Spiritual Diversity, Spiritual Assessment, and Māori End-of-Life Perspectives: Attaining ka ea,

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Abstract: The contemporary world is endowed with increasingly diverse spiritual and cultural perspectives, yet little is known about the spiritual concerns and spiritual resilience of Māori from Aotearoa New Zealand at the end of life. A context is provided for the value of spiritual assessment and identification of spiritual needs or concerns. Spiritual concerns and the desire to attain a state of ka ea (fulfillment, gratitude, or peace) may point to interventions, helping activities, or referrals that guide treatment. We reflect on qualitative findings from the 2017–2020 Pae Herenga study of 61 caregiving families, their helping professionals, and religious/spiritual leaders. We explore essential spiritual values and practices that support kaumātua (older tribal people) who have a life-limiting illness in achieving a sense of satisfaction and fulfilment at the end of life. Three themes emerged: the relational is spiritual, the need to live into the future, and value of spiritual end-of-life care. While some scholars have lamented the lack of culturally appropriate rapid assessment instruments, we suggest that a more open-ended assessment guide is better suited to understand key elements of spiritual diversity and spiritual concerns, particularly the spiritual strengths and resources that lead to well-being and even thriving at life’s end. Finally, learning about spiritual diversity can assist others to reconnect to lost meanings and regain a more holistic and centred view of life.

Keywords: spirituality; religion; spiritual assessment; Māori; spiritual strengths; spiritual concerns; cultural; palliative care; end of life

1. Introduction: A Context for Spiritually Diverse World Views

The spiritual marketplace (Roof 2001) has widened in the 21st century. At its stands, besides traditional religious views that fall directly in line with belief systems from Hinduism, Buddhism, Jainism, Judaism, Christianity, Islam, Zoroastrianism, Jainism, Confucianism, Daoism, Shinto, and Bahá’í, one can find indigenous spiritual views such as from American Indian or New Zealand Māori cultures (Nelson-Becker 2018; Nelson-Becker et al. 2017). Together with these are sometimes syncretised new age spiritual beliefs, folk religions, and philosophies. Adding to this mix are the “nones”, those who profess no religion or formal spirituality, yet are curious about community and sometimes are to be found as students in divinity or religious studies schools (Thiessen and Wilkins-LaFlamme 2017). Interfaith networks began to organise and grow in the late 20th century, showing respect and appreciation for each other’s doctrines and views. This is a perplexing array of viewpoints to sustain, and few healthcare practitioners, nurses, and social workers will be well-informed about each of them, particularly at the end of life. Yet, increasing evidence suggests that incorporating spiritual matters into healthcare can improve health outcomes (Hematti et al. 2015; Koenig et al. 2012), psychological outcomes, and well-being (O’Brien et al. 2018).
Each religious viewpoint brings a law or doctrine, tradition, perspective on authority, boundaries beyond which it may not stretch, and an ethical code. It is embedded in culture and customs, especially in its origins, even if it seeks to attract cross-cultural communities. Indigenous religions may hold a divergent view deeming cultural views and connections to ancestors primary. Partly, this is important because of marginalisation and misunderstanding by dominant cultures. Nonetheless, it is critical for healthcare professionals to better understand spiritual needs, spiritual concerns, and spiritual resources at the end of life, especially for people whose views may not be widely known or understood. Although individual views may vary from those of any group, at the end of life, family members may not be able to discuss general contexts due to the high emotional valence involved in death and dying. The purpose of this paper is to highlight some of the lesser known Māori spiritual views among the broader stream of spiritual assessment in healthcare.

This paper discusses spiritual assessment with Māori people at the end of life and exploration of spiritual perspectives. The key research question arose from the Māori community that requested this study. They asked how Māori older people could be better supported at life’s end. Thus, this paper presents findings from a study of 61 Māori caregiving families (including adults and older people with a life-limiting illness), indigenous healers, and health care professionals, highlighting what brings peace and spiritual resilience at life’s end.

2. Māori Spirituality and Religious Affiliation

The relationship of the Māori people of Aotearoa New Zealand with religion has changed over time and some individuals may blend other religious belief systems in a syncretic style that lives peaceably with Christianity. In Te Ao Māori, the Māori world, whenua, the land, is alive, connected to all living things. The people (tangata) and the land (whenua) belong to each other. Māori people understand their nation from the inside through spiritual connections that value sacred resources such as ancestors, greenstone, and mutual obligations with the land. Exchanges of breath, hā, hold sacred significance and connect people to each other often through the hongi (pressing noses) shared in greeting.

New Zealanders of European origin comprise 64.1 percent of the population and Māori people 16.5 percent (Statistics New Zealand 2018a). The 2018 Aotearoa New Zealand census suggests that nearly half of the population (48.2%) did not endorse any religion, a trend that has grown, as evidenced by 2006 census data showing 34% failed to endorse a specific religious belief (Statistics New Zealand 2018b). The 2018 census was done solely online (a digital first approach) and concerns have been raised about representativeness of Māori, who do not all have internet access; it is known that adult males below age 30 were undercounted in the 2013 census by 8 percent (Kukutai and Cormac 2018). Although raw data are available online, much of it remains to be analysed (See 2018 Census totals by topic—national highlights—updated 30-04-20). Māori religions comprise Rātana at the largest proportion, a smaller proportion of Ringatū, and the smallest group: Māori religions, beliefs, and philosophies that were not further defined nor categorised (Statistics New Zealand 2018a). Ringatū and Rātana are local New Zealand religions founded in the late 19th and early 20th century, respectively. Māori Christian religious affiliations had decreased 19.2 percent at the 2013 census from 2006 and 46.3 percent of Māori people were not affiliated with a religion (Statistics New Zealand 2013).

