

Practice paper

Māori perspectives on hospice care

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What is known on this subject

- There are inequalities in health and healthcare between Māori and non-Māori in Aotearoa/New Zealand.
- Māori people are likely to die at home; it is not known whether they are less likely than non-Māori people to receive end-of-life care within a hospice context.
- Māori people die at a much younger age than non-Māori people. Likewise, Māori patients who die in hospices are significantly younger than non-Māori patients.
- A widely accepted Māori model of health posits that there are four contributors to or aspects of well-being: spiritual, emotional and mental, physical, and family aspects.

What this paper adds

- The modern western philosophy of hospice care in this hospice was found to be generally compatible with the Māori model of health. However, the implementation of hospice care, especially the way that the family is involved, must be nuanced to recognise Māori beliefs and practices.
- Many Māori practices, such as use of *te reo Māori* (language), *mihi* (traditional greetings), *waiata* (song) and *kai* (food), continue to be highly valued in the culture, and were therefore found to be vital to culturally sensitive care at the end of life.
- Although various barriers were identified that could prevent Māori people from using hospice services, positive personal encounters with the hospice were found to change Māori perceptions of hospice care.
- The challenges and process of research within a Māori context are demonstrated.

ABSTRACT

Māori have the right to high-quality, appropriate care in all health settings. This study aimed to determine the perceptions and preferences of Māori for end-of-life care in a hospice. A *Kaupapa Māori* approach to research shaped this qualitative pilot study. Data were collected using semi-structured interviews with five elders from Māori communities and two focus groups with seven family members of Māori patients who had recently received hospice care. Thematic analysis identified (1) that participants perceived hospice as like a hospital, a place where people died, (2) what they appreciated and wanted from hospice, such as family-centred end-

of-life care and respect for Māori cultural practices, (3) what they perceived as problems and barriers to receiving hospice care, and (4) their potential solutions to these problems, such as community information seminars about the breadth of hospice services. These findings have implications for how Aotearoa/New Zealand hospices can ensure appropriate care for Māori patients and their families, as well as for clinicians and other hospice staff who aim to provide culturally sensitive care.

Keywords: end of life, family carers, hospice, Māori, New Zealand, palliative care

Introduction

Māori are indigenous to Aotearoa/New Zealand, and comprise approximately 15% of the country's 4.4 million inhabitants (Statistics New Zealand, 2011). Disparities between Māori and non-Māori in morbidity, mortality and the quality of healthcare services received are well documented (for example, see Robson and Harris, 2007). Māori are less likely to access healthcare services in general, despite having higher levels of need (Robson and Harris, 2007). Findings from a three-year chart review ($n = 1293$) conducted at a hospice based in Wellington, the capital city, showed that between 2006 and 2008 only 6% of patients self-identified as Māori, even though Māori represent 10% of the population of this region (Capital Coast District Health Board, undated). Although this chart review indicated that the length of time during which individuals received hospice services and the number of inpatient unit visits did not differ significantly by ethnicity, it was found that Māori patients were significantly younger and were more likely to die at home than non-Māori patients (Taylor *et al*, 2012).

Many Māori people express beliefs and practices with regard to what constitutes health and with regard to the processes of death and dying which appear quite distinct from those from other cultural backgrounds (Cram *et al*, 2003; Walker *et al*, 2008; Waldon, 2003). Specific traditional rituals at the time of death and bereavement are as unique as those from any culture. Indeed, they can vary slightly from one Māori tribe to another. Traditionally, for example, many Māori believe that it is spiritually important to die and be buried at one's ancestral home. Bodies are typically returned to this location if the deceased did not die there. Extended family and friends gather for 3 to 5 days to mourn the deceased at the local meeting house. Those who mourn talk, and even joke or sing, to the deceased to bring closure to their relationship. Mourners may sleep in the large meeting house where the deceased person is lying. At the end of the mourning period, the deceased person is buried (Schwass, 2005).

