

# Dying well in Aotearoa New Zealand for ethnic minority communities: a time for reclamation?

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## ABSTRACT

Despite technological advances and a disproportionate increase in health expenditure at the end-of-life, most New Zealanders die in hospital or in aged residential care. This counters the aspirations espoused by Te Whatu Ora (Health New Zealand) for all New Zealanders “to live well, age well and die well in their homes and communities.” Furthermore, despite reported inequities in end-of-life care experienced by ethnic minority communities (EMCs) overseas, and increasing proportions of people identifying with Asian, Middle Eastern, Latin American and African ethnicities in Aotearoa New Zealand, local data, research and policies addressing healthcare needs of EMCs at end-of-life are scant. Acknowledging this invisibility, we reflect on and discuss the current discourses on death and dying, the complex experiences at end-of-life for EMCs, including concepts of a “good death”, the impact of recent existential crises (e.g., COVID-19 pandemic, climate change) on death awareness, and the global rise to reclaim dying as an important part of living. We argue for the need: a) to partner with ethnic communities to co-design culturally safe end-of-life health services, and b) to adopt a “compassionate communities” public health approach that can support people of EMCs at the end-of-life to die well.

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Te Whatu Ora (Health New Zealand) has made explicit commitments to reduce inequities in healthcare and develop a people/whānau-centred, whole-of-society, population health system.<sup>1</sup> However, alongside clinical interventions, health technological advances and an overall rise in life expectancy (except for the most deprived populations where life expectancy has fallen), years lived without good health and poor symptom relief have increased from 8.6 years to 10 years.<sup>2</sup> In the last month of life, there is a disproportionate increase in health expenditure and acute hospital admissions, making dying, which was once an “otherworld journey” and “community affair”, an increasingly private, hidden, professionalised and institutionalised event.<sup>3</sup> Access to high-quality, culturally responsive palliative care is variable.<sup>4</sup> Most New Zealanders (65%, increasing to over 90% for those aged over 85 years) are likely to die in an institutionalised setting—either in hospital or, increasingly, in aged residential care.<sup>5</sup> In the *Palliative Care Action Plan*, Aotearoa New Zealand prioritised responding to the voices of people with palliative care needs and committed to implementing culturally appropriate responses to meet the needs of different cultural and ethnic groups.<sup>4</sup> Previous palliative care research

with Māori has highlighted that a Western biomedical approach does not meet the cultural palliative care needs of Indigenous peoples. We acknowledge the legitimacy and imperative to address this, mindful of the intergenerational impacts of colonisation, and the status of Māori as the tangata whenua of Aotearoa New Zealand. We also anticipate that diverse groups of migrant people have experiences that are similar, as well as different, to those of their primary Te Tiriti partner, and these require attention to achieve population health equity.

## Over-exposed yet unseen

Aotearoa New Zealand’s census population statistics indicate increasing populations of ethnic minority communities (EMCs), comprised of highly diverse ethnic groups identifying with Asian, Middle Eastern, Latin American and African (MELAA) origins.<sup>6</sup> EMCs have grown from 10% of Aotearoa New Zealand’s total population in 2006 to 16% in 2018, and over 200 ethnicities are reported in Auckland alone. However, data, research and national policies that specifically address their core healthcare needs, including at end-of-life, is scant.<sup>4</sup> Reported deaths in EMCs in Aotearoa New Zealand recorded as “Asian” at

level 1 ethnicity reporting account for 4.7% of total deaths and are projected to rise to 10.4% by 2043.<sup>5</sup> The default to homogenise and report meaningless categories such as “Asian”, “MELAA” or “other” in many publicly available reports and research publications in Aotearoa New Zealand masks the highly diverse experiences of Aotearoa New Zealand’s EMCs. These limitations are consistent with arguments in World Health Organization (WHO) and Lancet Global Health reports<sup>7,8</sup> that highlight the virtual absence globally of robust data to support the needs of migrant populations that are “*overexposed* [to risks] *yet unseen*” despite clear health inequities compared to host populations.<sup>8</sup>