The Māori world view is characterised by an interrelationship and interweaving between spiritual and material spheres (Hardy and Whaanga 2019). This is distinct from the more mechanistic Western world view that considered nature subordinate to humanity and has led to environmental abuse related to increased toxins, depletion of rain forests, thinning of the protective ozone layer, etc. (Lockhart et al. 2019; Sherkat and Ellison 2007). Although this may be changing now, to a Western-oriented mind well-practiced in dualistic thinking, this type of natural and material integration is not fully understood, nor usually experienced. Instead, Māori see themselves as part of an ecospiritual world.

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1 This was photographed on a placard at Te Kōngahu Museum of Waitangi, New Zealand in 2019 by the first author.
with a shared ancestry. The world view of Māori is one of harmony and balance, a lived reciprocity that pervades their spiritual perspectives and denotes mutual obligation and regard. At life’s end, working within this meaning system is fundamental to upholding values and facilitating a peaceful death.

Feeling spiritually connected with whānau (family including extended family and friends), tūpuna (ancestors), and future generations is an important element in kaumātua (older Māori) arriving at a state of ‘ka ea’ before death. For New Zealand Māori, ka ea can be described as arriving at a state within oneself where the individual feels satisfied, fulfilled, settled with a sense of gratitude. This state of emotional, cognitive, physical, and spiritual connectedness is attained rather than inherent (Moeke-Maxwell et al. 2020a). Belief in the wairua (spirit of a person that exists upon death), and participation in activities informed by wairuatanga (spirituality) is a crucial cultural conduit that helps to strengthen and fortify indigenous kaumātua (older tribal people) at end of life. Although the concept of ‘wairuatanga’ is vast and moves beyond the following explanation, for descriptive purposes we define it as a spiritual dimension that encompasses both the metaphysical and physical realms and includes whakapapa (genealogy), pūrakau (Māori creation stories), cosmology, mātauranga Māori (indigenous tribal knowledge), philosophies, and tikanga (cultural customs) (Duggleby et al. 2015). Therefore, wairuatanga (spirituality) should be viewed as an intertwining creative life force that energetically joins everything, binding together the atua (gods), universe, Earth, people, animals, plants, and bird and sea life.

Spirituality, and spiritual assessment as a means of identifying the value of this domain, remain important aspects of end of life health care, yet little information is available about how health care practitioners support the spiritual needs of older Māori. We reflect on spirituality, spiritual assessment, and spiritual needs through findings from the Pae Herenga study, where we briefly explore some essential spiritual values and practices that support kaumātua who have a life limiting illness to achieve a sense of satisfaction and fulfilment at the end of life. We draw from their narratives and their whānau manaaki (family caregivers’) stories about caring for kaumātua before death (Moeke-Maxwell et al. 2020c). Our aim in this paper is to showcase our findings that manaakitanga (kindness, generosity, a process of showing respect and the reciprocal care of others) moves beyond the individual to be inclusive of tūpuna (ancestors), whānau (extended family), and future generations; being connected in this way helped kaumātua (older Māori) to achieve a state of ka ea before death.

3. Spirituality and Spiritual Assessment in Palliative Care

Spirituality has a number of definitions that relate well with end-of-life and palliative care. Spirituality was once viewed as a subcategory of religion, and has generally evolved to a construct separate from religion (Steinhauser et al. 2017). This development has aligned with greater emphasis on individual experience and philosophy in most contexts, though it is somewhat different in communal cultures. Two related definitions are the following: spirituality is that aspect of humanity that refers to the way individuals seek and express meaning and purpose by connecting to nature, to significant experience, or the sacred (Puchalski et al. 2009, p. 887); spirituality is the dynamic discovery of purpose, meaning, relationship, and connectedness that is the essence of human experience2. Many definitions share commonalities in underlying aspects of significance, interpretation, and wholeness.

Reese (2013) distinguishes between intellectual and experiential elements that may lead to self-transcendence. The relational dimensions of spirituality are highlighted by Callahan (2017), who identified the value of and learning potential through spiritual relationships. Spiritual care, embedded in spiritual world views, denotes responding to the soul’s need for compassion and facilitating expression as desired (Nelson-Becker 2018; Gijsberts et al. 2019). Spiritual care assists patients to manage the uncertainty of treatment, sustain a sense of peace, and understand fear

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2 This definition came from a subgroup discussion and was co-created with the first author at the Improving Spiritual Care National Palliative Care Consensus Conference in 2009.
(Hu et al. 2018). It invites discussions of spirituality and religion in regard to needs, support, concerns, and treatment decisions (Balboni et al. 2013; Edwards et al. 2010). In healthcare this would only come about under a patient’s request and it may include referral to religious and spiritual leaders within their tradition. If a patient has no interest in further discussion or follow-up related to spirituality or religion this also must be respected. No additional discussion is needed, though this may be reassessed over time at different points in the illness.

Spiritual assessment is an important part of palliative care provision. It forms one aspect of biopsychosocial spiritual appraisal, which is a fundamental and formal element of palliative care. Some health care professionals, however, are not well trained in addressing this holistic aspect of assessment and care. Mirroring a general avoidance in society, social workers and nurses often have less training in addressing this topic unless they have a natural affinity to listen for and hear spiritual needs and concerns (Callahan 2017; O’Brien et al. 2018). Practicing with spiritual sensitivity denotes a type of cultural competence (Pentaris and Thomsen 2020). It may be layered with specific cultural knowledge that can result in a positive outcome of care and regard for the patient and his/her family or whānau that includes extended family and non-living ancestors.

