

# **Palliative Care and Māori from a Health Literacy Perspective**

---

Citation: Ministry of Health. 2014. *Palliative Care and Māori from a Health Literacy Perspective*. Wellington: Ministry of Health.

Published in August 2014 by the  
Ministry of Health  
PO Box 5013, Wellington 6145, New Zealand

ISBN 978-0-478-42841-4 (online)  
HP 5916

This document is available at [www.health.govt.nz](http://www.health.govt.nz)



MANATŪ HAUORA



This work is licensed under the Creative Commons Attribution 4.0 International licence. In essence, you are free to: share ie, copy and redistribute the material in any medium or format; adapt ie, remix, transform and build upon the material. You must give appropriate credit, provide a link to the licence and indicate if changes were made.

---

# Contents

<b>Executive summary</b>	<b>v</b>
Introduction and aim	v
Methods	vi
Māori access to palliative care services	vi
Māori health literacy in palliative care	vii
Factors influencing Māori access to palliative care from a health literacy perspective	vii
Enhancing Māori health literacy in palliative care	x
<b>Introduction</b>	<b>1</b>
<b>Palliative care and Māori health literacy in New Zealand</b>	<b>2</b>
The concept of palliative care	2
Palliative care services	2
Māori and palliative care	3
Health literacy	5
<b>Research design and methods</b>	<b>9</b>
Research approach and methodology	9
Research methods and characteristics of participants	10
Literature reviews	15
Limitations	15
<b>Research findings – Bay of Plenty and Auckland regions</b>	<b>16</b>
Access to palliative care services	16
Health literacy demands	19
Health professionals’ concepts of health literacy in practice	21
Health literacy demands	22
Health literacy practices used by patients and whānau	24
Barriers	28
Facilitators	32
Summary	35
<b>Research findings – Waikato region</b>	<b>37</b>
Findings from kaumātua interviews	37
Findings from whānau hui	44
Findings from focus groups with palliative care workers	50
<b>Findings from analysis of palliative care written resources</b>	<b>55</b>
Functional and technical health literacy	55
Cultural competency	57
Enhancing the value of written resources	59

Summary	59
<b>Discussion and recommendations</b>	<b>60</b>
Māori access to palliative care services	60
Māori health literacy in palliative care	61
Factors influencing Māori access to palliative care from a health literacy perspective	61
Enhancing Māori health literacy in palliative care	68
Concluding comments	69
Recommendations	69
<b>Glossary of Māori terms</b>	<b>71</b>
<b>References</b>	<b>73</b>
<b>List of tables</b>	
Table 1: Individual patient pathways and palliative care services accessed	17
Table 2: Health literacy demands – medicines	19
Table 3: Health literacy demands – providing care to the patient	20
Table 4: Health literacy demands – navigating the palliative care system	21
Table 5: Kaumātua interview themes and health literacy	43
Table 6: Whānau hui themes and health literacy	49
Table 7: Palliative care worker focus group themes and health literacy	54
<b>List of figures</b>	
Figure 1: Example of diagram – managing pressure areas	56
Figure 2: Symbols used in the brochures	57

---

# Executive summary

## Introduction and aim

The New Zealand Palliative Care Strategy recognised the need for local and national policies that support the specific needs of Māori.

Two kaupapa Māori research projects (ie, projects carried out within a Māori philosophical framework) were commissioned by the Ministry of Health and the Health Research Council of New Zealand Māori Health Joint Venture programme. While there are increasing numbers of research projects about access to palliative care for Māori and others, these are the first studies to have taken a health literacy perspective.

Health literacy impacts on both providers and patients. The Institute of Medicine defines health literacy as ‘the degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions’. For health professionals, health literacy is about their ability to communicate health information and build skills and knowledge. For health organisations, health literacy is about the appropriateness of the health information and services they provide for patients and their families, as well as the organisational systems and processes that support health professionals to build health literacy.

The aim of the research projects documented in this report was to identify, from a health literacy perspective, issues for Māori and their whānau (extended family) in accessing palliative care services. By identifying these issues, the research was designed to contribute to better service delivery of palliative care and improved access to palliative care for Māori and their whānau.

The first project was led by the University of Auckland (Kidd et al 2014) in partnership with UniServices, Workbase, and the Māori and palliative care communities. This project was carried out in the Bay of Plenty and Auckland regions.

The second research project was led by the Rauawaawa Kaumātua Charitable Trust Project Team (2013) in collaboration with research team members from the Te Kotahi Research Institute (University of Waikato), Te Rūnanga o Kirikiriroa, Te Puna Oranga and the Palliative Care Unit (Waikato District Health Board), and the Waikato Clinical School (University of Auckland). This project was carried out in the Waikato region.

This document combines the original research of both projects, and unless otherwise specified the analysis is derived from both studies. Generally the two projects reached similar conclusions. The preparation of this document was commissioned by the Ministry of Health and the Health Research Council.

# Methods

The research projects took a primarily qualitative approach and involved literature reviews; interviews, hui (meetings) and/or focus groups with patients, whānau and health professionals and others involved in palliative care provision; and analysis of written resources provided by different palliative care services providers using a health literacy framework.

The Auckland and Bay of Plenty study interviewed 22 carers for 15 people – all but two had passed away by the time of the interview. Fifty-four kaimahi (staff) from organisations which provided palliative care were interviewed in ten focus groups. Six key informants including service managers, health team leaders and specialists were also interviewed. Interviewees were asked about their own experiences and perceptions of health literacy demands from their particular perspective.

The Waikato study carried out 21 interviews with kaumātua who were either whānau or close friends of people who had received palliative care, or in two cases patients. Five hui were also held with 39 whānau members representing 14 whānau groups. These too addressed people's experiences with palliative care and health literacy demands. Three focus groups were conducted with palliative care kaimahi.

Both projects reviewed written resources provided by hospices, hospitals and other providers of palliative care. These were reviewed against literacy and health literacy criteria.

An observational study using record linkages explored palliative care patients' use of emergency departments within the Waikato District Health Board was also carried out. Findings from that work are reported separately as they did not directly inform health literacy issues for Māori and their whānau.

Both studies included reviews of New Zealand and international literature on the experience of Māori and other ethnic groups. These are included in the original reports but are not included in this summary report, which focuses on the original research.

## Māori access to palliative care services

Access to palliative care services concerns not only service utilisation, but gaining entry into and through services, as well as timeliness and quality in terms of how services were used (processes) and what was achieved (outcomes). According to the Auckland and Bay of Plenty study, Māori entry into palliative care took many forms, from self-referral through to specialist referrals. Difficulties with access were identified in both research projects as issues for the patients and whānau. The Auckland and Bay of Plenty project found that late referrals when death was imminent were a particular concern. Often there was insufficient time for patients and whānau to develop relationships with providers, to become familiar and comfortable with facilities and services, to negotiate health literacy demands, have needs for support and equipment met, or arrangements made for the patient's preferred death experience.

The Auckland and Bay of Plenty report noted that health literacy is a function of the demands placed on the patient and whānau by the health care system (eg, the complexity of access to services), as well as by the patient's disease processes and associated intensive physical health care needs. These demands include the knowledge and task components of the disease management focus of medicines, patient care and the wider focus of navigating the palliative care system. Findings indicate that these demands are further amplified in the emotional environment of palliative care, with whānau negotiating the acquisition of new knowledge and skills within a context of shock, grief and loss. In discussing issues for Māori and their whānau

in accessing palliative care, this report takes a broad view in considering health system factors, health organisation factors and patient and whānau factors.

## **Māori health literacy in palliative care**

The research project carried out in the Auckland and Bay of Plenty region focused specifically on Māori health literacy in palliative care. The Waikato-based project had a dual focus on Māori health literacy and cultural competence in palliative care.

Despite evidence of low health literacy among Māori generally, whānau who participated in these research projects used complex health literacy practices (actions to meet health literacy demands). These practices utilised a range of literacy and numeracy skills and included critical thinking and decision-making. The health literacy practices used included seeking out and utilising whānau and friends for information and support, as well as advocacy on behalf of patients with health professionals and health care providers, and keeping written records and communication books. Waikato research participants also held regular whānau meetings and established systems to coordinate tasks. Other health literacy practices identified in the Auckland and Bay of Plenty report were researching information, especially on the internet, and dispensing medicines (including using syringe drivers and naso-gastric tubes). These health literacy practices were used in spite of significant barriers that were often related to a lack of effective communication in palliative care.

## **Factors influencing Māori access to palliative care from a health literacy perspective**

Many health care professionals demonstrated an understanding of what was required to reduce health literacy demands and achieve health literacy. The Auckland and Bay of Plenty report identified that some health professionals were individually working with patients and whānau to build their health literacy. However, health care professionals experienced systems barriers to improving their practice in the area of health literacy, and there was little evidence of palliative care service providers using systemic approaches to reducing health literacy demands. There is a growing appreciation that health literacy does not focus solely on individual skill, so reducing health literacy demands needs to be an active, purposeful process driven by the health care organisation and including a systems level focus.

Health system, organisational, and individual and whānau factors influencing Māori access to palliative care from a health literacy perspective were identified in the research projects. Health system factors relate to the health system as a whole, rather than to the characteristics of individual services. Organisational factors relate to specific health organisations and services. The focus within these first two categories, from a health literacy perspective, is on reducing the health literacy demands imposed by systems, organisations and services. Patient and whānau factors operate at the level of the person and their whānau. The focus at this level is on factors that influence the achievement of health literacy among individuals and whānau so they are able to manage health literacy demands. Some factors may be expressed as a barrier or a facilitator, such as health professional cultural competence: low workforce cultural competence is a barrier to Māori access to palliative care, while high workforce cultural competence is a facilitator.