Overseas, inequities in care of the dying are reported in non-white ethnic groups who are more likely to die in intensive care, receive invasive procedures in the last 6 months of life and have poorer access and uptake of hospice services and participation in advance care planning compared to host populations.<sup>9-12</sup> A narrative literature review found that preferences of EMCs at end-of-life were influenced by migration experiences (e.g., exposure to racism, discrimination, acculturation level, migration trauma, enforced poverty, fragmented cultural identity), age, gender, cultural and spiritual practices, generational differences and level of available social support and healthcare.<sup>13</sup> Tensions between individualism and familism, religious and secular positions, perceived power imbalances between minority and dominant cultures and fear and mistrust in healthcare institutions were also reported. Self-management through prayer, spiritual healers, herbal remedies and traditional medicine was viewed as important. In addition, a recent integrative review of barriers to equitable access to healthcare in Aotearoa New Zealand for migrants and refugees reported attitudinal barriers (lack of culturally competent healthcare providers, discrimination and personal socio-cultural factors) and structural barriers (cost of healthcare, accessibility to interpreters, length of appointments and difficulties navigating the health system).<sup>14</sup> Although studies suggested death was perceived as taboo in some EMCs with a predominant collectivist approach to decision making and cultural value of filial piety, experiences were varied and heterogeneous; there is no “one size fits all” approach to end-of-life care, which unfolds in relation to others and beyond the individual. Other factors reported to promote positive experiences at end-of-life included

access to professional interpreters, language aids, cultural navigators or mediators of similar culture or ethnicity, healthcare professionals spending time with whānau, involvement of EMCs in policy making and being accompanied by someone close to advocate and communicate their needs.<sup>13</sup>

Recommendations for an inclusive, equitable health service for migrants and refugees included promoting a sense of belonging, enabling a whole-of-society approach through stakeholder collaboration and national policies that specifically address healthcare needs of EMCs.<sup>14</sup> Many systematic reviews also recommended the need for culturally appropriate, relational, whānau-centred care focussed on compassion, humility and respectful listening in discussions at end-of-life.<sup>13</sup> As Aotearoa New Zealand continues to grow and evolve as a multi-ethnic society, it becomes increasingly imperative to: a) better understand and respond to the diverse needs and aspirations of people from EMCs living with life-limiting illness so they can die well with dignity, b) re-vision the way EMCs, who informally carry the bulk of caring yet are often unprepared, are supported to care for whānau at end-of-life, and c) equip our current and future health and community workforce to meet and support the needs and aspirations of EMCs to die well with cultural safety.

## The “good death” no longer good enough?

An integrative literature review supports the argument that the concept of the “good death” may no longer be “good enough” in an increasingly Westernised neoliberal society in which individual autonomy and control are central values.<sup>15</sup> The good death is challenged as a form of social control and means for controlling the dying process, designed to ease care demands for health professionals, and incongruent to the desires of dying individuals. The concept is also threatened by an increasingly ageing population with unpredictable illness trajectories due to chronic illnesses that make it difficult to know when dying begins (the “ambiguous dying syndrome”), culminating in a theme of denial of dying and a dominant discourse on assisted suicide to control timing of death. The *End of Life Choice Act* was legislated in Aotearoa New Zealand on 7 November 2021, making assisted dying a funded option for all New Zealanders with a terminal illness.<sup>16</sup>

It is unsurprising that EMCs have poorer

uptake of hospice services and participation in advance care planning,<sup>9</sup> as both practices emerged from Western philosophical concepts of autonomy, choice, self-determination and neoliberal frameworks for managing dying, and do not reflect more interpersonal, relational and family-oriented approaches as found in cross-cultural contexts. Conversations focussing on “what matters most” have been proposed by Abel et al.<sup>17</sup> as an alternative, inclusive, public health approach to advance care planning that recognises the experience of “living with dying” and the linkages between identity (sense of value through compassion, love, laughter and friendship), place and supportive social environments, and well-being, as opposed to crisis planning and final treatment options.<sup>17</sup> It describes a “process of positive choices” that offer hope, shared understanding and “affirmation of what each person wants in the life that remains and how best the network around them is able to support this.”