3.1. Spiritual Assessment

Spiritual assessment is central to good care for a number of reasons (Puchalski et al. 2009; Steinhauser et al. 2017). It opens up conversations in a neutral way, where patients may identify areas of meaning and purpose that are religious/spiritual or existential. Assessment ensures that individual and collective community rights are respected: if religious or spiritual rituals matter, these may be conducted in a supportive environment. Assessment is the pathway to develop care plans to maintain well-being. Finally, while many patients do not maintain spiritual or religious beliefs, many prefer health care professionals to ask about their views (Ernecoff et al. 2015). A spiritual assessment differentiates the kind of spiritual needs a patient may hold, if any, and helps craft a response sensitive to need (Hodge 2015; Nelson-Becker et al. 2015). This includes sensitivity to varied cultural customs and worldviews. Although studies vary, the relationship of spirituality to positive health outcomes is generally supported (Koenig et al. 2012) and spirituality may offer comfort when individuals face life-limiting or terminal illness.

Spiritual awareness develops through mindful attention to lived experience. Hosting spiritually-oriented conversations may unfold where the term spirituality is not mentioned, in implicit discussions about what provides deep meaning in patients’ lives (Nelson-Becker 2018; O’Brien et al. 2018). Areas of spiritual strength, as in the Māori-based research study detailed in this paper, and areas of potential spiritual struggle or conflict are beneficial to address (Pearce et al. 2012). Relationships with mentors, nature—plants, trees, and animals—and the cosmos, transpersonal powers such as with deceased loved ones, or energies and beliefs about death, the afterlife, and the spirit world may be reviewed. A holistic discussion might centre on the importance of spirituality and religion, among other elements, both individual and community-related. A pre-condition to these conversations is establishing a relationship of mutual trust and posing questions in a fluid and flexible manner, open to any kind of response and inviting the patient’s own vocabulary for experiences that may lie outside of the boundaries of language.

3.2. Spiritual Assessment Forms, Instruments, and Māori Models

There are several types of assessment that may be conducted as suggested in the Clinical Practice Guidelines for Quality Palliative Care of the National Consensus Project for Quality Palliative Care (Ferrell et al. 2018). These consist of a spiritual screening, a spiritual history, and a spiritual assessment. The spiritual screening may or may not include the terms spiritual and religious, but seeks to discover beliefs that may affect health and well-being. The spiritual history would be a formal, usually standard, assessment that would provide more details to assist the staff. Finally, the spiritual assessment is deemed the most extensive approach in this structure.
A number of tools have been developed to formally assess and provide spiritual care. One paper by Balboni et al. (2017) reviewed tools in each of the three structural categories above, stipulating that such tools should be applicable; inclusive; quantifiable, valid, and reliable; acceptable to patients, and clinically relevant for needs. Another study by Aslakson et al. (2017) reviewed 152 palliative care instruments across domains and concluded there was a dearth of tools that were particularly culturally relevant or sensitive enough to detect change. Furthermore, the more instruments are developed for universal appeal, the less they connect to unique aspects of culturally relative situations.

Several models of healthcare apply directly to Māori people (Durie n.d.; Moeke-Maxwell et al. 2020b). One model depicts the concept of ‘te whare tapa whā”—the four cornerstones (or sides) of Māori health—and resembles the image of a house. Spirituality is addressed through taha wairua (spiritual wellbeing), one of the four cornerstones or foundations of the house; the other three health dimensions include physical health, family health, and mental health. It is important to note that te whare tapa whā model is anchored within the environmental/physical and practical foundational support needed to sustain people living in this physical world. The spirituality of both the group and the individual is honored, including the present situation, the past, and future. During assessment, care is taken to address any spiritual aspects of the illness that may emerge physically and contribute to ill health. The Te Wheke model (Pere n.d.) addresses health through the symbolic concept of an octopus with ten dimensional tentacles and an overarching total wellness dimension. Spirituality, wairuatanga, may be assessed separately, though at one time all dimensions were intermingled with no separation. These forms of spiritual assessment align well with the Māori worldviews and are well-known in New Zealand. The POI Community of Care Hospice model (https://www.poiproject.co.nz/resources/), in addition, suggests asking whether a dying individual wants their whānau (extended family) to be present, to eat kaimoana (seafood) from their homeland and listen to karakia (prayers to elicit guidance and support) from their marae (family communal gathering and sacred space). Details of the Pae Herenga study addressing spiritual wellbeing among other supports follow.

4. Methods: Pae Herenga Study

Kaumātua advisers from the Te Ārai Palliative Care and End of Life Research Group from the School of Nursing, University of Auckland, called for a qualitative study to gather evidence of traditional Māori end-of-life care customs. They were concerned that culturally disenfranchised Māori were lacking in cultural knowledge to support them to carry out end-of-life care. With the steep projected increase in older Māori deaths, they anticipated this vital information would be needed to support whānau (family) caregivers. They appointed Tess Moeke-Maxwell to lead the study. The aim of the Pae Herenga study was to investigate the traditional end-of-life care customs of Māori whānau and to identify what helps or hinders them to use their care customs in different health care settings through conducting face-to-face interviews with Māori whānau who were either previously or currently providing end-of-life care, rongoā (natural healing practitioners), tohunga (spiritual care) practitioners, and Māori health professionals.

Kaupapa Māori research design methods were employed and a social constructivist, Māori-centred thematic analysis incorporated (Eketone 2008). Kaupapa Māori research provides a philosophical, theoretical, ethical, and practical framework that acknowledges and responds to te ao Māori (the Māori world) and peoples (Bishop 1999; Hudson et al. 2010). Kaupapa Māori research places Māori and Māori participants at the centre of the research. As such, research questions, methodological design, fieldwork, analysis, publication writing, and dissemination all evolve from Māori leaders, academic researchers and community collaborations and reflect a collective Māori worldview. Kaupapa Māori research is research that is led by Māori, for Māori, with Māori.