### **Health system factors**

The research projects indicated that the health system makes health literacy demands on Māori patients and whānau trying to obtain access to palliative care services. Health system factors

identified in the research that contribute to the extent of health literacy demands and influence access to palliative care services are:

- the total population focus of the palliative care system (which means that it is perceived as Pākehā – non-Māori)
- inadequate coordination between palliative care providers
- lack of a representative palliative care workforce
- poor quality written information about palliative care in terms of being understandable and relevant to Māori.

The Auckland and Bay of Plenty report also identified poor ethnicity data quality and use as an issue.

The palliative care system has a total population focus and is generally perceived as ‘Pākehā’. There is a lack of Māori presence within most services and relatively few efforts throughout the system to accommodate Māori cultural values and preferences. This undermines Māori confidence in the ability of hospice and other palliative care service providers to deliver culturally competent care that will meet their needs. Findings from both research projects indicated a need to integrate culture into palliative care services. Patients and whānau emphasised the critical importance of whānau involvement in palliative care, including in hospice and hospital settings. A whānau-oriented approach is not, however, embedded within the palliative care system.

## **Health organisation factors**

At the organisational level, research findings indicated a low level of commitment from palliative care organisations to building Māori health literacy. The following organisational factors were identified that influence the level of health literacy demands on Māori patients and whānau trying to access palliative care services:

- the mixed quality of health care professionals’ communication
- low health literacy of health professionals
- poor workforce cultural competence
- the need for Māori navigator roles in palliative care to provide advocacy and support in navigating the system.

Effective communication greatly enhanced the whānau experience of palliative care. Patients and whānau found the following communication processes used by health care professionals were effective in supporting them:

- ability to communicate with health professionals when required
- full communication from health professionals
- practical training provided for whānau caregivers to support their knowledge and skill development
- establishing respectful rapport and relationships with patients, including respect for the knowledge that whānau already had
- use of plain speech
- communication books to record what was happening
- culturally competent communication processes.

In addition, participants in the Auckland and Bay of Plenty research identified the following factors:

- supporting oral communication with quality written resources, and taking the time to explain written material
- opportunity to have regular meetings with those providing care to the patient to discuss progress
- help with predicting future care needs.

For kaumātua and whānau respondents in the Waikato project, effective communication also involved collaborative ways of working with whānau. However, patients and whānau commonly experienced poor communication by health professionals. Across the two studies they expressed dissatisfaction with the quality, type and extent of information provided; with their understanding of language used; how they were informed about the patient's condition; and poor communication of 'bad news'. They also were dissatisfied with health professionals:

- lack of skills in having these difficult conversations
- not being available to provide updates
- being reactive rather than proactive around providing information
- lack of acknowledgment of pre-existing whānau knowledge and expertise.

Generally, research findings indicate low levels of cultural competence among the palliative care workforce, with examples from the Waikato project including lack of understanding of Māori cultural preferences for end-of-life care and culturally inappropriate practices (such as inappropriate placement of urinals and use of pillows). Biased attitudes, uninformed beliefs and discriminatory stereotyping were also indicated in both reports. Health professionals acknowledged the need to increase their cultural competence and expressed a willingness to develop knowledge and skills in that area.

## **Patient and whānau factors**

At the patient and whānau level, health literacy and whānau values, preferences and context were identified as influencing access to care.

Research findings indicated that low health literacy is a barrier to access to palliative care services. Conversely, those whānau with higher levels of health literacy were better able to navigate the system and access resources and services.

The Auckland and Bay of Plenty study found that some patients and whānau were reluctant to accept palliative care because of misconceptions that these services were only available as an inpatient, that the purpose of hospice care was to hasten death, and that to accept palliative care was to accept that death was imminent. Health professionals had stories about helping patients to overcome a fear of hospice as 'the place to die', which was consistent with New Zealand research. Misconceptions and initial reluctance were often overcome once patients and whānau gained entry into palliative care, although in some cases insufficient time was left for patients and their whānau to benefit fully from palliative care and adequately prepare for preferred death experiences.

Findings from the research projects indicate that the level of health literacy is likely a factor in whether a referral to palliative care is accepted. Currently, due to low health literacy Māori patients and whānau are not well positioned to make informed decisions about palliative care prior to contact with those services.

Health literacy and access to palliative care services may be influenced by the extent to which patient and whānau values and preferences are expressed in palliative care services and the context for palliative care. Cultural factors were identified as playing a central role in participants' experiences of palliative care related to death and dying and whānau involvement in care.

Whānau participating in the Waikato project described the last days and hours spent with a dying whānau member or friend as a spiritual experience, and emphasised the critical role of tikanga (cultural practices). They specifically discussed the importance of waiata (song) and karakia (prayer) in managing pain and facilitating the dying person's spiritual journey through making connections between the spiritual and material worlds. These cultural practices were an expression of Māori beliefs and values and often involved strengthening interpersonal relationships (including spiritually) between the person dying and whānau members, and among whānau members.

The free expression of cultural values by patients and whānau was identified as important during the end-of-life journey in the Waikato project. Also important was the balancing by whānau of tensions between some of these values, such as the importance of maintaining the mana and self-determination of palliative care patients while meeting needs for a deeply connected and supportive relationship with whānau.

The right of whānau to actively participate in caring for their dying relatives was given strong emphasis in the Waikato report, and this aligned with comments that expressed the high value patients placed on being surrounded by whānau at this time. Participants in both studies emphasised the importance of palliative care services that were able to fully accommodate whānau and therefore enable whānau to function as a practical support network for patients and one another in palliative care settings. In the Waikato report, concerns were highlighted around differing expectations between whānau and health professionals as to the role of whānau in palliative care. In some instances, clinical staff did not listen to whānau wishes to provide care for their loved one.

According to the Auckland and Bay of Plenty report, it is important to recognise that patients and whānau experiences of shock, grief and loss create emotional environments that may influence whānau health literacy during the end-of-life journey. Absorbing new or complex information takes time, and can be affected by emotional state, vulnerability following diagnosis, and being in unfamiliar environments such as hospitals.

The Auckland and Bay of Plenty report indicated that whānau caregiving was another factor that influenced the emotional climate in which health literacy occurred. The Waikato report noted that for whānau, the role of caregiver, while a responsibility that was willingly accepted, was very demanding. This was particularly the case for those who did not have support, for example, due to low health literacy (eg, they were not aware of available financial and other support) and feelings of cultural isolation.

## **Enhancing Māori health literacy in palliative care**

Both research projects identified health system, organisational, and patient and whānau level factors that have the potential to influence the achievement of health literacy and access to palliative care for Māori patients and whānau. Findings indicate that key measures to improve Māori health literacy in palliative care and service delivery relate to strengthening a Māori focus

and presence, and a whānau orientation within the palliative care system. This should be reflected in:

- the constitution of the workforce (ie, Māori representation)
- increased coordination between providers, including Māori community organisations
- the availability of quality palliative care information that is tailored to Māori
- quality ethnicity data that is routinely analysed and reported to inform palliative care planning and decision-making
- health professionals who engage in health literacy and cultural competence training that enables them to communicate effectively with Māori and support the integration of Māori culture into palliative care
- specific Māori navigator roles
- palliative care services that reflect the values and preferences of Māori
- high health literacy among Māori in palliative care.

Health literacy for Māori in the palliative care context is a complex topic. The final chapter of this report contains recommendations for actions to enhance Māori health literacy and access to palliative care. The actions are intended to contribute to the achievement of health literacy by palliative care systems, organisations and health professionals in order to realise the potential of palliative care for Māori. That is, palliative care that supports whānau, optimises quality of life for patients including the maintenance of their mana, and enables preferred death experiences that give free expression to cultural values and practices relating to death and dying.



---

# Introduction

Two kaupapa Māori research projects were commissioned by the Ministry of Health and the Health Research Council of New Zealand Māori Health Joint Venture programme. The projects aimed to identify, from a health literacy perspective, issues for Māori and their whānau in accessing palliative care services. By identifying these issues, the projects were designed to contribute to better service delivery of palliative care and improved access to palliative care for Māori and their whānau.

The first research project was led by the University of Auckland in partnership with UniServices, Workbase, and the Māori and palliative care communities in the Auckland and Bay of Plenty regions. The second research project was led by the Rauawaawa Kaumātua Charitable Trust in collaboration with research team members from the Te Kotahi Research Institute (University of Waikato), Te Rūnanga o Kirikiriroa, Te Puna Oranga and the Palliative Care Unit (Waikato District Health Board), and the Waikato Clinical School (University of Auckland). This project was carried out in the Waikato region and focused on both health literacy and cultural competence in palliative care.

Both research projects took a primarily qualitative approach and involved literature reviews; interviews, hui and/or focus groups with patients, whānau and health professionals and others involved in palliative care provision; and analysis of written information provided by different palliative care services providers. An observational study using record linkages of palliative care patients' use of emergency departments within the Waikato District Health Board was also carried out. However, findings from that work are reported separately as they did not directly inform health literacy issues for Māori and their whānau (Lawrenson et al 2013).

This document combines the research reports of the projects, and unless otherwise specified the analysis is drawn from both studies. Generally, the two reports reached similar conclusions.