Hospices in Aotearoa/New Zealand are striving to respond to the New Zealand Palliative Care Strategy (Ministry of Health, 2001) that advocates culturally sensitive palliative care for all. A recent qualitative study of Auckland area indigenous and immigrant clinician, patient, and family perspectives on challenges to hospice services described several barriers to accessing hospice care among Asian, Pacific and Māori people in northern Aotearoa/New Zealand (Frey *et al*, 2013). These barriers included unfamiliarity with what hospice care involves, perceptions of hospices as a place in

which to die that costs a lot of money, language barriers, gatekeeping physicians who assumed that members of these groups would prefer not to use hospice services, and fear of discrimination from the predominantly white hospice clinicians (Frey *et al*, 2013).

These issues relating to end-of-life care are not unlike those found among other indigenous peoples, for example, in Australia, Canada, and the USA. All of these have been described as often having in common the following factors that affect end-of-life care (see, for example, O'Brien *et al*, 2013; Johnston *et al*, 2013; McGrath and Phillips, 2009; Kelly *et al*, 2009; Hotson *et al*, 2004):

- remote homes, resulting in social isolation when the patient is taken to an urban-based palliative care service
- beliefs and customs, such as spiritual connection with the land of one's heritage, prompting the desire to die at home
- low economic status and distrust of western medical care contributing to delayed entry into a westernised healthcare system
- respect for traditional and spiritual healers and healing modalities
- the vital importance and involvement of an often large, extended family
- deference to elders in the community who can provide knowledge pertinent to end-of-life care
- holistic philosophies about how to live and die, which include a spiritual component.

Given the known health and healthcare disparities between Māori and non-Māori in Aotearoa/New Zealand, and the trend among indigenous peoples of the South Pacific and North America, it is plausible that Māori may not receive the same quality of end-of-life hospice care as non-Māori patients do. However, Māori have the right to high-quality, appropriate care in all health settings (United Nations, 2007).

With the exception of the study by Frey *et al* (2013) which recruited only six Māori patient or family carer participants, there is a paucity of documentation about Māori perceptions and experiences of receiving end-of-life care from a hospice. A search of six databases (including CINAHL, PubMed and PsycINFO) revealed no other report of Māori patient or family perspectives. Therefore the purpose of this pilot study was to address the following questions. How do Māori perceive hospice care? What cultural practices would be desired if they were receiving care at a hospice? What aspects of hospice support are appreciated? What are the barriers to entering hospice services? What could hospices do to improve care for Māori patients?

Cultural and philosophical underpinnings

Hospices provide palliative care for those with a life-limiting illness. Palliative care aims to ease suffering and maintain quality of life by addressing physical, psychosocial, cultural and spiritual symptoms and needs (Palliative Care Subcommittee, New Zealand Cancer Treatment Working Party, 2007). In Māori society this care is usually delivered by a multidisciplinary team, and places patient and family/whānau at the centre of care. The Māori *te whare tapa whā* model of *hauora* (health) is based on four pillars: *wairua* (spiritual well-being), *hinengaro* (emotional and mental health), *tinana* (physical well-being) and *whānau*

(family, including extended family, and the wider social system) (Durie, 1985; Ministry of Health, 2012). According to this model, *hauora* is supported not only by disease prevention and cure but also by health promotion that recognises and builds upon existing assets, such as *whānau* support.

Both palliative care and the Māori *te whare tapa whā* model emphasise holistic caring and value the role of *whānau*. However, this study aimed to determine more precisely which aspects of palliative hospice care are appreciated by Māori people, and what other aspects could be improved to ensure that Māori patients receive appropriate care.

For an explanation of the *te reo* Māori terms that are used in this paper, see Table 1.