A research grant was awarded by the New Zealand Health Research Council, 2017, and ethical approval was gained from University of Auckland Human Participants Ethics Committee (UAHPEC). A large multi-disciplined bicultural team (over 30 people) was formed to provide the necessary cultural, clinical, academic, and local support to undertake this qualitative project (Moeke-Maxwell et al. 2020a).
Moeke-Maxwell was able to sensitively collect parts of participant life stories. They knew she would understand and could interpret for non-Māori health professionals without a lot of initial context. Sharing a similar cultural background, she was able to easily establish rapport and create a relational environment that invited trust.

Consistent with a Kaupapa Māori research approach, Māori researchers were deeply and personally involved in the research through their invested interest in producing research outcomes that are committed to the decolonisation of Indigenous people by contributing to equitable health outcomes. The second author drew on her existing relationships with Māori elders, Māori community groups, and Māori end-of-life care experts in four regions in the North Island of New Zealand and their local hospices, to collaborate on the project. These Community Research Collaborators (local Māori elders, Māori end-of-life care experts (hospice workers), and several hospices) provided recruitment support in the Mid-North, Hawkes Bay, Wellington, and Whanganui regions (Moeke-Maxwell et al. 2020a). Whānau recruitment criteria were based on recent and current experience of providing end-of-life care to adults and older people and face-to-face interviewing methods were used with both individuals and families. Interested participants’ contact details were forwarded to the lead researcher (Moeke-Maxwell) who made contact with each participant and conducted each interview. Some interviews were supported by research assistants and members of the Te Ārai kaumātua advisory group, particularly when interviews were conducted primarily in te reo Māori (Māori language). To ensure the cultural safety of participants, we observed Māori customary practices of karakia (prayers, incantations, chants) and waiata (singing) at the start and end of interviews. Koha (gifts) of food and/or petrol vouchers were given to participants as a sign of respect, and kai (food) was shared at the interview conclusion to remove the tapu (restrictions) associated with the subject material and interview context.

Participants provided written and verbal consent and indicated their preference for the use of real names or pseudonyms at the start of each interview. Individual/whānau interviews spanned between one and four hours; the duration depended on the time availability of participants and also the number of people taking part in an interview (more participant involvement increased the length of interviews). Interviews were conducted at a place chosen by participants; whānau interviews were generally conducted in a private home and non-whānau participants selected a work environment for their interviews. Interviews were digitally recorded and transcribed with permission. Participants were provided with a summary report (thematic written story of their interview) as a form of member checking (Moeke-Maxwell et al. 2018).

A coding framework using traditional Māori pūrākau (creation stories) was developed to code data using the NVivo software programme. Data analysis and publication writing on various aspects of traditional end-of-life care was led by different team members reflecting their specific areas of academic, clinical, or cultural expertise. For example, analysis and academic publications on rongoā (indigenous healing methods), wairuatanga (spirituality and spiritual care practices), tangihanga (funeral customs), and health provider practice that either helped or hindered whānau to carry out their customs is currently underway (Moeke-Maxwell et al. 2020a).

A further data-gathering component involved three digital story-telling workshops (Moeke-Maxwell et al. 2020c). Sixteen participants/whānau were invited to take part in a digital story-telling workshop to produce a three-minute video about an aspect of traditional caregiving. Verbal and written consent was gained prior to the workshop. The workshop spanned three days and each person/whānau storyteller was assigned a university-trained film editor who helped to co-create their story. We adapted the digital story-telling method to include an Indigenous format by introducing a marae (tribal gathering place) to conduct a pōwhiri (formal welcome ceremony), and poroporākī (farewell ceremony) providing storytellers with an opportunity to share their digital stories. The purpose of these workshops was to produce digital stories to share on a public website to support future whānau caregivers and health professionals to provide culturally rich end-of-life care to Māori adults and kaumātua; the Pā Te Aroha website will be available in 2021 for public viewing (Moeke-Maxwell et al. 2020c).
5. Results

The study produced 61 face-to-face interviews with an even spread across cohorts, including whānau (family of or person with a life limiting illness), rongoā healer (Māori medicine/natural healers), tohunga (spiritual practitioners), and Māori health professionals. The age of participants was mostly clustered in the 40–70 age band and included both males and females. However, some whānau interviews included children and older people. Participants came from a range of tribal groupings from different geographical areas and most identified with more than one tribal group, consistent with other New Zealand Māori. There was an even mix of people from both rural and urban communities and most could speak te reo Māori to some degree.

Three digital-story telling workshops were held in the Mid-North, Hawkes Bay, and Wellington regions and produced 16 digital stories. Each story highlights a different aspect of traditional caregiving, values, and practices (Moeke-Maxwell et al. 2020c). Digital stories were mainly produced by female whānau carers in the 40–60-year age range, although five men either solely produced or co-produced their own stories, including one grandson in his early 20s, and older male kaumātua who were in the 70-year age band.

In this paper we draw from participant narratives to explore the influence spirituality had on kaumātua (older tribal people) arriving at a state of ka ea (fulfillment, gratitude, or peace) before death. Real names accompany quotes, as these participants did not request anonymity. Three themes emerged out of the analysis that address Māori spiritual strengths and resilience at the end of life. These themes concern: (1) the relational is spiritual; (2) living into the future; and (3) spiritual end-of-life care.

5.1. The Relational Is Spiritual

Arriving at a state of ka ea happens when kaumātua (older tribal people) feel connected to, and nurtured by, their whānau (family). For example, participant Marj, who was diagnosed with life-limiting cancer, expressed her satisfaction and gratitude over the care her son provided:

[T]he speciality with my son [who is] 40—he cooks, cleans, does the grounds; he does everything. He does everything.