Bendle states: “Death may be purchased and consumed, valued and depreciated, managed and administered in a fashion entirely consistent with any other commodity or bureaucratic transaction under ‘free market’ principles, with ever-increasing superficiality and lack of lasting meaning or significance.”<sup>18</sup> The review concludes with the need “to reframe and reclaim dying” towards the positive aspects of dying, recognising it as an important part of living and that by denying dying, opportunities for individual growth, validation and celebration of lived experiences, and to find meaning and memories to carry into subsequent generations, may be lost.<sup>15</sup>

## Benefits of death awareness

Recent existential crises and multiple losses (financial, social and personal security) due to the COVID-19 pandemic and severe climatic events have been described as a “collective calamity for meaning.” They threaten a sense of self-efficacy and control and increase awareness of the inherent impermanence and uncertain nature of life and death. In contrast, the potential life-enriching impact of increased death awareness, as evident following the COVID-19 pandemic, can motivate people to make significant changes towards greater authenticity, appreciation of self/others, and meaning and purpose.<sup>19</sup> It is associated with improved psychological and physical health (reduced stress, increased immune functioning, longevity and interpersonal relationships) and a

richer existential, spiritual life that contributes to wisdom.<sup>20</sup> Specific cultural/spiritual beliefs that subscribe to more holistic theories of the world or where death awareness is actively encouraged may also act as buffers against death anxiety.<sup>21</sup> Meaning-making strategies including recounting and reframing one’s story, meaningful encounters with others to explore evolving self and expressive writing may also provide means of rediscovering meaning in life at times of uncertainty.<sup>22</sup> As Pacheco states: “Some of us might only become deeply aware of our life when faced with a near-death experience or severe illness. But we don’t need to wait for a terminal diagnosis. We can begin right here, right now, wherever we are, and start to see mindfulness of death as a precursor to truly living. The benefits of this type of contemplation are numerous and worth exploring.”<sup>21</sup>

## A call to reclaim dying

Globally, there is increasing call to reclaim dying as an important part of living: “To be present in daily life, spoken about and accepted, not hidden away.”<sup>23</sup> Compassionate Communities, a public health promotion approach to palliative and end-of-life care, fosters this by de-professionalising death, dying and grieving, raising public awareness and death literacy, building sustainable network-based caring capacity within communities by supporting solidarity among community members at end-of-life and giving voice to and celebrating a community’s spiritual traditions and storytellers.<sup>24</sup>

There is a growing international movement of death positivity through public health initiatives, book and media publications, death cafes, death doulas and a growing number of Facebook groups, dedicated to increasing society’s awareness of dying and to give authority and voice to the experiential knowledge of community members as equal to, if not more valid than, professional knowledge.<sup>9,23</sup>

## The power of story (pūrākau)

The importance of celebrating the cultural and spiritual lived experiences relating to death, post-death care of the deceased and their family, reconciling a sense of belonging and reclaiming and passing on knowledge of traditional care customs to strengthen whānau at end-of-life has been explored in EMCs and in Indigenous communities.<sup>25</sup> As death was considered normal and an inevitable process that was not the end but a transition to the next life, “preparing the spirit”

was most important. This involved a process of understanding “where we come from”, including one’s beliefs, values and perspectives about “the heart and spirit” or essence of life. Sickness was viewed as more than a disease and reflected historical collective and individual pain, both of which harmed the spirit. Healing was through connecting with other people’s pain, which enabled individuals to cope with the suffering in their experience, in turn allowing them to come to a sense of acceptance, peace and connection with “*greater beings, kin, previously deceased family members, and the homeland*” and strengthen the spirit to enable its journey forward.<sup>25</sup>

As human beings, we are by nature meaning-making creatures who are defined by the stories we create. Storytelling is an age-old tradition that brings people together through shared knowledge and experience. For Māori, stories (pūrākau) are viewed as a powerful means of reclaiming and promoting Indigenous and collective knowledge where the pū (roots) and rākau (tree) can “*help people flourish when they are nurtured and shared.*” They are individual and fluid, as experiential understandings change over time and fulfil our human need for connection. They can motivate change in behaviours, attitudes and beliefs; bring together different people, places and realities; uncover complexities and challenge established knowledge and practices of knowing and doing.<sup>26</sup>