---

# Palliative care and Māori health literacy in New Zealand

## The concept of palliative care

In New Zealand a frequently used definition of palliative care (Palliative Care subcommittee: New Zealand Cancer Treatment Working Party 2007) is:

‘Care for people of all ages with a life-limiting illness which aims to:

1. optimise an individual’s quality of life until death by addressing the person’s physical, psychosocial, spiritual and cultural needs
2. support the individual’s family, whānau and other caregivers where needed, through the illness and after death’.

The definition requires that palliative care should be provided in such a way as to meet the needs of Māori (Palliative Care Subcommittee: NZ Cancer Treatment Working Party 2007).

According to the World Health Organization (WHO) (2011), palliative care affirms life and regards dying as a normal process, intends to neither hasten nor postpone death, and uses a team approach to address the needs of patients and their families. There is increasing recognition internationally that palliative care is needed in chronic as well as life-limiting illness, there is no time limit or prognostic limits on when palliative care should be delivered, that palliative care should be delivered wherever a person receives care, and that palliative care is needed at primary, secondary and specialist levels of care (Connor and Bermedo 2014).

The following success factors for the implementation of palliative care have been recognised by WHO: ‘... a multidisciplinary and multisectoral approach; adaption to the specific cultural, social and economic settings; and integration into existing health systems, with emphasis on primary health care and community- and home-based care’ (World Health Organization 2013). The WHO Secretariat noted that palliative care should be integrated into national health systems’ continuum of care for people with chronic, life-threatening illness and should be linked strategically to prevention, early detection and treatment initiatives (World Health Organization 2013).

## Palliative care services

The New Zealand Palliative Care Strategy (Minister of Health 2001) focused primarily on establishing palliative care services. The Strategy recognised the need for accessible and appropriate services for Māori, care coordination of services in conjunction with Māori providers of culturally appropriate palliative care services, development of plans with local Māori to ensure appropriate access to services, and linkages between palliative care providers and Māori development organisations. He Korowai Oranga, the Māori Health Strategy, notes the importance of palliative care for the achievement of Whānau Ora (the health and wellbeing of families) (Minister of Health and Associate Minister of Health 2002).

Palliative care in New Zealand has tended to be described in terms of two categories relating to who is providing the care and to whom – primary palliative care or specialist palliative care (Naylor 2012).

Primary palliative care (also known as generalist palliative care) is provided by individuals and organisations that deliver palliative care as a component of their services, but their substantive work is not in the care of people who are dying. The key elements are that the individual has a life-limiting or life-threatening condition and they are receiving palliative care as an integral part of standard clinical care by any health professional who is not part of a specialist palliative care team. Primary palliative care providers include general practices, Māori health providers, aged residential care services, public hospitals, district nursing services and home health care agencies. Approximately 80% of those who die from life-limiting or life-threatening conditions will receive care from a primary palliative care provider. Half of these will be cared for through a collaborative arrangement with a specialist palliative care service (Palliative Care Council of New Zealand 2013).

Specialist palliative care is palliative care by those who have undergone specific training and/or accreditation in palliative care/medicine, working in the context of an expert interdisciplinary team of palliative care health professionals. This care is usually provided by hospice or hospital-based palliative care services where patients have access to palliative care specialists. Specialist care may be delivered through direct involvement with the individual and whānau or indirectly through advice, support and education to other health professionals and volunteers within the primary palliative care framework. Specialist palliative care providers include hospitals and hospices.

## **Māori and palliative care**

The number of older Māori is growing and the number of Māori dying of conditions amenable to palliative care is growing with it. Recent projections (Palliative Care Council 2014) estimate that the percentage of Māori who will die aged 65 or over will grow from 51.4% (of all Māori) to 63.6% in 2026. This trend is likely to lead to an increase in the demand for palliative care for Māori. However, it is difficult to estimate what percentage of this growth will be amenable to palliative care. Different methodologies (for example Murtagh et al 2013) which include or exclude different conditions are currently being debated. The Palliative Care Council is currently working on projections.

The most recent data on the number of Māori who received hospice care and inpatient palliative care in hospitals is for 2010/11 financial year (Palliative Care Council of New Zealand 2013). That year there were 10,878 new referrals to hospice care and 3,374 patients were already in care – a total of 14,252. Of the 12,064 (84.6% of the total) whose ethnicity was recorded, 10% were Māori. Of the 7,049 accepted referrals to hospital palliative care services, ethnicity was recorded for 6,140 (87%), and 9.4% of these were Māori.

Caution needs to be applied when using this data for a number of reasons. Hospices have different information systems, it was not always clear how ethnicity was prioritised, some institutions recorded patients in care when the data was sought while others did not, and no ethnicity is recorded for some patients.

An observational study using record linkage looked at Waikato patients on the palliative care register who used emergency departments (ED) over a 12-month period (across 2011 and 2012) (Lawrenson et al 2013). There were proportionately more Māori on the register (17%) than would be expected based on regional population (8%), and the mean age of Māori was younger than that of non-Māori (63.3 years compared to 72.5 years). The length of time Māori patients were on the palliative care register was similar to non-Māori. Attendance at the ED was also similar for Māori and non-Māori after adjustment for age and the cause of the palliative care.

There is some indication in the literature that very late referrals to hospice when death is imminent as well as low use of hospice services relative to need may be an issue (Nelson Marlborough DHB et al 2006; Cottle et al 2013). Analysis of mortality data over a five-year period (2003 to 2007) demonstrated that Māori were less likely to die in a hospice or in residential care, and more likely to die in a private home or hospital (Palliative Care Council of New Zealand 2011). A survey of 186 rural general practitioners (GPs) indicated that Māori patients were more likely to die at home compared to all palliative care patients (62% versus 46.5%) (Lawrenson et al 2010).

The Liverpool Care Pathway for the Dying Patient (LCP) is an integrated care pathway that was developed to transfer the hospice model of care into other care settings. The LCP is intended to guide health care professionals to deliver best-practice care to dying patients and their whānau in the last days and hours of life, irrespective of diagnosis or care setting (Ellershaw and Wilkinson 2011).

In New Zealand cultural goals of care have been integrated into the standardised National LCP documentation (Batten et al 2011). A three-year study is underway to investigate the goals, their use, and how the LCP may be further developed to facilitate culturally appropriate end-of-life care for Māori. Preliminary findings from the study have demonstrated a lack of ethnicity data recording in over one-third of LCP records. Checks against NHI ethnicity data showed that those missing ethnicity were New Zealand European/European (just one record did not have ethnicity in the National Health Index). There was very low use of the LCP tool in caring for Māori patients (only around 2%). Further, there was very limited documentation concerning cultural needs with few comments. Findings indicated that the cultural goals were not facilitating the documentation of cultural care.

An investigation of stakeholder experiences and views of how the goals influence culturally appropriate care for Māori patients and their whānau found that:

- there were concerns raised about the cultural appropriateness of the LCP approaches in the care of Māori who were dying in any setting
- there were substantial organisational blocks to palliative care workers' abilities to provide 'cultural care'
- there may be issues with culturally inappropriate use of imagery in written resources
- there was generally little documentation of cultural care
- cultural goals were considered to be more difficult for staff and an area where support was required (Batten et al 2012).

The LCP is being withdrawn in the United Kingdom due to independent review findings indicating poor implementation. A review of models of care, including the LCP, is underway in New Zealand as part of the Last Days of Life Initiative.

Concerns are widely expressed in the literature that palliative care services are not meeting the needs of Māori (Muircroft et al 2010; Penney et al 2009; Waikato District Health Board 2005). It has been suggested that Māori access to palliative care services has been affected by a number of issues, including:

- uncertainty about what palliative care means and available services
- low numbers of Māori palliative care provider organisations
- lack of education about palliative care among Māori providers
- under-representation of Māori health workers in palliative care
- a lack of understanding among mainstream providers of Māori models of health and Māori cultural beliefs relating to providing care for the dying (Nelson Marlborough District Health Board et al 2006, Waikato District Health Board 2005).

Further, many Māori live in rural areas or return to rural *turangawaewae* (tribal homelands) when terminally ill, which may limit their access to specialist palliative care services (Lawrenson et al 2010).

Muircroft et al (2010) argued for palliative care services tailored to Māori that are culturally appropriate and include a focus on language and culture. The need for palliative care services to accommodate *whānau*, including in terms of physical space, and their desire to be involved in the management and provision of ‘hands-on’ care is recognised in the literature (Bellamy and Gott 2013; Bray and Goodyear-Smith 2013; Frey et al 2013a; Lawrenson et al 2010). Further, more time is required to identify key people within the *whānau* and for communication (Lawrenson et al 2010). However, concerns have also been expressed that assumptions may be made that Māori prefer to be cared for by *whānau* (Patiki Associates 2002). Provider perceptions of Māori preferences about palliative care and dying at home may influence access to hospice services (Cormack et al 2005).

## Health literacy

Health literacy has been defined as ‘the degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions’ (Kickbusch et al 2006). This implies that the effects of health literacy relate to how an individual perceives messages; however, individuals do not operate in isolation from the context in which health messages are delivered, received and processed. Health literacy is, therefore, also recognised as relevant to communities (Kickbusch 2002). The benefit of a broad approach to health literacy is that it enables a vision of personal and collective empowerment (Zarcadoolas et al 2005; Nutbeam 2000). Further, the exchange of health information has been described as a complex process involving the provider, the health professional and the recipient, with consumers of health services seen as active receivers and seekers of information who also generate and synthesise information of their own (European Health Policy Forum 2005). For health professionals, health literacy is about their ability to communicate health information and build skills and knowledge. For health organisations, health literacy is about the appropriateness of the health information and services they provide for patients and their *whānau*, as well as the organisational systems and processes that support health professionals to build health literacy.