Tina commented that when her chemotherapy finished she decided to write a bucket list of the things she wanted to do before she died. It was important to her that she travel to see her whānau, as she knew this would have reciprocal benefits. Reconnecting in person helped to cement their relationships and provided an opportunity for aroha (care, empathy, and compassion) to be expressed:

But the most important one [on my bucket list] was to keep in contact with my family, letting them know what I was going through, what time my appointments were, where I was going for them. They’re giving me comfort, and I’m and giving them what I’m feeling so, it’s basically like- what I’m looking like for … peace of mind … For me, you know, to see if they understand what I’m going through and what they’re feeling. And it’s nice to hear their feedback of how I’m looking, how I’m feeling.

Importantly, connecting and being with whānau helps strengthen connections with wider whānau networks and with tūpuna (ancestors). Being reminded of who they are (ancestral connections) and where they fit into the whānau can help to re-establish bonds with whānau who are still living as well as those who have departed. These connections help to affirm a sense of identity and belonging, which is important, particularly when physical life is losing its hold. Tina further reflected on her road trip and reconnecting with relatives:

Yeah my aunties and uncles when they saw me you know, they were shocked. Because one aunty couldn’t let me go she was busy hugging me that tight. I said, ‘Come on Aunty, I need to breathe’ … She goes, ‘Yeah but I can’t believe it’s you’ … Yeah, my uncle couldn’t stop staring at me. He said I look like the other aunties like, ‘Oh God, you look like my sister [name].’ ‘Oh God, you look like my brother [name].’
Knowing that whānau are there to love and to care for their ill and dying family member provides a korowai (traditional cloak) of protection and safety as kaumātua approach the ārai (veil between this realm and the next). Ripeka was independent throughout her journey and welcomed whānau support, directing husband Jeff on how to care for her:

It was whānau being around her to support her in one sense. But also to meet her needs . . . As soon as she got sick we just formed a circle around her, you know, take care of her, any of her needs and whether it be a karakia [prayer] or waiata [song], anything. Very independent all the way through, but she liked to have the whānau support, so I was there. Tell me off occasionally if I got it wrong, or got her the wrong kai [food] or not thinking ahead for her needs . . . Because I was in there living the moment and she was thinking, ‘You know, you just passed that shop! Why didn’t you get me one of those [drinks?]’. So, I’m sick, I can’t think for myself—you should be able to think for me!’ . . . Just tryin, trying to meet her needs along the way on that journey, and making sure that I was there, and this is where, mine and [daughter’s] role come [sic] in. We always made sure that when she was in hospital that one of us was there, or both of us.

5.2. Living into the Future

Arriving at a state of ka ea was evident for kaumātua whose motivation for living was propelled by their desire to be with their whānau for as long as they could. Being with their whānau meant being there for their whānau. Kaumātua enjoyed a sense of ka ea when they felt they had given their whānau everything they possibly could; this also includes transitioning mātāuranga (Māori knowledge), whenua (lands), and taonga (treasured objects) before dying. Being there for whānau was particularly relevant for kaumātua who had adult children and mokopuna (grandchildren) who they wanted to continue giving their love and practical support to. Although Aggie was given a poor prognosis, for example, having hope and maintaining a positive outlook was important to her:

[Even] though the doctors say ‘there’s no hope’ I believe that there is. I always believe there is . . . I said to the kids ‘I’m gonna fight like heck, and I’m gonna try everything and anything and I’m not just gonna give up.’ . . . I say to them, ‘I just want positive thoughts, I don’t want any, you know, the negative ones. I just want positive [energy] all around me all the time,’ and they’ve been really good.

Aggie’s children helped her to keep focused on beating her illness, “My kids are driving me at the moment. My kids and my will to want to beat this and be here a lot longer.” Encouraging words from her whānau helped Aggie to arrive at a state of ka ea:

Especially, especially my ones [children] in Australia, they go ‘we know you’re strong Mum, we know you’re strong; you, you’ll get through this’. And that’s exactly what I want to hear. You know, that kind of kōrero [talk] and people who really know me, they go ‘we know you’re strong’. Yeah, and that encourages me, even [though] you know, I do have blue moments.

During this final part of her life, Aggie made a decision in relation to the future of her family that was aimed at easing their bereavement when she died. This undoubtedly helped to ease her mind:

I’ve also gone and put a will in place. And it’s mostly for the safety of my kids. You know, it’s for their safety so that they don’t have uncles or aunties come back and saying ‘oh this is our family home’. You know, things like that, just give my kids peace of mind.

5.3. Spiritual End-of-Life Care

Kaumātua who had a life-limiting illness who took part in the Pae Herenga study spoke about their spiritual beliefs, values, and their various cultural practices. Regardless of whether these spiritual
beliefs were traditional (tribal), handed down from tūpuna (ancestors), or they derived from a form of Christian or New Age discourse, having a strong spiritual belief system appeared to fortify kaumātua before they died. Knowing that their spirit would cross the ārai to return to Hawaiki (ancient spiritual homeland and place/s where the spirit return to after death) or a heavenly realm to be united with beloved gods and tūpuna contributed to them arriving at a state of ka ea. For example, in the following narrative Marj commented on her childhood memories of being matakite (seeing the dead) and her ability to communicate with the spiritual realm signalling her acceptance of the wairua and its transition at time of death:

I’d seen when people very close to me can’t move, going to heaven. I could see the patterns come through . . . And above that lake, a stream of cloud, and above the cloud was a space, an empty space. And then above that was the picture of, from here up, people’s (well they call them busts) but I call them like a photo shoot and it’s all in black and white. Everything was in black and white and they were different ages. Different, different era. Different year. And I thought ‘hmm’. When I was young, I saw it all the time and I used to think they [wairua] were all coming in, in fancy dress. But no, it was the era that they died in, that[s] the clothes that they wore . . . Yes, they all came from different eras. And when I asked things, I would ask in my mind because if I could see and I got to know how real everything was; if I could see they would answer me in my thoughts. So I would look and think, and get an answer.