Table 1 Explanation of *te reo* Māori terminology

<i>te reo</i> Māori	the Māori language
<i>Mihi</i>	traditional greetings
<i>Waiata</i>	song
<i>Kai</i>	food
<i>Kaupapa Māori</i>	Māori ideology; a philosophical doctrine incorporating the knowledge, skills, attitudes and values of Māori society
<i>Whānau</i>	family (usually extended family)
<i>te whare tapa whā</i>	the 'four-sided house', a Māori model of health that considers four key aspects
<i>Hauora</i>	health
<i>Wairua</i>	spiritual well being
<i>Hinengaro</i>	mental health
<i>Tinana</i>	physical well-being/health
<i>Kaumātua</i>	Māori elder, who may be male or female
<i>Iwi</i>	tribe(s)
<i>Marae</i>	traditional meeting house
<i>Tikanga</i>	culture and cultural practices
<i>Karakia</i>	incantation or ritual chant
<i>Tūrangawaewae</i>	place where one has the right to observe one's own protocols for behaviour, and freedom to express one's emotions and opinions; this place is linked to kinship and genealogy
<i>Rongoā</i>	healing practice using native plants, spiritual care and therapeutic massage
<i>Tohunga</i>	practitioner
<i>Mirimiri</i>	massage
<i>Pā</i>	Māori settlement
<i>Whānau ora</i>	family well-being

Methodology

Project design

This pilot study was shaped by the *Kaupapa Māori* research paradigm. The Treaty of Waitangi, the founding document of Aotearoa/New Zealand, sets out the principles of partnership, self-determination, equity, and protection for Māori (www.nztaot.com/downloads/contribute/TheTreatyofWaitangiAFrameworkforMaoriHealth.pdf). *Kaupapa Māori* applies these principles in a research setting for the benefit of Māori people, particularly the community in which the research takes place. *Kaupapa Māori* is oriented towards restoring justice, reclaiming resources and recovering histories (Smith, 1999). The Health Research Council of New Zealand mandates that any research involving Māori people must involve consultation with Māori and, in particular, Māori in the community in which the research will have an impact (Health Research Council of New Zealand, 2008). Thus *Kaupapa Māori* research is characterised as research by Māori, for Māori and with Māori (Health Research Council of New Zealand, 2008). Although the principal investigator of this pilot study (EJT) did not identify as Māori, the co-investigators included a university-based health researcher (SS), the Chief Executive of a hospice (RE), and a Māori Liaison from the same hospice (PT), all of whom identified as Māori. This project was initiated by the Māori chief executive, who requested the hospice's non-Māori Research Director to direct it. *Te Pou Tautoko* (meaning the central post supporting a meeting house), the hospice's Māori advisory group, was consulted throughout the design and implementation of the study. This group provided affirmation for the design, suggestions about how to collect data, and recommendations about who to interview. The Māori researchers led and guided all communication and consultation with the Māori study participants and Māori community. They also ensured that appropriate protocol was adhered to at meetings and interviews.

The hospice

This study was conducted at Mary Potter Hospice (MPH), a charitable trust that serves the Wellington region of Aotearoa/New Zealand. This hospice offers free multidisciplinary palliative care, primarily in the home but also in day units and an 18-bed inpatient unit. Although there was a sense among the MPH staff that Māori hospice use was increasing, no empirical data to substantiate this observation existed.

Participants and recruitment

Participants were recruited in 2010 from two groups, namely *whānau* and *kaumātua*.

Whānau

Whānau are family members of Māori patients who had utilised the hospice service and who had died during the 6- to 18-month period prior to the study. Once they had been identified (by a computer search of hospice patient records), individuals were sent a letter of invitation and then contacted by telephone by the Māori Liaison to discuss participation. Face-to-face or personal contact is preferable in *Kaupapa Māori* research (Smith, 1999). Given the salient role of *whānau* support, the researchers chose to allow multiple members of one *whānau* to participate. Opening the invitation to the wider *whānau* was considered congruent with Māori culture.

Kaumātua

Kaumātua were invited to take part in interviews. *Kaumātua* are male or female elders who are selected by their community for their knowledge of *Māori* customs and their ability to instill this knowledge in the younger generations (Barlow, 1994). *Kaumātua* may be called upon to settle disputes or to represent the community to those outside it. These elders are honoured and shown considerable respect. The *kaumātua*, who were identified by the Māori advisory group or Māori Liaison, were approached by either the Chief Executive or the Māori Liaison. *Kaumātua* were selected not only because they could provide wisdom informed by a deep knowledge of Māori culture, but also because they could represent their communities at large. *Kaumātua* from diverse *iwi* (tribes) were selected. Although this was not planned, all five of them had had relatives who had received hospice care.