Many skills are required for individuals and *whānau* to function effectively in the health care environment and act appropriately on health care information. These skills include the ability to interpret documents, read and write prose (print literacy), use quantitative information (numeracy), and speak and listen effectively (oral literacy) (Berkman et al 2011).

Health literacy has been conceptualised within two different approaches: seen either as a risk factor or as an asset. In the risk model, health literacy is conceptualised as a potential risk factor; for example, the lack of health literacy will act as a barrier to patients becoming compliant with treatment. Alternatively, it can be seen as an asset, where improved health literacy is an outcome of personal empowerment in decision-making (Nutbeam 2008). Recent literature tends to focus more on an asset model which aligns closely with principles of adult education, where the patient's prior knowledge and experience is recognised (Workbase 2013). This reflects a shift in thinking from a concept of the individual 'risky patient' to a view that acknowledges health professionals, health service providers and the health system as having a critical role to play in building health literacy (Nutbeam 2009).

As health care systems become more complex, the health literacy demands placed on patients and whānau also become increasingly complex. The changing face of health care means that patients are now expected to have a more active role in their care, develop new skills to find and manage information, understand and manage their rights and responsibilities, and make the best health decisions for themselves (Institute of Medicine 2004). International evidence shows that patients' knowledge and skills are usually below those demanded of them by their health system (Rudd et al 2007). As Koh et al (2012) state, 'a wide chasm often separates what providers intend to convey in written and oral communication and what patients understand'.

The content and context of health messages is so complex that a person with high health literacy skills in one context may experience moments of poor health literacy in another. These episodes occur when patients and whānau find themselves dealing with a new context, particularly when the patient is in very poor health (Nutbeam 2009). The physical and social environment of health care settings also influences the efficacy of health literacy (Rudd 2013). Rudd identified the key components of health literacy as individual skills, health tasks undertaken, health materials used, skills of providers (including the 'oral exchange') and the reciprocal physical and social environment (Rudd 2013).

A qualitative study involving case studies and interviews with Māori whānau who were currently, or had experience of, providing care for loved ones with life-limiting illness explored their experiences of death and dying and the processes associated with end-of-life (Moeke-Maxwell et al 2012). The research indicated that whānau had poor palliative care health literacy, including a lack of skills required to navigate the palliative care system. Further, whānau faced substantial health literacy demands generated by structural factors (eg, poverty), the health care system (eg, cost of medication) and palliative care organisations (lack of a representative and culturally competent palliative care workforce resulting in care that was at odds with Māori cultural preferences). Whānau identified the need for increased Māori representation within the palliative care workforce, strengthening of palliative care workers' cultural competence (including in relation to spiritual dimensions of care), and development of a Māori-specific palliative care tool to support end-of-life care, advanced care planning and navigation of the palliative care system. The researchers argued for strengthened measures to increase health literacy in palliative care for Māori.

Five aspects of health literacy have been identified: functional, technical, interactive, political and cultural competency<sup>1</sup> (Nutbeam 2000; Zarcadoolas et al 2005).

<sup>1</sup> The Waikato report sometimes used the term cultural health literacy used by Zarcadoolas et al (2005). This is not a common term in the study of health literacy and the term 'cultural competency' is used in this summary report where not specifically related to the Zarcadoolas article.

Functional health literacy depends on basic reading, writing and comprehension skills, and is conceptualised as the ability of individuals to obtain, interpret and understand basic health information and services, and make decisions in ways that enhance health and facilitate health service encounters (Ratzan and Parker 2000; Kickbusch et al 2005). International research has found that low functional health literacy is associated with lower levels of knowledge about diseases, health status and health service utilisation, and higher service utilisation costs (Baker et al 1998; Kalichman et al 2000; Lindau et al 2002).

Technical literacy is the ability to explain and understand medical terms and processes associated with diagnoses and service delivery such as terminal illness and palliative care (Zarcadoolas et al 2005). Interactive health literacy requires more advanced cognitive and literacy skills that, in conjunction with interpersonal communication skills, enable people to talk about care, health issues and problems, with clinicians, caregivers and whānau, and develop positive relationships (Nutbeam 2000).

Political health literacy concerns more advanced cognitive and social skills that combined, enable individuals and communities to critically analyse information, events and issues, and make individual, family and community-based decisions that benefit, personal, family and community health (Nutbeam 2000). The term 'cultural health literacy' relates to collective beliefs, customs, worldviews and social identity that guide engagement with, interpretations of, and actions associated with health information and issues (Zarcadoolas et al 2005). In the context of palliative care needs, cultural health literacy is the knowledge, skill and capacity of palliative care providers to convey health information and practice in ways that take account of, and engage with, cultural understandings of Māori.

There is evidence that there is a relationship between an individual's level of health literacy and their health status (Nutbeam 2008; Korhonen 2006; Knight 2006; Kickbusch et al 2005; Institute of Medicine 2004; Canadian Council on Learning 2008). Low levels of health literacy are a barrier to health care access (Minister of Health 2010) and are thought to be associated with a greater risk of experiencing poor health status and health outcomes. Conversely, high levels of health literacy are likely to enable patients and whānau to take more responsibility for the management of their health throughout the continuum of care (Nutbeam 2000).

According to results of the 2006 Adult Literacy and Life Skills Survey, Māori have poor health literacy skills compared to non-Māori across all age groups and regardless of level of education, labour force status and household income (Minister of Health 2010). Four out of five Māori men and three out of four Māori women have poor health literacy. Māori aged 50–65 years have the lowest health literacy scores of those surveyed (aged 16–65 years), and four out of five have insufficient skills to cope with typical health literacy demands. The Ministry of Health's (2010) Kōrero Mārama survey report on Māori and health literacy argued that instead of viewing health literacy as an issue for individuals, with the responsibility on individuals to build their skills, the solution required a concerted effort from all sectors, including schools, government agencies and the health care system.

The literature indicates that Māori have low health literacy in relation to palliative care (Cottle et al 2013; Frey et al 2012; Waikato District Health Board 2005). A study by Frey et al (2012) that involved interviews with Māori and non-Māori cancer patients, whānau and health professionals found that Māori were unaware of the hospice philosophy of care and how hospice services can be utilised, misunderstood potential costs and were fearful of discrimination based on previous experiences within the health system. For example, for families wanting temporary relief from caring there was confusion around availability of hospice respite care or its use during an acute episode. Further, a hospital or hospice was seen as a place to go to die (Frey et al 2012) and this perception is likely a barrier to using palliative care services, particularly for families wishing to remain hopeful (Bellamy and Gott 2013).

A qualitative research project investigating cultural perspectives on challenges to the use of hospice services involved interviews with Māori, Pacific and Asian cancer patients, whānau and health professionals (Frey et al 2013b). Study findings indicated low levels of health literacy in palliative care, with patients and whānau reporting a lack of familiarity with the role and availability of hospice services and misconceptions about palliative care, including that hospice services were only available to those with the ability to pay. Assumptions by general practitioners about Māori preferences to remain at home were identified as a barrier to information access. There was some indication that Māori experiences of discrimination within the wider health system may deter use of hospice services. Overall the findings of the study indicated 'the importance of knowledge of hospices for utilisation of services'. The researchers identified practices that reduce health literacy demands, including engaging with whānau throughout the palliative care journey and taking the time for whakawhanaungatanga (building relationships), having meetings between whānau and health professionals providing care, and utilising community organisations to facilitate discussions about hospice services. The development of palliative care education resources specifically for Māori health providers and Māori whānau was also recommended.

---

# Research design and methods

## Research approach and methodology

Both research projects adopted a kaupapa Māori approach. This approach is located within a Māori worldview and therefore its starting point is Māori beliefs and values, and Māori views and practices are normalised (Kennedy and Cram 2010). The nature or essence of the approach is expressed in the following underpinning kaupapa Māori principles that have been applied throughout the research (Bishop 2005; Tuhiwai-Smith 2005; Cram et al 2006; Pihama 2001).

- Tino rangatiratanga (self-determination). This principle was expressed through recognition of the rangatiratanga of Māori collectives such as iwi (tribe), hapū (subtribe) and whānau, the rights of Māori as indigenous people and Treaty partners, Māori leadership and control of the research, and the generation of Māori knowledge that may contribute to increased self-determination.
- Benefits for Māori. The research will directly benefit Māori (including kaumātua (elders), whānau, hapū and iwi) and support Māori development.
- Emancipation and transformation of power relationships. Critical awareness of power relationships and how these serve to maintain the 'status quo' that privileges the dominant (non-Māori) community and maintains inequalities.
- Validity of Māori worldviews and importance of cultural heritage. The research seeks to understand Māori knowledge and experience on its own terms.
- Māori are located at the centre. Māori concerns, priorities and realities, such as whānau ora, shaped the projects.

A kaupapa Māori approach may be used simultaneously with other research approaches, and within kaupapa Māori a range of methodologies and methods may be applied. What is required, however, is that all aspects of those other approaches, methodologies and methods are consistent with kaupapa Māori principles. For example, the Waikato project concurrently utilised a community-based participatory research partnership approach that proactively seeks to incorporate meaningful community participation, decision-making and practices (Wallerstein and Duran 2006). This collaborative approach equitably involves partners in the research process and recognises the unique strengths that each partner brings (Oetzel et al 2007).