A state of ka ea can also be achieved when kaumātua feel as though they have had an opportunity to complete the work that their tūpuna inspired them to do. For example, when asked if Ripeka needed much time to process her situation before she crossed the ārai, Jeff stated his wife “just [needed] a little space” to process her impending death.

Because of her religion, she looked at it and she probably knew she was one of God’s workers. Yeah. And she actually told me in the, in the conversations that she used to have with her tūpuna. It was that her pathway was already chosen. Most of us that are born into this world we can choose our own pathways; hers was chosen for her... And towards the end of it, like up until probably 18 months before, there was all of a sudden, a big rush. Her tūpuna says, ‘You know you’ve got to hurry up and do this, hurry up do that,’ and in the back of her head it was going ‘oh they want to push this, this piece [of work] through’. But I think, looking back now, she had so much to do, but she didn’t know at the time, you know, the tūpuna already planned, you know, we need to help others with us.

Not all kaumātua had an established faith, but the end of life can bring new opportunities for spiritual growth and expansion. Faith-based experiences can help people to understand themselves more fully in the context of a greater, larger spiritual existence than what they can see with their eyes or feel with their hands. For example, Tina stated she was not brought up with karakia, but since her diagnosis, she had started praying more often. When she was in hospital, she would visit the chapel and pray. This started after she had an experience during a dream. Tina’s cousin thought this might have been Tina’s wairua guidance:

You know, to be honest with you, I was sleeping. I was asleep. And for some reason, two guys . . . in a uniform stood up on me, I could see the outlook of them with their hat and the gun. And they . . . one was pointing, and the other one was waving, so I dunno what that meant, but when I was dreaming, or day dreaming, I just happened to get out of my bed, grab my wheel thing [walking frame] and walk to the chapel . . . [Later] I told my cousin, because I thought I was losing my marbles. I honestly thought I was, yeah. I said, “Hey Cuzzy, you know there were two guys in the army suits, you know, (pointing at chapel). I didn’t know if I was sleeping or day dreaming.” And she said to me, ‘So what did you do Cuz? It mighta [sic] been your wairua telling you like, go do something about it.’ I said, ‘Oh well, I grabbed my walker and went to the chapel and I been going ever since.’ . . .
goes, ‘Good on you Cuzzy.’ … And she said to me, ‘Have you learnt anything from this?’ I said, ‘Maybe I have or maybe I haven’t, but I found out when I go there I do find it quite warm, heart-warming when I go in there and I look at the cross and that and I’m thinking, my gosh, that could’ve been me hanging up there’ sorta [sic] thing I told her. But I said to her, ‘It felt good, because every time I spoke in there to Him too, I felt my prayers were getting answered.’

Tina reflected that it was quite possible that the spirit kaitiaki (guardians) were her t¯upuna (ancestors) who had come to encourage her to do her forgiveness work before she passed:

… both grandfathers, my Mum’s dad and my dad’s dad were both in the M¯aori Battalion so I assumed, ya [sic] know, they were getting me to that way to maybe to forgive myself or pray for myself...

Practicing tikanga (customs) such as karakia (prayers) and singing waiata (songs) is very helpful in preparing older peoples’ wairua to pass through the ¯arai. When kaum¯atua (older M¯aori people) were calm and were satisfied that everything was all right, it was often considered easier for them to let go and pass through the ¯arai. Aggie commented on an important traditional aspect of care to help the wairua (spirit) on its journey, also highlighting the sacredness, yet ordinariness of the spiritual:

When a person passes away … you’ve got to tukua te wairua [release the spirit]. You know, once that person’s gone you’ve gotta [sic] tukua the wairua. So that, that journey doesn’t get hindered. And that’s what happens with a lot of our urban families, they don’t have people there to tukua te wairua. To let that wairua keep its journey going. Even just a simple ‘Our Father’ you know, a simple ‘Our Father’ and then say, ‘We’ll let your wairua go.’ As simple as that. Doesn’t have to be these big, flash, long, karakia …

This section established that manaakitanga (kindness, generosity, a process of showing respect and the reciprocal care) is a belief and participation in things spiritual; it moves beyond individuals and individual concerns to relationally embrace wh¯anau, ancestors, and future generations. Kaum¯atua (older M¯aori people) and their wh¯anau (family) practice manaakitanga and in so doing they invoke their spiritual beliefs and practices, because they know this helps them achieve a state of ka ea before death. Therefore, kaum¯atua resilience is reliant on beliefs in wairua, engagement with wairuatanga (spirituality) and the interconnectedness between the past, present, and future. It interweaves everything and settles the wairua bringing a sense of satisfaction, fulfilment, and gratitude for a life lived and loved.