Ethics

The Central Regional Health and Disability Ethics Committee granted approval for the study. All of the participants (focus group members and *kaumātua*) gave their written consent after receiving information about the study. The consent document advised participants that if their participation caused distress, the hospice's spiritual carers and counsellors would be available to them.

Methods

Research based on *Kaupapa Māori* tends to favour qualitative methods, as these are based on social interaction. Two methods were selected:

- 1 *Whānau* participants were invited to take part in one of two focus groups, both of which took place in a Māori health clinic adjacent to a meeting hall (*marae*). These focus groups were conducted in accordance with accepted practice, with limited group size, a pre-set structure for questions and the meeting, guided by a trained facilitator, with a secondary researcher in a supportive role (Ruff *et al*, 2005).
- 2 *Kaumātua* were interviewed privately in their homes.

Both the focus groups and interviews followed Māori protocol relating to *mihi* (introductions), and were led by the Māori researcher, with the non-Māori principal investigator taking a secondary role. The Māori language, *te reo*, was encouraged if participants chose to speak it. Each participant used a number of Māori words and idioms, and one elder chose to conduct most of the interview in *te reo* Māori. (Translation of the occasional word or phrase was done by a Māori member of the research team after the transcription. The interview in *te reo* was transcribed by the Māori research team member who had conducted the interview, and was then translated by a professional language translation service.) Following each focus group, *whānau* participants were acknowledged with *kai* (food), which is central to Māori gatherings, and *kaumātua* were thanked with a gift voucher for NZ\$30.

The focus groups and interviews ranged from 1 to 2 hours in length and addressed the same topics (see Box 1). If the participants agreed, interviews and focus groups were audio-recorded. One *kaumātua* requested that his voice should not be recorded, but agreed that notes could be taken. The recorded focus groups and interviews were all transcribed by either a professional service or a hospice employee.

Various strategies were used to ensure the trustworthiness of the findings (Lincoln and Guba, 1985). These included prolonged in-depth engagement with participants for at least 1 hour, creating an audit trail

(audio recordings or notes of data collected and documentation about the analysis process), peer debriefing with project team members during regular meetings, and obtaining validation for the findings from a non-research team member who was an expert in Māori perspectives on hospice care.

Analysis

An inductive thematic analysis (Patton, 2002) was completed by the two researchers who conducted the interviews. This analysis involved extracting from the transcriptions the data that were relevant to the study questions. These data were then condensed into themes, keeping with them pertinent illustrative data. The themes were clustered mostly around how hospice care was perceived, what was appreciated or desired at a hospice, possible barriers to using hospice services, and miscellaneous observations about how the Māori participants related to death and dying. Although the findings were written by the non-Māori project team leader (EJT), they were reflective of separate analyses performed by both herself and the Māori co-researcher (SS). During this final stage of the analysis, these researchers discussed their respective perspectives on the data to ensure reliability and cultural sensitivity; this discussion revealed only minor discrepancies.

Findings

A total of 35 *whānau* were identified as eligible to take part in the study. However, when the Māori Liaison attempted to contact them it was found that either they were either no longer contactable by the telephone number listed in the deceased patient's chart, they were not Māori themselves, they did not have transport, they did not have a family member to accompany them, they were afraid to participate, or they declined to participate for an unstated reason. The Māori Liaison perceived that this was evidence of

Box 1 Topics for focus groups and interviews

- If one of your loved ones has received care from a hospice, please tell us about what that was like for you.
- Tell us what you think hospice care or service is.
- Tell us what you think a hospice should be.
- What *kaupapa Māori* and *tikanga Māori* (practices) would be especially important for hospice care providers to understand? Are there aspects of hospice care that are particularly valuable or helpful for Māori people?
- What sorts of reasons might prevent a Māori patient from seeking (or obtaining) hospice care?
- If you were to help to create a hospice that was just for Māori, what would it be like?
- What else about Māori perspectives of hospice care do you think we should know?

Participants were also asked how they would like the findings to be given back to the Māori community.

a fear of talking about death. Finally, seven *whānau* (one man and six women, aged 34–74 years) agreed to take part in the focus groups. They were the husband, daughter, mother and wives of the deceased persons. Each individual brought a relative who also participated, sharing their own stories of living with a loved one who had received hospice care. These *whānau*, who represented the experiences of three hospice patients, all became study participants ($n = 7$). Five *kaumātua* (four women and one man, aged 62–79 years) were approached, all of whom granted interviews. They were the spouses or parents of the deceased persons.