Both projects utilised a qualitative research methodology. This methodology is consistent with a kaupapa Māori approach in that it is naturalistic, context-sensitive, holistic and inductive (Patton 2002). Therefore, Māori experiences may be investigated within natural contexts, findings emerge from the data, and in-depth detailed data is collected.

Advisory groups were established for both the Auckland/Bay of Plenty project and the Waikato project. The groups fulfilled different purposes. The Auckland/Bay of Plenty project established an advisory group with academic membership. The group provided expertise and support for the study, including feedback on the draft report. The Waikato team established a kaumātua advisory board that provided oversight with regard to tikanga and cultural integrity.

# Research methods and characteristics of participants

## Overview

The research was primarily qualitative but included a quantitative component and used multi-methods. The methods included literature review, individual interviews, hui and focus groups, and analysis of written resources. Literature reviews were carried out by the research teams, who reviewed documents relating to Māori health literacy and palliative care.

The two research projects involved participants from three regions. Interviews for the first project were carried out in Auckland and the Bay of Plenty. Interviews for the second project were carried out in Waikato.

## Bay of Plenty and Auckland regions

The Bay of Plenty and Auckland regions were chosen as they enabled investigation of Māori health literacy and palliative care in large urban, small urban and rural environments; in specialised palliative care settings (hospital and community-based specialised hospice services); and in generalist services (including primary care providers, both Māori and ‘mainstream’).

## Recruitment

In September 2012, hui were held at the Whakatane Palliative Care Forum, Waipuna Hospice (Tauranga), Mercy Hospice (Auckland), Hospice Eastern Bay of Plenty and Hospice West Auckland to introduce the study. At those hui support was sought to identify Māori patients and whānau who could be approached to participate in the study. At the same time, health professionals were invited to participate in focus groups and key informants were identified. Health professionals were also recruited through formal and informal workplace networks.

Patients and whānau whose details were supplied to the research team or who indicated to their palliative care service provider that they wished to participate in the study, were individually contacted by a Māori researcher. The researcher sought their informed consent to participate. The participant information sheet and consent form were available in both English and Māori.

## Data collection

Interview schedules were used in collecting data from patients and whānau, key informants and focus groups.

- **Patient and whānau interviews:** The research conducted 15 interviews with 21 people. Two of the interviews were with people discussing the same palliative event. Nineteen of the interviews were with whānau carers for palliative care patients and two were patients. All but two of the patients that whānau carers had been caring for had died before the interview was carried out. Ten of interviews were conducted one to one (including one with a patient) and the other five involved more than one person (one of whom was a patient).

Most interviews took place in participants' homes and ran for between 30 minutes and two hours. Information was gathered from participants on the way they used palliative care services, how they obtained information about the services, positive aspects of the palliative care services provided and what could be improved.

- **Key informant interviews:** Semi-structured interviews were carried out with six key informants: a medical specialist, a service leader involved in developing culturally specific responses to patients, two Māori service managers, and two Māori health team leaders. Key informants were based with a range of service providers including district health boards, hospices and cancer services. Key informants were selected for their broad understanding of the palliative care service environment and to contribute a management perspective.

Interviewees were asked about their perspectives and understandings of Māori access to palliative care services, health literacy demands, and how services and health professionals took these demands into account when delivering palliative care services to Māori patients and whānau.

- **Focus groups with palliative care providers:** Ten focus groups were held involving 54 people from organisations providing palliative care services. The main inclusion criterion was that participants were providing primary or specialist palliative care. Focus groups included staff from four hospices, two Māori palliative care providers, one general hospital, one primary health care service, general practices and the Cancer Society. Of these organisations, seven provided specialist palliative care services and three were primary palliative care providers.

Focus group participants came from a range of professional backgrounds including nursing, medicine, counselling, social work, psychology, chaplaincy, administration and management. Participants also included kaumātua, Māori support workers and navigators. Nurses participated in all the focus groups, and one focus group was exclusively specialist nurses working in a secondary palliative care setting. One patient attended a focus group with her caregiver.

Focus group participants were asked about their perspectives and understandings of Māori access to palliative care services, health literacy and palliative care for Māori patients and whānau, the health literacy demands of palliative care, and how services and health professionals took health literacy demands into account when working with Māori patients and whānau.

- **Review of written resources:** Focus group and key informant participants were asked to supply copies of written resources about palliative care services provided to Māori patients and whānau. Forty-two written resources about palliative care services from hospices, a DHB, a whānau ora provider and a nursing services provider were reviewed. The resources were provided by participants in focus groups and key informant interviews.

## Data analysis

- **Interviews and focus groups:** A general inductive approach was taken to analysing the interview and focus group data and eliciting key concepts and recurrent themes (Thomas 2006). A detailed index of codes (categories with short text descriptors) was developed, and the transcripts were coded and re-coded manually. The codes were then organised into themes reflecting the key areas of focus. Trustworthiness and reliability of the general inductive approach was tested by sharing transcripts among the research team, and using an agreed framework of codes and definitions to ensure coding consistency. This was further tested by sharing analysed texts among some of the research team both individually and through two hui to discuss the findings.

The categories and themes were taken back to the research communities in a series of five hui for discussion and validation in March and April 2013.

- **Written resource analysis:** Written resources were analysed using criteria derived from Ministry of Health (2012) and Workbase (2013) reports on aspects of health literacy. These focused on aspects such as:
  - how clear, or implied, the purpose of the resource was
  - the audience for the resource, whether specified or implied
  - resource type
  - the point in the palliative care process at which the resource was accessed
  - readability
  - vocabulary
  - language and text features, such as layout, white space as well as use of visuals
  - inclusion of Māori concepts and values.

For each resource, there was an evaluative summary produced on what worked well (how the resource might help build health literacy) and what could be improved (in terms of purpose and relevance, usability/accessibility/navigation, and overall building of health literacy).

## Waikato region

Literature reviews were carried out by the research teams, and documents relating to Māori health literacy and palliative care were reviewed. It should be noted, however, that there is a very limited literature base in relation to Māori and palliative care.

### Recruitment

Kaumātua, whānau and health workers were recruited through the established networks of Rauawaawa and the research team. Kaumātua and whānau were initially contacted to invite their participation in the research by phone and/or face to face. The contact was made by a kuia (female elder) member of the research team who was known to most potential participants. At first contact preliminary information was provided and for those who wanted to discuss the research further a follow-up meeting was scheduled. Health workers based with the hospital and hospice were recruited into the study.

### Data collection

- **Kaumātua interviews:** Twenty-one interviews with kaumātua were carried out. Two of those interviewed had been patients – recipients of palliative care services. The remainder were interviewed as whānau or a close friend of individuals who had received palliative care. Five men and 16 women took part in the interviews, and their average age was 68 years. Nineteen interviewees were Māori, one was Pākehā, and one was Pacific.

The interview location, processes and research tools were designed to elicit information in a culturally meaningful way for kaumātua, and therefore were consistent with local tikanga. For example, participants had the option of being interviewed in te reo Māori (the Māori language) and were able to use te reo freely, research tools were developed in both Māori and English, interviews were carried out in familiar Māori environments, community research team members were known to most participants, and sufficient time was allocated for whakawhanaungatanga as an opportunity to meet all members of the research team involved in interviews. Importantly, the research utilised environments and people who were familiar to kaumātua participants as a means to allay fears about the research. As well, the contribution of kaumātua interviewees was acknowledged through koha (gift) to participants. They were not informed in advance that they would receive a koha.

Interviews were run concurrently by 10 research team members in morning and afternoon sessions in separate spaces at the Rauawaawa complex. Prior to interview sessions potential interviewees were welcomed as a group by kaumātua who were known to most. The process was consistent with tikanga Māori, and included mihimihi (greetings), karakia and shared kai (food). This provided an opportunity for whakawhanaungatanga between potential participants and research team members. It was intended that this process would make kaumātua more comfortable in sharing their palliative care experiences.

Following shared kai, further information was provided about the study and the agreement of kaumātua to take part in interviews was reconfirmed. Each interview was carried out by two researchers, at least one of whom was Māori. Generally one researcher led the interview and the other researcher was in a support role (eg, organising informed consent forms). This approach best ensured that at least one interviewer was able to pay full attention to the interviewee's palliative care story for the duration of the interview. Interviews generally ran from one to one-and-a-half hours. However, in order to respect participants, and given the sensitive nature of their experiences, no interviews were stopped if the participant wanted to continue to share their stories.

An interview guide was used that focused on getting kaumātua to tell their own stories about their experiences with palliative care. A set of probing questions around key areas identified in the literature review were also used.

At the completion of individual interviews, the interviewees and research team members returned to the larger group where a whakawhiti whakaaro (group debrief) session was facilitated by the lead kaumātua on the research team, Matua Beau Haereroa. At the close of the session, the group had a shared kai. Potential interviewees arriving for afternoon interviews were invited to join morning groups for the shared kai and whakawhanaungatanga.

- **Whānau hui and focus groups with palliative care workers:** Five hui were held with whānau and were facilitated by two researchers. The hui locations, processes and research tools were selected or designed to elicit information in a culturally meaningful way for kaumātua. In terms of location, sites chosen were Māori contexts familiar to kaumātua. The hui followed similar tikanga-based approaches to those described above for the individual interviews. For example, Māori process was followed throughout the hui. This included use of karakia, opportunities for whakawhanaungatanga and shared kai.