6. Discussion

Spiritual diversity finds one of its many expressions through service among people with different belief systems. Yet, without understanding the unique features of different religions, spiritualities, cultures, it can be difficult for health and mental health professionals to fully offer support. When people fail to understand, trust may diminish or disappear. Spirituality and religion are often flashpoints for misunderstanding and create conflict, even war. Where trust is harmed, people stand at the edges of their own beliefs, unable or unwilling to move into larger truths. One positive aspect of interfaith movements has been a search for universal commonalities, ground on which to build trust. Yet if the search for common ground fails to heed the sacred particularities of existential, religious, and spiritual perspectives, people and groups may be harmed, as possible breaches in respecting tapu (restrictions/sacredness and safety) and noa (freedom from restrictions) in M¯aori culture remind us. The capacity for cultures to call majority groups back to the ground of being they have forgotten is a rare opportunity (Hardy and Whaanga 2019). Sometimes representatives of the public sphere, scientists and politicians, show interest in recapturing some of this content. However, it is in the health professions where the need is most critical. Paradoxically, what can be offered by the majority culture, which is space and time and understanding, is the very gift that will boomerang back to offer far
greater depth and awareness of the absent dimensionalities of life. This is a gift of cultural awareness
generally and a gift working to support and learn from people of Māori background as shown in their
narratives above about achieving a state of ka ea.

Spiritual assessment is a necessary action to ascertain spiritual needs and concerns, which may
frequently surface in life-limiting illness. However, simply embedding this as a routine part of
all assessment done with palliative care patients has not been simple. Studies show that general
practitioners (GPs) and other non-palliative care physicians or specialists are not comfortable opening
conversations about end of life, and less so spiritual concerns (Ernecoff et al. 2015). Even when family
members may broach the topic, physicians in the US often redirected or dropped it. Further, important
personal boundaries can be breached by well-meaning professionals. On one side, well-intentioned
professionals with religious faith may step over or around these boundaries and try to impose their
own views. On the other side, they may ignore the significance of the spiritual dimension to health
and well-being. Health care professionals may consider themselves less spiritually competent if they
have no faith of their own, not realising that sometimes holding no belief can mean they are in the best
position to support, if they are curious and relational in their approach.

Presenting a range of common human questions and needs at the end of life, as in Table 1 Examples
of Spiritual Concerns, begins to sensitise professionals to the breadth of concerns/needs and helps
them visualise possible responses (Nelson-Becker 2018). The table lists common areas of spiritual
concern, a further explanation under the heading primary condition, an example of the concern, and a
possible response. Based on this study, several items have been added to the table—item 3: collective
marginalisation of minority groups (aging, ethnic) which may play out in treatment decisions; item
4: communication of needs; item 6: dying away from home; and item 14: specific cultural values. The table was designed to address common human needs at the end of life that involve existential,
spiritual, and religious concerns. What was added here from an earlier version includes some items
particularly sensitive to indigenous cultures and the column that suggests a variety of possible clinical
responses to specified needs. Achieving ka ea for New Zealand Māori in this study often occurred
through resolution of prior struggles and interpersonal conflict. Respecting tapu involved respect
for the interconnections of people with all of life and the environment and ensured noa or safety
was upheld. The results of this study were about finding ka ea (fulfilment, gratitude, and peace)
which most of the participants were able to achieve through compassion expressed by their informal
and formal carers, cultural practices such as special food, prayers, singing, and their inner knowing
and experiences.

<table>
<thead>
<tr>
<th>Spiritual Concern</th>
<th>Primary Condition</th>
<th>Illustration</th>
<th>Response Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Anger toward God or others</td>
<td>Projects anger toward religious figures or clergy, inability to forgive</td>
<td>Why would God allow this cancer? I’ve been good.</td>
<td>Listen, encourage sharing of feelings to process them, begin to transform suffering through touching it and dialogue</td>
</tr>
<tr>
<td>2. Belief that a miracle will occur</td>
<td>May reflect ethnic or religious group’s beliefs and expectations</td>
<td>I have always done what you ask, God; please do this for me.</td>
<td>Listen, provide realistic support</td>
</tr>
<tr>
<td>3. Collective experience of marginalisation during large-scale conditions such as pandemic, war</td>
<td>Scale of personal loss is magnified under unfolding societal conditions</td>
<td>My loved ones are unable to visit; my needs and the needs of my group are overlooked</td>
<td>Offer reasonable reassurance, facilitate contact, and communication</td>
</tr>
</tbody>
</table>
Research has suggested a dearth of established and reliable tools for measuring spiritual needs across cultures (Balboni et al. 2017). The Māori narratives provided above also suggest that some of the spiritual needs would not have been well-captured by a standardised assessment tool that asks some important questions, but misses questions of specific value to this cultural group. If those needs fail to be discovered and addressed, then valuable opportunities for possible healing and growth are also overlooked or neglected. These opportunities exist for whānau as well as health care professionals who care for them during an episode of conscious dying. For this and other cultures,