### Urgent need for data and research

There is an urgent need for comprehensive ethnicity data and high-quality research on EMCs, and translation into policy and action, as recommended by WHO’s 2023 first global research agenda on health, migration and displacement.<sup>7</sup> Research questions include but are not limited to understanding: a) what dying well means and what matters most for people from EMCs living with life-limiting illness in Aotearoa New Zealand, and their whānau, including their end-of-life care experiences, preferences and needs, b) how migration experiences (e.g., migration trauma, and loss, acculturation, racism, discrimination, enforced poverty, fragmented cultural identity), cultural/spiritual practices, generational status and other existential concerns impact on these experiences, and c) the barriers, challenges and solutions to providing culturally safe end-of-life care to EMCs. One possible research methodology to explore these questions is digital storytelling, which has been successfully used for exploring

palliative care, and traditional and contemporary preferences for optimal end-of-life care in Indigenous Māori whānau.<sup>26</sup> Due to its participatory and co-productive nature, it has the potential to break down power hierarchies, befitting and benefitting the communities and cultures in which research takes place while enabling a public health approach. It is often used when working with vulnerable, marginalised, under-served groups and in exploring sensitive topics. Its strength lies in its simplicity, accessibility and intention “*to stimulate reflection, deeper learning and perhaps transformation.*”<sup>27</sup>

### Cultural safety and community engagement

Many reviews exploring the end-of-life experiences of EMCs speak of the need for culturally appropriate, holistic relational care that focusses on compassion, humility and listening in order to build mutual trust, respect and understanding. While health professionals were once asked to demonstrate cultural competency as part of their training, it is now recognised that this is limited due to the constant evolving nature of culture and the focus on knowledge that may lead to assumptions and stereotypical views.<sup>28,29</sup> In contrast, cultural safety and cultural humility involve an ongoing process of self-exploration and self-reflection, combined with a willingness to learn about others for who they are, to honour their views, beliefs, customs and values, towards building honest and trustworthy relationships. Cultural safety recognises that culture is ever-changing and uniquely defined in the context of a person’s life experience and beliefs. It encourages health professionals and health systems and organisations to proactively engage with caring curiosity about each person and how they fit into a broader cultural community. It also involves a commitment to lifelong learning and reflection on addressing the power imbalances that exist in healthcare by focussing on respectful egoless dialogue, examining white privilege and power, and sharing this with those who have less, in particular Māori as tangata whenua and, by extension, migrants to Aotearoa New Zealand.<sup>28</sup>

Cultural safety also involves directly engaging with individuals and communities in their healthcare and decision making, giving them power to comment on practices and policies, and to contribute to the achievement of positive health outcomes and experiences. The need for community

engagement and collaboration on practice and policies is supported by a recent integrative review of barriers to equitable access to health-care for migrants and refugees,<sup>14</sup> and the Compassionate Communities approach to palliative and end-of-life care.<sup>24</sup> A recent qualitative study exploring enablers and barriers to culturally safe end-of-life care highlighted the need for appropriate resourcing, and value and recognition of Māori health practitioners undertaking unpaid and often unrecognised cultural and connecting work supporting culturally safe end-of-life care for Māori patients and their whānau that was often time consuming and not remunerated.<sup>30</sup> The study noted how structural-level change related to institutional power shifts and racism, and a supportive leadership, were important to realise the aspirations of delivering culturally safe, equitable palliative and end-of-life care. The engagement of EMCs in service development and participatory research can support more authentic understandings of the needs and preferences of people from diverse cultures and enhance the development of valued and trusting relationships between healthcare providers and the diverse communities they serve.

## Conclusion

Dying well is a universal aspiration, yet its interpretation and realisation largely remains

unknown. Most New Zealanders, currently, are likely to die in hospital or in aged residential care. The notion of the “good death” is strongly argued in the context of today’s increasingly diverse, multicultural society where views, beliefs and attitudes to death and dying are widely heterogeneous, even within similar ethnic and cultural groups. There is no “one size fits all” approach to death, yet there appears to be a common thread among the experiences of the dying—the need to be seen, deeply understood, connected to, cared for and loved in a profoundly intimate, individual and relational way.

Exploring the myriad of cultural and spiritual diversity, and unique perspectives on death and dying, in Aotearoa New Zealand’s diverse EMCs may help to enrich our understanding of the tapestry of end-of-life experiences. In addition, de-professionalising death and exploring dying, grief and loss in our communities and everyday lives may help us to understand what it means to live and die well in an increasingly complex, volatile and uncertain world, and reach the possibility and potential life-enriching benefits of death’s presence in everyday life. Aotearoa New Zealand has real opportunity and potential to reclaim and reframe dying, to give voice to and celebrate our community spiritual traditions and storytellers, towards the provision of culturally safe end-of-life care for all New Zealanders that truly honours the diverse range of human experiences.



**COMPETING INTERESTS**

Nil.

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