Theme 1: How do Māori people perceive hospice care?

Although some of the participants described receiving a hospice nurse's care for their loved one at home, they all equated hospice care with the inpatient unit (IPU). A few referred to it as being like a hospital, a place where 'they have their rules ... [and] they are in charge', and consequently 'you don't have the freedom you do at home ... you are a guest there ... it isn't your space' (*kaumātua* participant). Several participants were aware of the hospice as a place of care for those with cancer and also for elderly people, inferring that younger people or those with terminal non-malignant diseases may receive care elsewhere.

The hospice was most frequently perceived as a place that 'you don't leave alive.' It is where one dies: 'the last ride out', 'the end, doom and gloom!' (*kaumātua* participant and *whānau* participant, respectively). The participants stated that most Māori people whom they knew shared this perception. However, they added that their personal experiences did not support this perception, and that they now recognised the hospice as a place for respite care and symptom management. A *whānau* participant described how she came to realise that hospice care for her loved one meant that 'it wasn't just the end ... there was more that could be done.' One *kaumātua* participant went further than this, stating that hospice care could prolong life 'at least a few days as it eases pain and suffering.' This elder posited that *whānau* who do not take their suffering, dying loved one to a hospice 'are selfish to themselves and not caring about the sick.'

What aspects of hospice care do Māori appreciate?

The participants' views provide insights into what Māori people value. Those who had witnessed respite care for a loved one found it an extremely positive experience: 'for my children and family if I'm at Mary

Potter, leave me there. [Be]cause I do know the strain on the family' (*whānau* participant). Others perceived benefits of hospice care included the quietness in the IPU, which allowed the 'spirit to settle' (*whānau* participant), patient care equipment for use at home, information about how to care for the patient and what was happening, counselling and 'someone to talk to' (*whānau* participant), follow-up bereavement care, the presence of spiritual carers (clergy) and the availability of a chapel, a non-denominational memorial service, and the availability of and feeling comfortable with asking staff for help. One *kaumātua* participant described a visit to support someone at their death with *karakia* (prayer), and experienced the nurses as culturally ignorant and disrespectful. However, all of the other participants enthused about the compassion that they experienced from hospice staff. For at least one individual, the hospice IPU could create a comforting sense of community: 'There is a sense of everybody knowing ... it's like we're all *whānau* even though you are all strangers. ... I was able to go there, not just to be with [my husband], but with the people that are around, that are just sitting there, just to be part of ... if they wanted ... have a talk ... I like it in there' (*kaumātua* participant).

What aspects of Māori culture are desired in hospice care?

Whānau-centred care was of vital importance to the participants. They appreciated being allowed to visit and stay at any time, being 'free to come and go' (*whānau* participant). *Whānau* carers wanted staff support so that they could continue to provide care such as bathing, and wished that staff would ask their permission to provide care for their loved one. *Whānau* also emphasised the importance of letting their loved ones spend their final days at home. Elders in particular preferred to die at home. The reasons for wanting to go home for the final days of life were varied, and included the following: 'Māori take care of their own ... it's better, more flexible, they prefer their own space' (*kaumātua* participant); '[my mum] didn't want to die in somebody else's bed' (*whānau* participant); 'their own home is their roots, it's everything—*tūrangawaewae* [a place where one has the right to observe one's own protocols for behaviour, and freedom to express one's emotions and opinions; this place is linked to kinship and genealogy]' (*whānau* participant). The importance attached to dying at home could create internal conflict when the *whānau* carers became exhausted. The hospice's respite service was welcomed both as an option when this occurred, and for those patients who did not have local *whānau* support: 'It takes people in to give the family a break' (*kaumātua* participant).

What caring practices do Māori people use?