Thirty-nine whānau members, representing 14 whānau groups, participated in the hui. Most participants (35) were Māori. Thirty women and nine men took part in the hui, and those for whom ages were recorded ranged from 32 to 85 years. All participants had experienced end-of-life care for parents or other whānau members.

Three focus groups were run with palliative care workers in workplaces. The first focus group was run with six non-Māori hospital palliative care workers. The second focus group was run with eight non-Māori hospice palliative care workers (the director, six nurses and a counsellor), and the third was with Māori community-based workers who provide wrap-around services for kaumātua and were experienced in working with palliative care services. The focus groups were facilitated by two researchers. Informed consent was sought from participants prior to starting the hui and focus groups.

- **Review of written resources:** Thirty-three hospices identified on the New Zealand Hospice website were emailed explaining the research and seeking written resources used to communicate information about their services to users and their whānau. Seventeen responses were received and 15 of those were able to provide resources. Material from palliative care services at three district health boards (Auckland, Taranaki and Waikato) was also gathered. Only brochures that targeted palliative care service users and their whānau were included. Those with 10 or more pages were excluded, as were any documents from other non-palliative care agencies. Ninety-nine brochures were included for initial analysis.

## Data analysis

- **Interviews and focus groups:** Interview and focus group data was analysed using thematic analysis and the method of constant comparison (Boyatzis 1998; Braun and Clarke 2006; Owen 1984). Data from transcripts was coded and themes were identified based on three criteria: recurrence (at least two mentions of a particular idea), repetition (repeated words, phrases or sentences) and forcefulness (emphasis of certain points because of intensity). Initial identified themes were reviewed by the research team and then validated by participants. Participants were invited to comment on themes and provide critique and clarification.

Analysis was carried out by a Māori and a Pākehā researcher in order to incorporate insider and outsider perspectives and enable triangulation. A separate initial analysis of data from kaumātua interviews was also carried out by two kuia to check whether there were differences in coding when a kaumātua lens was applied.

- **Written resource analysis:** Brochures were analysed using a cultural-discursive approach incorporating Te Ao Māori (the Māori world) and rhetorical perspectives (eg, Liu 2005; Gill and Whedbee 1997).

A small group was established to review the pool of 99 brochures and identify those with appeal through an assessment on the basis of imagery, colour, quality of printing, font size, density of text, diagrams, language and the way the text spoke to them. The group comprised two members of the Kaumātua Advisory Group and a person associated with the research who had experience in creating documents. In making the assessments each group member drew on an informed understanding of the research, Māori worldviews and their own experiences with palliative care. As a result of the process, 25 brochures were selected for further analysis. This set of brochures was examined in two focus groups, one with kaumātua and one with whānau. Question guides developed by the researchers were used to elicit participants' own views and responses to the selection of brochures, including comments on presentation, writing style and use of Māori language and images. Following the focus groups, three brochures were excluded as their text was essentially the same.

Twenty-two brochures were analysed by the researchers for readability, writing style and vocabulary. They were then examined in terms of three dimensions of health literacy: functional health literacy (readability and writing styles), technical health literacy (use of medical vocabulary) and cultural health literacy (how the brochures texts and images connected with Māori readers).

# Literature reviews

Both studies included reviews of recent New Zealand and international literature on ethnic minorities' experience of palliative care. Some of this literature has been drawn on for the section on Palliative care and Māori health literacy in New Zealand in this document. Readers who wish to review this in greater detail are referred to the original documents accessible on [www.health.govt.nz](http://www.health.govt.nz)

## Limitations

Both research projects were qualitative, exploratory studies. The inductive nature of qualitative research means that predetermined frameworks are not imposed. This enables issues to be explored without fully developed preconceived notions, and therefore findings are able to emerge from the data. Each study used small purposive samples that enabled in-depth and detailed exploration of the views of participants in the palliative care system, especially in relation to Māori. This was the purpose of the research, as opposed to trying to make 'objective' generalisations.

An 'opt-in' recruitment strategy was used for patient/kaumātua/whānau participants (in that participants chose to opt-in to participating as opposed to opting out). This means that it is possible that those who responded to a request to participate in the study had extreme experiences (either good or bad) of palliative care services.

The Waikato region focus groups did not include Māori hospital or hospice-based palliative care workers. The Auckland and Bay of Plenty regions study did not ask focus group participants to identify their ethnicity. Therefore, it was not possible to identify Māori-specific views among health professionals based in hospitals or hospices.

The report of the Auckland and Bay of Plenty regions study noted that there was little or no dissent during focus groups. This may have been because of a perceived risk to the health professionals individually or to the organisation of being 'found' to be 'culturally unsafe', with the participants desiring to present a united front of excellent, professional service delivery. In debriefing after each focus group, research team members frequently described a sense of initially being told what was 'correct' rather than what happened in practice. This was addressed in the focus groups by asking for examples from practice, which tended to deepen and diversify the discussion. When this occurred, some of the group would cease to participate, perhaps indicating dissent, but nothing was overtly indicated or said. Therefore, the internal uniformity of the focus group data should be regarded as a limitation and further research carried out to confirm findings.

Neither study involved direct observation of interactions between palliative care providers and patients and whānau. This was not the purpose of the research, and would have required very different ethical and logistical considerations, but may have added to the richness of the findings.

It should also be noted that it was beyond the scope of both studies to involve Māori patients and whānau who had not used hospice and other palliative care services. For example, the research teams did not interview Māori patients and whānau who had declined a referral to these services, or were unaware that the services existed, although health professionals discussed some of their experiences of service refusal. It is not known from a direct account what the barriers for these types of Māori patients and whānau might be.

---

# Research findings – Bay of Plenty and Auckland regions

This chapter reports on research findings from the Bay of Plenty and Auckland regions only. The findings have been organised into the following overlapping themes: accessing and utilising palliative care services, health professionals' concepts of health literacy in practice, health literacy demands, health literacy practices, barriers, and facilitators.

Quotes are included to illustrate themes and categories, from numbered patient and whānau interviews (denoted PW with relationship of carer to patient included), focus groups (denoted FG with type of service and location included) or key informant interviews (denoted KI with role and location).

While this study did not evaluate satisfaction with palliative care services, it is interesting to note that most patients and whānau reported positive experiences, especially in relation to particular health professionals and the provision of equipment.

Everything was really good, actually. It was – yeah, the nurses, actually, they were very mindful and respectful of people in general. (PW wife and daughter)

The hospice they brought everything we needed. I got a hospital bed ... when I was having real trouble and needed to clean her up. I said, 'I just can't handle this double bed that she's in' and so [hospice] gave me a hospital bed. (PW husband)

Although patients and whānau identified a generally positive palliative care experience, many of the findings in later sections of this chapter indicate that there are many issues to address in order to achieve quality care for Māori. Three whānau discussed very distressing experiences, all of which involved general hospital care rather than specialist palliative care.

It has been hell. I didn't know what palliative care meant – I guessed it meant dying but what does it mean? No one explains anything, they give you pamphlets. But no one says this is what this one does and this is what this one does – hospital, GP, public health nurses, district nurses, hospice, chemist ... And most important, what they don't do – 'Oh, we don't do that'. Well who does and how do I find out about that and who do I have to talk to about them and when and where? ... There is so much information and it is so confusing. (PW wife)

## Access to palliative care services

This theme includes the pathways experienced by patient and whānau participants, the timeliness of their referral to palliative care, and access to written resources. Fifteen participants agreed to provide details of referrals (including timeliness) and palliative care pathways.

## Access pathways

**Table 1: Individual patient pathways and palliative care services accessed**

Source of referral to palliative services	Primary palliative services	Specialist palliative services
Hospital	Hospice home visits Patient already had equipment	Specialist care
Self-referral	Hospice home visits, respite, 24/7 availability and equipment Pastoral community nursing in hospice	Specialist care
Hospital	Limited hospice care, as ineligible while under specialist care Pastoral community nursing	Specialist care, no referral for home follow-up after discharge from hospital
Hospital	Hospice initial home visits, 24/7 availability and equipment – bed, wheelchair, and walking frame Ambulance – 24/7 availability Rest home for final month of life	Oncologist Chemotherapy
General practitioner/hospital	GP consultation and advice Hospice home visits, 24/7 availability and equipment Home help	Specialist care Chemotherapy
Cancer navigator	GP consultation but poor advice Chiropractor advice Nebuliser (Asthma Foundation) Hospice provided some equipment, and made two home visits Other equipment hired by whānau	Specialist care
Whānau member a health professional	Hospice daily home visits – pain relief injections, day stay and longer respite options offered Equipment: chair, mattress, personal care item provided, shower rail procured from other whānau Physiotherapist home visit, exercises but no home assessment	Specialist care
Established relationship with hospice service	Hospice initial home visits daily then twice daily, 24/7 availability and equipment – bed, ripple mattress, training for primary caregiver, journal writer provided	Surgeon – specialist care Use of bathing facilities in the hospital
Hospital	Hospice home visit to support caregiver	Team of specialists
Self-referral	Hospice provides social activities, 24/7 advice, social service support on-site Home help Equipment already provided by other services	Team of specialists
Nurse	Hospice provides social activities, 24/7 advice, community nurse	Unknown
Emergency department admission, referral to palliative care nurse then to hospice	Hospice 24/7 advice, home visits, pain relief medication, equipment although bed did not arrive in time, and cultural advice and support	Unknown
Hospital referred to hospice in an effort to avoid hospital admissions	Hospice in-patient care, monitor and control nutrition and exercise, provided training in administering medication Community programme provided regular social interaction	Unknown
Official referral was too late, but hospice were notified by hospital	Hospice home visits, 24/7 availability and equipment – chair lift and bathroom equipment Whānau purchased walking frame	Specialist care
Hospital social worker	Hospice provided some equipment, but this was returned when patient improved Later, GP made referral for more equipment – bed with monkey bars, trolley, wheelchair, bed pans	Specialist care

## Timeliness of referral

Most whānau and health care professionals expressed frustration and distress at the lack of timeliness of patient engagement with palliative care services. Some whānau were referred very late to palliative care services and the patient often died within a short time of referral. In one case this occurred despite the fact that the patient had a long-term condition and was frequently hospitalised.