<table>
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<th>Spiritual Concern</th>
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</thead>
<tbody>
<tr>
<td>4. Communication of direct spiritual needs</td>
<td>Majority group culture does not understand or respond to indigenous needs, as one example</td>
<td>All whānau (Māori family) and health care staff wash their hands when entering/exiting room of the dying to spiritually ‘cleanse’ spiritual energy</td>
<td>Work to facilitate requests, ensure tapu (restrictions/sacredness) maintained</td>
</tr>
<tr>
<td>5. Despair, Desolation</td>
<td>Inconsolable</td>
<td>No one can forgive me for this</td>
<td>Ensure safety; explore reasons. Support value and worth; look for avenues of hope</td>
</tr>
<tr>
<td>6. Dying away from home, ancestral land</td>
<td>Discusses sense of dislocation, sad</td>
<td>I want to return home</td>
<td>Build connections with symbols/objects from home, ask about underlying need.</td>
</tr>
<tr>
<td>7. Existential concerns</td>
<td>Poses questions about life meaning, what will happen after death, what is the purpose of suffering</td>
<td>My life has no meaning. What happens when I die?</td>
<td>May respond with thoughtful questions; share texts from patient traditions if known; proverbs, prayers, songs, poetry for insight</td>
</tr>
<tr>
<td>8. Forgotten</td>
<td>Worried that one’s death won’t matter</td>
<td>No one will care when I die.</td>
<td>Gently challenge and confront belief; what matters is present life and how one lives it, even if there is no witness.</td>
</tr>
<tr>
<td>9. Guilt/shame</td>
<td>Deep regrets, lack of self-worth</td>
<td>I’m so sorry I hurt him. I was never good enough</td>
<td>Acknowledge feelings and awareness, use cognitive restructuring</td>
</tr>
<tr>
<td>10. Isolation or alienation</td>
<td>Shows feelings of loneliness</td>
<td>I feel so alone</td>
<td>Problem-solve together and refer for support</td>
</tr>
<tr>
<td>11. Immediate spiritual concern</td>
<td>Specific thought, feeling, or action related to what is spiritual or a religious community</td>
<td>I will be judged as a failure by God</td>
<td>Listen, explore, stay within client/patient belief system</td>
</tr>
<tr>
<td>12. Legacy</td>
<td>Worry about how family may continue after death</td>
<td>How can I provide for my family physically, emotionally, spiritually</td>
<td>Explore family resilience, explore interconnecting life tasks separately</td>
</tr>
<tr>
<td>13. Loss/grief</td>
<td>Feels deep sorrow loss of good health/home, loss of other support systems</td>
<td>I don’t know how to go on without my sister. I wish I could still walk every day</td>
<td>Silence for holding space; mindful presence; meditation; breathe together</td>
</tr>
<tr>
<td>14. Tapu and Noa Cultural Values</td>
<td>Need to achieve a balance between tapu (restricted, sacred, set apart, or forbidden) and safety (noa)</td>
<td>I am at risk, since tapu may be breached by those who do not understand.</td>
<td>Take cues from whānau, learn about cultural values, arrange conditions to facilitate safety</td>
</tr>
<tr>
<td>15. Relationship with God/Doubt</td>
<td>Does not sense God’s presence, or presence of the Ultimate</td>
<td>Where is God now? Why can’t I feel him/her?</td>
<td>Reflect content of thought; summarise change over time-places of challenge and growth</td>
</tr>
<tr>
<td>16. Religious or spiritual struggle</td>
<td>Displays deep level of discomfort with spiritual questions which are pervasive</td>
<td>Why am I feeling this way?</td>
<td>Accompany; refer to religious or spiritual leaders for specific competencies</td>
</tr>
</tbody>
</table>

Adapted from (Nelson-Becker 2018).
it is likely that a narrative open-ended assessment would best elicit the kinds of spiritual needs to be met in palliative care. A similar study of resources for resilience at the end of life in hospice patients showed that qualitative assessment elicited more meaningful data than quantitative instruments (Nelson-Becker 2006).

In Western cultures, advance directives are intended to allow people to determine care of the body at the end of life. Seldom do these advance directives include psychosocial, spiritual, and emotional plans for dying or attaining a state of ka ea. In the narratives above, the presence of whānau (family) and the opportunity to both receive and give care and compassion at this life phase offered powerful opportunities for sharing and feeling cared for (the relational is spiritual). Living into the future was another central theme. For what does one hope when the end of their days are in view? In some cases it may be to live well with people who share mutual care and affection for the time that remains. In other cases, it may be to stretch the death trajectory out further and perhaps keep it at bay a little longer. Aggie certainly expressed both viewpoints, but she also remained in the flow of life by writing a will for her children, the generation to follow.

The final theme addressed provision of spiritual care. Moeke-Maxwell provided a visual image, knowing that their spirit would cross the ārai to return to Hawaiki assisted people in achieving ka ea. Marj, one of participants, remembered a vision or waking dream that provided her with comfort and helped her prepare for crossing through the door to what would be next: “Above that lake, a stream of cloud, and above the cloud was a space, an empty space. And then above that was the picture . . . ” Family members spoke about their dying loved ones undergoing life review during the time leading to death. Individuals spoke about intuitive dreams directed by spiritual guardians that helped them to return to earlier sources of support, providing renewed peace and strength. Prayers were spoken and songs were sung to send the deceased spirit on its journey, consistent with traditional ways. These actions helped whānau achieve a state of ka ae after the loss.

7. Conclusions

The Pae Herenga study brought an important and seldom accessible type of knowledge forward for palliative and health and social care professionals. It was rich in providing the viewpoints of Māori whānau (family of or person with a life limiting illness), rongoā healers (Māori medicine/natural healers), tohunga (spiritual practitioners), and Māori health professionals. Spiritual stories are those which nourish and help people flourish across generations. They are a type of legacy that connects ancestors to future ancestors-in-the-making, hand-to-hand. These stories are not often shared, because the level of intimacy required for them must be earned. Because we live in a larger society that looks for the next best thing, the quick fix, and people who share vulnerabilities are sometimes disparaged, one must also be brave to open space to share spiritual worlds. Yet, in the sharing, there can be astonishing growth for the storyteller and the audience, be it one or many.

It is tempting to try to capture cultural beliefs and actions through validated tools to help with assessment, but trying to combine cultural and spiritual assessment in quantitative tools would miss much of the richness of experience, which can only be delivered in trust. Instead, future research should continue to capture the voices of indigenous and other cultures through qualitative questions in emic perspective, not only for health and social care professionals to gain knowledge and skills to support, but also to help outsiders recapture elements of holistic living that have been lost and could signify our own way to ka ae, consonant with our respective cultural values and modernity.

Author Contributions: H.N.-B. wrote the context for the study, background on Māori religion and culture, developed the spiritual concerns table and wrote the Discussion/Conclusion. She did the final editing. T.M.-M. explained elements of Māori culture, reported the study design, methods, and study results. She also contributed to editing. All authors have read and agreed to the published version of the manuscript.

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