The participants identified a range of *tikanga Māori* (cultural practices) (see Box 2). Speaking *te reo Māori* (Māori language) to those who spoke *te reo* 'got through' and 'settled' them (*whānau* participant). *Te reo* 'language is important ... it's much nicer and much softer in your own language' (*kaumātua* participant). This same participant recommended that nurses learn some *te reo*, especially greetings and farewells, and the everyday terms such as the words for *eating, toileting and bathing*.

Other *tikanga* reflected Māori beliefs about people, places and conditions being either *tapu* (sacred or restricted) or *noa* (unrestricted or ordinary). For example, when a person died, the room and the body of the deceased became *tapu*. Sprinkling water provided spiritual cleansing, and *karakia* [prayer] was used to mark the transition of the person from one state to the other. When visitors arrived to view the deceased person, they washed their hands when entering and leaving the room. *Karakia* and sprinkling of water in the hospice room after the deceased person had been removed was regarded as essential before that room could be used again. Other examples concerned the use of linen, care of personal valuables, disposal of body tissue, and types of food and drink. One family was displeased with the lack of privacy afforded them when they accompanied their deceased loved one from the IPU room to the undertaker's room, which is regarded as a very sacred moment.

Several *kaumātua* recognised the requisite of institutional support of *tikanga Māori* practices if they were to occur. Policies supporting *tikanga Māori*, staff cultural training, and the employment of Māori staff who are respected and in leadership positions were

seen as contributing to positive hospice experiences for Māori people. The lack of staff knowledge was evident in one poignant negative experience: 'We did our *karakia* [in this case sung] and we were strong, but the nurses were just a nuisance with their applauding and wandering around. They didn't realise that *tikanga Māori* was taking place' (*kaumātua* participant).

What are the barriers to accessing or receiving hospice care?

Many of the problems that the participants encountered with hospice care were also considered to be reasons that discouraged Māori people from accessing hospice services. The most frequent and salient response to queries about these barriers was the perception of hospice care as the 'end of the line' (*whānau* participant). One *kaumātua* participant believed that the denial of death prevented people from learning about and using hospice care. The other major reason thought to prevent Māori people from using hospice care was the cultural imperative around 'caring for our own' (*whānau* participant). There is a perception among many Māori that 'there are no options given to *whānau* who want to look after their own' (*kaumātua* participant). Elders in particular do not want to leave their own space, and the grandchildren they may have raised, in order to enter an institution likened to a hospital. The struggle to care for one's own was sometimes intensified by this imperative. Those who accepted respite care in the IPU for their loved one recognised that they 'just couldn't do any more', and stated that receiving respite care at the hospice was 'a release' (*whānau* participant).

Other problems or barriers to receiving hospice care included difficulties with transportation and parking,

Box 2 Māori caring practices

- *Rongoā* (traditional healing, often using native plants) requires the skills of a *tohunga* (practitioner). However, receptivity and support from a hospice's allopathic doctor are essential if *rongoā* is to be useful.
- Māori touch ('we're very touchy-feely people' as one *whānau* participant stated), such as *mirimiri* (massage), 'just rubbing till you go to sleep ... and keep them by you and listening to their heartbeat' and hugging (*whānau* participant). At least one informant recognised that some Māori prefer to be touched or 'handled' by Māori people (*whānau* participant).
- *Karakia* (prayer), to be offered by *kaumātua* or Māori ministers if possible, both on a daily basis and at around the time of death 'to transition the patient for where they are going' (*whānau* participant).
- Kai (food) that can be brought, prepared and shared by the *whānau* when visiting the IPU.
- *Kaumātua*, who could not only offer *karakia*, but also guide the *whānau* with regarding to cultural practices around the time of death.
- *Waiata*, or singing Māori songs that one has grown up with, was also observed to comfort and calm the dying.
- Using introductory Māori courtesies such as taking off one's shoes when entering the home, and greeting the patient using Māori protocol.

and wishing that the hospice was closer to the *pā* (Māori settlement), particularly if one was ‘the only brown face’ (*kaumātua* participant), as the presence of other Māori people allowed one to feel more comfortable and understood. Medical jargon and the lack of open communication were not helpful: ‘I got really annoyed about [the staff] giving people false hope when the truth is they’re going to die’ (*whānau* participant). An additional issue was the lack of privacy: ‘We went in there and there were two or three [patients] in the room. ... Here we were going to look at my nephew, to weep for him, and to say ‘The time has come for you to leave, but your path is clear before you.’ How could we weep? How could we show our grief in that room when others were there?’ (*kaumātua* participant).