We were told on the Monday, I brought him home on the Wednesday and he passed on the Friday. (PW daughter)

Yesterday a Māori patient I went to see, has had cancer for months and she has been known to be palliative for months, but [we are] just going in now and that is probably why it is so awful, because I haven't had months to build up a rapport and then you are going in and saying mum's got days, just bring this wedding forward, or, yeah, because it is so late. (FG Hospice Auckland)

The other thing that I've found is that often families don't want us. They're the families that we receive really late and they're the patients who are literally dying and we might – there's a heck of a lot of hard work goes on in that initial time, but their resistance to us is very strong. So we have to try and break down that barrier and in doing so, I mean by the time we do it, the patient's died. (FG Hospice Auckland)

## Written resources

Participants generally agreed that the efficacy of written resources relied on the quality of the relationship between the patient and whānau and the health professional, which needs to be characterised by effective communication.

Health professional and key informant interviewees indicated difficulties in finding time to discuss resources, and expressed doubts as to whether patients and whānau read written material that was left with them.

We don't have the time I guess. And at the time we give [information] to them we don't have the time to go through it, so it's often just left there; whether they read it even is debatable. (FG Hospice BoP)

There were often conflicting needs to engage with the patient and whānau, conduct an initial assessment, and provide mandatory information such as health and disability literature and an agreement to receive care. Some participants identified these high health literacy demands as barriers to achieving effective engagement.

When you go to the initial assessment you have a big envelope that has got stuff about the hospice and then rights and everything you can imagine and I have some time reading it, but I don't think it gets read. (FG Hospice Auckland)

Often you give people lots of stuff to read, but when you go back the next time, not only can they not find it, they don't even know that they've had it and I do feel as though it's a burden for them often. It's a really big ask for them to get through a whole lot of written material when they're struggling with complexity and often sudden bad news. (FG Hospice BoP)

# Health literacy demands

## Categories of health literacy demands

Three categories of health literacy demands, based on the schema developed by Rudd et al (2004) were identified by research participants. The categories were medicines, providing care to the patient, and navigating the palliative care system.

Each category was divided into knowledge and tasks. The knowledge component is where patients and whānau had to ‘obtain, process and understand information’ (Minister of Health 2010) about palliative care. The task components were the tasks that patients and whānau reported they had to do to meet the health literacy demands of palliative care services.

The health literacy demands were found to be substantial and complex, requiring problem solving and resourcefulness on the part of patients and whānau. The full list of health literacy demands are detailed in the following three tables.

**Table 2: Health literacy demands – medicines**

<b>Knowledge</b>
How each medicine works
How to take each medicine
How different medicines can be used to treat pain
Side effects and serious side effects of each medicine
What to do in the event of serious side effects
Contraindications for each medicine including food
Reliable sources for more information about medicine eg, pharmacist, GP, internet
How to keep medicines safe
How to use devices that deliver medicines
Need to maintain a supply of medicine
Entitlements around medicines
<b>Tasks</b>
Read medicine labels and follow instructions
Read medicine cards or pill cards supplied by other health professionals
Use maths skills when giving medicines (number, dose, time)
Give medicines according to specific directions
Titrate medicines according to directions eg, PRN medicines
Explain to patient and whānau about medicines
Ask questions of health professionals and pharmacists in relation to medicines
Research medicines using internet and other reliable sources
Read food labels to identify which foods to avoid
Develop and apply medicine safety plan
Discuss complementary medicines with patient, whānau, health professionals and pharmacists
Operate devices eg, syringe drivers in accordance with instructions
Discuss treatment of pain management with patient, whānau, health professionals and pharmacists
Keep records of medicines given
Maintain patient’s mana when giving medicines
Synthesise often conflicting data from multiple sources and make decisions eg, seek more information, take action, seek specific directions or instructions

**Table 3: Health literacy demands – providing care to the patient**

<b>Knowledge</b>
Understand disease/condition and physical and mental impacts and different methods for managing those
Understand progression of disease/condition and physical and mental changes
Understand importance of nutrition and how to provide adequate nutrition as required
Understand importance of hydration and different ways to maintain this
Understand palliative treatments offered and how they will improve quality of life for patient
Understand other matters that have to be attended to eg, financial, legal, spiritual
Understand importance of personal care for patient's wellbeing
Understand importance of infection control when providing personal care, especially wound care
Understand importance of skin integrity and how to maintain this
<b>Tasks</b>
Read information about disease/condition and its progression
Discuss disease/condition and progression with patient, whānau and health professionals
Work in partnership with whānau and health professionals
Describe and discuss symptoms to health professionals as required
Request assistance from health professionals
Discuss nutrition and hydration needs with patient, whānau and health professionals
Read food labels to check nutritional analysis
Meet nutrition and hydration needs of patient
Provide personal care to patient including bathing, showering, toileting, changing dressings
Manage infection control when providing personal care, especially wound care
Maintain mana of patient while providing personal care
Monitor patient's physical, mental and spiritual wellbeing
Maintain own physical, mental and spiritual wellbeing
Discuss caregiving needs with patient, whānau and health professionals
Set up roster for whānau to provide care for patient
Maintain diary of patient's appointments
Arrange for patient to attend all appointments or make alternative arrangements
Research alternative treatment options for patient
Make and maintain contact with community organisations for assistance eg, Cancer Society
Discuss with patient and whānau the need for ongoing social, mental and spiritual support
Arrange social, mental and spiritual support for patient as required
Provide regular information to whānau about patient's physical, social, mental and spiritual wellbeing
Manage patient's and own time to ensure adequate rest and sleep
Advocate on behalf of patient as required with whānau, health professionals and community organisations in relation to treatment
Make decisions with other whānau members about when additional resources required or change in treatment required
Discuss new requirements with health professionals or community support organisations
Synthesise often conflicting data from multiple sources and make decisions eg, seek more information, take action, seek specific directions or instructions
Receive training from health professionals about how to provide care, give medicine and use equipment

**Table 4: Health literacy demands – navigating the palliative care system**

<b>Knowledge</b>
Understand what palliative care is
Understand what palliative care services are available in the area
Understand range of palliative care service providers in the area
Understand how to access palliative care services
Understand what palliative care services are suitable for patient and whānau
Understand range of services provided by palliative care provider and how these can be accessed
Understand rights and entitlements of patient and whānau in relation to palliative care
Understand entitlements of whānau in relation to palliative care services
Understand concept of informed consent in relation to palliative care services
Understand patient's right to confidentiality
<b>Tasks</b>
Read palliative care services information pamphlets including consent form
Sign consent forms for palliative care services
Communicate with health professionals about services needed
Maintain rights of patient while navigating the system
Maintain confidentiality of patient's information
Discuss with patient about who should have access to information
Research other palliative care services available
Advocate on behalf of patient for additional palliative care services
Arrange for patient to attend palliative care programmes
Support patient while resident at hospice
Read and respond to any correspondence from palliative care services provider
Support patient by participating in palliative care service provider's activities eg, social events, recording personal histories
Synthesise often conflicting data from multiple sources and make decisions eg, seek more information, take action, seek specific directions or instructions

## Health professionals' concepts of health literacy in practice

Health professionals discussed their understandings and roles in relation to health literacy. Health literacy was understood as an element of communication between the health care professional and the patient and whānau, and the need to engage effectively with individual patients and whānau at their own level and pace was emphasised. Health literacy was understood as a multidimensional concept that involves clear communication of information to patients and whānau, the extent to which patients and whānau are able to understand and apply health information, and the capacity of health professionals to understand their perspectives. Comments indicated that health literacy permeates palliative care practice, whether or not health professionals actively consider the concept.

I think too, it's how you put things, not make it sound so clinical, you've got to turn the words around to their understanding and get their point as well, see what they think. (FG Māori health service BoP)

It's walking through them with them, and it's not about giving them a pamphlet on morphine. It's saying to them, 'This is what you're doing; this is what morphine does. How about let's try giving her this little bit in this many hours and see how we go?' (KI Māori health professional BoP)

It's the difference between what we say, between spoken and what is written and what is understood and how people grasp what that actually means for them and their family ... health literacy is just – we live and breathe that whether we think about as a concept or not. (FG Hospice Auckland)

Some health care professionals reflected on the challenges to existing practice, particularly the need to further develop communication skills and cultural competence.

... increasing the cultural awareness, the cultural sensitivity of the people that are in the palliative care team. (FG GP BoP).

