an understanding of your experiences. I invite you to explore what influences the views you hold including your past experiences personally and professionally, your culture, your upbringing, your religious beliefs, your education or anything else you feel is important to you and informs your views.

The prompts are:

Tell me about your current role as a nurse supporting patients and families at the end of life.

Tell me about any experiences you have had where a patient or family have asked about hastening death.

Tell me how you feel towards assisted dying and supporting patients and families who may request this mode of death.

Tell me about the end of life choice act and your experiences both personally and from patients and other health care professionals such as your colleagues when discussing the end of life choice act. Do you find your views align or are conflicting?

Tell me about your understanding of the end of life choice act, the role of nurse and how you would feel about meeting the code of conduct and code of ethics and any other legislation or education in your work place about this?

Tell me about the current holistic support you have in your work place, working frequently with patients at the end of life and if you would be willing to be involved in assisted dying, what additional support you perceive may be required?

Is there anything else you would like to add?

Appendix D *Consent forms for participants*



Consent Form: For interviews

Project title: Exploring the views of nurses who work in frequent end of life care settings towards assisted dying: policy and practice implications

Project Supervisor: Dr. Rhona Winnington

Researcher: Rosalie Davis

- ☐ I have read and understood the information provided about this research project in the Information Sheet dated 28/04/2021.
- ☐ 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 understand that if I disclose any illegal activity or professional misconduct the researcher may be obliged to report this.
- ☐ I agree to be contacted for a brief subsequent meeting if required to clarify any points to ensure full understanding. Yes ☐ No ☐
- ☐ 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 06/07/2021
AUTEC Reference number 21/179 Note: The Participant should retain a copy of this form.

Oral Consent Protocol

For participants who are unable to complete and sign a consent form, I will gain oral consent. Prior to the interview commencing I will explain that I am gaining oral consent. I will subsequently read the below consent. If they agree to all the below questions the interview can commence. This will be recorded separately to the recording of the interview and not given to the transcriber.

Today's date is _____.

I will now read the following consent form for the project titled *Exploring the views of nurses who work in frequent end of life care settings towards assisted dying: policy and practice implications* the project supervisor is Dr Rhona Winnington the researcher is myself Rosalie Davis

If have any further questions about the research I can answer these as we go through each of the questions.

Can you confirm your full name:

- ☐ Can you confirm you have read and understood the information provided about this research project in the Information Sheet dated 28/04/2021?
- ☐ Can you confirm you have had an opportunity to ask questions and to have them answered?
- ☐ Do you understand that notes will be taken during the interviews and that they will also be audio-taped 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 my data may not be possible.
- ☐ Do you understand that if you disclose any illegal activity or professional misconduct I may be obliged to report this?
- ☐ Do you agree to be contacted for a brief subsequent meeting if required to clarify any points to ensure full understanding?
- ☐ Do you agree to take part in this research?
- ☐ Do you wish to receive a summary of the research findings (tick one)? Yes ☐ No ☐

Approved by the Auckland University of Technology Ethics Committee on 06/07/2021 AUTECH
Reference number 21/179

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

Appendix E *Transcriber confidentiality agreement*



Confidentiality Agreement: Transcriber

Project title: Exploring the views of nurses who work in frequent end of life care settings towards assisted dying: policy and practice implications

Project Supervisor: Dr. Rhona Winnington

Researcher: Rosalie Davis

- ☐ I understand that all the material I will be asked to transcribe is confidential.
- ☐ I understand that the contents of the tapes or recordings can only be discussed with the researchers.
- ☐ I will not keep any copies of the transcripts nor allow third parties access to them.

Transcriber's signature:

Transcriber's name:

Transcriber's Contact Details (if appropriate):

.....

Date:

Project Supervisor's Contact Details (if appropriate):

.....

Approved by the Auckland University of Technology Ethics Committee on 06/072021 AUTEK

Reference number 21/179

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

Appendix F Example of early thematic maps