These factors led participants to offer the following specific suggestions about how to counteract these challenges:

- offering better support for *tikanga*, such as providing a place for *kaumātua* to carry out cultural practices, and training staff about *tikanga*
- offering better support for *whānau*, such as providing facilities for *kai* preparation, childcare for visiting young children, a laundry service, encouraging the family to appoint a spokesperson to interface on their behalf with clinicians, and addressing transportation and parking limitations
- improving the environment, moving closer to the *pā*, and making the hospice more like a *marae* [Māori meeting house]
- counteracting misperceptions of hospice care by providing information seminars within the Māori community and advertisements about hospice care, encouraging Māori patients and *whānau* to share their positive stories of receiving hospice care, and changing the term ‘hospice.’

These suggestions were offered in the hope that other Māori people would similarly come to benefit from hospice care.

The participants all recognised that their culture was changing in terms of how it perceived end-of-life care should be. It was acknowledged that some individuals, especially older people, were more observant of *tikanga Māori*, while others were less aware of their culture’s beliefs and practices with regard to end-of-life care. For example, some might want *rongoā*, *mirimiri* or *karakia*, while others might not.

Discussion

This small study presents the perceptions held by some Māori *whānau* about hospice care. The findings demonstrate how the holistic Māori framework for well-

being is compatible with the perceptions of and preferences for end-of-life care for Māori patients and *whānau* (Ministry of Health, 2012). The physical and mental health of the individual, their spiritual well-being and spiritual realities were all of concern to Māori people. Central to the quest for *hauora* is *whānau ora*, family well-being, and support for and by members of the wider family. Encompassing these perspectives is *tikanga Māori* (Māori cultural practices). Indeed, these findings demonstrate how many practices, such as *te reo Māori*, *mihi*, *waiata* and uses of *kai*, continue to be highly valued in the culture and are therefore vital to culturally sensitive care at the end of life (Barlow, 1994).

All of the participants identified various barriers that could prevent Māori people from using hospice services, and these were similar to the findings of Frey *et al* (2013) and Bray and Goodyear-Smith (2013). However, positive personal encounters with the hospice changed their perceptions. Patients could enter and leave the IPU, which meant that more could be done to help. Respite care allowed families to have a break but still remain as involved as they wished. Hospice clinicians generally showed them compassion and respect. These factors, taken together, led most of the participants to endorse hospice care.

Hospices could provide better support with end-of-life care for Māori people. Marketing hospices as resources that support *whānau* as they care for their loved one with a terminal illness at home or within the hospice would help to address negative perceptions of hospice care (Bray and Goodyear-Smith, 2013). There was also a need to counteract misperceptions of hospice care as shortening life, and to make it clear that hospice care could ease unnecessary distress, and potentially prolong life (Temel *et al*, 2010).

The participants recognised that their culture was changing and that there was a diversity of Māori beliefs and practices. Given the extraordinarily dynamic nature of Māori culture, it is important to continue to study how best to support Māori people at the end of life, and to exercise flexibility. Clinicians must be prepared to cater for diverse expressions and experiences of Māori culture and incorporate *tikanga Māori* practices with sensitivity.

Study limitations

This study has some limitations that will affect the extent to which the findings can be generalised. It was a very small study, with only 12 participants from the Wellington region, so it cannot be assumed that the perceptions held by these participants are reflective of all Māori patients and *whānau*. The perspectives of Māori people from the south end of the North Island

or other regions of the country were not included. In addition, the study focused on those who had experienced hospice care at one particular hospice, and the results are therefore inevitably specific to this particular service.

Conclusion

This exploration of the perspectives of Māori people about end-of-life care in a hospice shows how one indigenous people's knowledge and praxis in this regard interfaces with a Eurocentric approach to care. Although the concept of hospice care reflects a western paradigm, these findings suggest that there are aspects of holistic hospice care that could be readily aligned with the Māori *hauora* framework and used by palliative care professionals to provide culturally safe care.

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