Participants acknowledged that complex health literacy demands are placed on patients and whānau, and that their role as health professionals is to reduce those demands.

They have to process a lot of information from a lot of health professionals, and sometimes the information that they're processing is conflicting ... our role is actually trying to orchestrate some consistency in the information that's being provided to the family and to the patient. (FG Hospital-based service Auckland)

## Health literacy demands

### The emotional climate

The emotional climate of palliative care creates a further layer of demand for an already complex health literacy environment. The participants described the additional health literacy difficulties for patients and whānau that arise because of the shock, grief and anxiety associated with the knowledge that a whānau member is dying, the timeframes around receiving that information and receiving palliative care services.

You get the: 'Oh well, we can't do anything more. Do you have any questions?' You've just been told that your loved one is going to pass away shortly. Do you have any questions? Well – you know? All within that five minutes. (PW daughter)

I think it also shows what big demands people and their whānau have when they get a diagnosis like that. They have to take on board so much information and the knowledge of their loved one's time being limited and I just think it is just a huge thing for any whānau to come to terms with and then on top of that we have got all the health professionals, different environments, and the jargon, different people that come in, learning how to do wound care, or maybe stoma care, it is mind boggling when you think of what people have to do. (FG Māori health service BoP)

Whānau caregiving is another factor that influences the emotional climate in which health literacy occurs.

... when it comes to your own family ... you do it yourself ... And who's going to be responsible for all the different things, you know? And that's all done beforehand. Because you know you're gonna lose him – it's no good leaving it for the last minute, yeah ... You know, it's about allocating different things to different ones, within your little group of family, and then you send it out to the extended whānau, do the rest there... (PW wife)

Having a single spokesperson for the whānau increases the responsibility and workload for that person, and has the potential to create problems for that individual. However, it is the perception of some health care professionals that this is the method of communication preferred by patients and their whānau.

I think often for us in the larger whānau especially that we do try and identify one spokesperson to then filter that information through to others ... giving them a lot of information, but then encouraging them to talk with the rest of the whānau. (FG Hospice BoP)

Very recently we had this woman who was the spokesperson for the whānau who was an in-law and she felt really responsible and she had to make a decision ... we said to her, 'Our role here is to support you. If you feel ... you could blame us, that whatever was decided, you could bring it back to the hospital as the outlet'. But she was really relieved and you could almost see the tension on her face, particularly being an in-law. (FG Hospice BoP)

Participants' comments demonstrated how, in the whānau context, all members are potential caregivers.

In terms of the treatment and what-have-you, it was the dialogue, it was the little kōrero [talk] that the mokopuna had with her nanny. That was the medicine. In terms of importance, it was the mokos that were the most important that could actually help navigate and move the pathway. (FG: Māori health service Auckland)

He always looked forward to having his feet [massaged] – he must have had the tidiest feet and nails, the hospital used to say. But that was just sharing with his mokopuna. (PW wife and daughter)

Participants reflected on the level of difficulty for whānau in responding to health literacy demands.

It was just so hard ... being at the hospital and talking to the doctors and nurses all the time and taking care of the kids. The older ones had to move home to look after the younger ones. And the younger ones were so angry and confused ... I needed to stay with him when they needed me to be at home. And the school didn't really understand and were giving them a hard time for not going to class. (PW wife)

The tension around whānau caregiving in the home, and wanting support but also needing to respect the patient's desire to remain independent was highlighted.

Those [hospice] nurses are my lifeline but [husband] won't let them in the house. He says if they come in that means he is dying and he isn't dying. So the nurses and I meet on the lawn or the front steps and they give me the drugs he needs. They also give me equipment to help with showering and so on. They are also available on the phone any time if I need them. (PW wife)

## **Reducing health literacy demands**

Most of the health professional discussions included ways that individuals had attempted to reduce health literacy demands on patients and whānau.

We're generally pretty mindful of whether it's the right time and the right place and right people are there. So there would be some enquiry as to: 'Is it okay for you?' ... 'Is there anyone else you would like here before we proceed further?' (FG Hospital-based service Auckland)

Many of the health professionals described individually adapting their practice to help patients and whānau gain confidence in their service provider and greater skill in utilising the service.

I think, to me, that translates into slowing down and acknowledging to myself that there is going to be more time required to get to know. The things that are already known and don't need to be spoken when you share a culture, yet you need to have the time to develop some stuff and it is about us getting to know and about standing still quietly and you know, being known. (FG Hospice Auckland)

I think actually when we do it well and you spend that time making a rapport in the first place, the amount of time that it takes from then onward ... should make up for it. It is efficient to develop a relationship where people are confident to ask questions they are not sure about ... I saw the same patient yesterday and I spent, it would have been like four hours at their house and getting this rapport and then today I was there for ten minutes. They figured out the driver, most patients I have to do that every week ... once the trust is there, you are fast and efficient ... you create a learning environment. (FG Hospice Auckland)

Some informants provided examples of proactive efforts to reduce health literacy demands on patients and whānau.

We have this communication card system, and we actively encourage patients and their family to take this with them to every appointment ... it's a handwritten overview ... we work very hard in the inpatient unit to put it in user-friendly language. Even the dosages as well: if it's 3mg of dexamethasone we're going to be putting that there's a 1mg pill and they've got to take three of them and in absolutely simple words ... 'this one is to stop you feeling sick' or 'this one is for constipation'. So that gets talked through with the patient going home and particularly with their carer as well. Often our patients aren't going to be in a position to be absorbing all that or managing to retain all that, but as part of our checklist on that card it's also signed that the carer has received it and that we've talked our way through it. (FG Hospice BoP)

Reducing health literacy demands needs to be an active, purposeful process driven by health care organisations (Rudd 2013). There were few examples in this research to demonstrate that the building of health literacy skills by health professionals was supported by their health care organisations. This likely indicates a need for institutions to strengthen policy and other support for workforce development in relation to health literacy.

## **Health literacy practices used by patients and whānau**

Health literacy practices are the actions that patients and whānau take to meet health literacy demands. Health literacy practices involve the use of health literacy skills such as reading, writing, speaking, listening and numeracy as well as critical thinking and decision-making.

Patients and whānau demonstrated a wide range of health literacy practices in order to meet the health literacy demands placed on them in the context of palliative care services. The health literacy practices most commonly used by patients and whānau in this study were that they:

- sought support from whānau and friends
- maintained written records
- researched information

- read written information
- dispensed medicines
- advocated on behalf of patients
- interpreted unspoken messages.

## **Sought support from whānau and friends**

Many of the patients and whānau used whānau members and friends who had previous experience with palliative care, were health professionals or who were working in roles such as social workers, to provide advice and assistance particularly with navigating the palliative care system. In some cases, this involved the whānau member with health care experience stepping in and directly advocating on behalf of the whānau carer. In other situations, it involved the whānau member coaching or supporting the whānau carer to access the system to achieve desired outcomes.

I was just full on, 24 hours, and I ended up sleeping right through to about half past nine I think it was and Mum needed to go toilet and I wasn't up, she couldn't wake me up. So it was pretty much then I called one of my mates ... She was an ex-nurse at a medical centre ... she came over and she brought a social worker over to have an interview with me ... And then we had a meeting and they ended up bringing in another person. (PW daughter)

There was some evidence in this study that whānau members were used in this way because whānau carers felt more comfortable talking to someone they knew and who they perceived was more knowledgeable about the system. There was also evidence that advice was sought from whānau members because patients and whānau were not provided with information to enable them to understand how the different parts and players in the palliative care system worked together.

There's always somebody that knows somebody who's just been through it. It's that sort of kōrero, and you look after each other ... often it's the nurses in the whānau or an advocate in the whānau. 'Ah, yeah, I'll ring up the blah blah – she'll know what to do.' ... So we are talking to each other now and giving each other advice, sharing – sharing the love, sharing the resources, sharing the care. (KI Māori health professional BoP)

Utilising the skills and expertise of other whānau members was a way of 'working around' barriers and obstacles posed either by the system itself or by those working within the system.

I was back and forth on the phone to my aunty ... she's a social worker. So I had to ring her up and say, 'Look they're not gonna let her in', and she goes, 'No, you get back on the phone and you get ...' you know. So yeah, I just kept on doing it. (PW daughter)

## **Maintained written records**

One of the key health literacy practices used by patients and whānau was keeping written records about the day-to-day experiences of the patient and whānau carers. Participants identified multiple reasons for keeping these records:

- to inform other whānau members who were living at a distance and so were not intimately involved in caring for the patient
- to make sense of the different information that was being provided to whānau
- to keep records of medication and other treatments
- to enable whānau to check that health professionals were providing the correct medication
- as a whānau resource for others who might take on a carer role.

I ended up having a diary, so the first day I started writing down and started noting down anything they had said. And then my sisters would just read it. So that's how we kept up ... And I was able to do the same thing for my brother-in-law and his family too, so it sort of quite paid off. (PW daughter)

These written records were a powerful and practical tool for whānau in a health care system which privileges written information. One whānau noted that their record keeping was a source of discomfort for health professionals.

When Dad's fistula popped open, we went to the A and E ... He [a registrar] goes, 'Oh, look, I've got my meeting and I've got to go. He should be okay'. And so my sister ... she's like, 'Should be okay? What does that mean?' ... So I started writing down and I think I looked at the time and I wrote down the time and he goes, 'Oh, what are you writing from me? You make people nervous when you write'. And actually I had that said to me by about three people at the hospital. And he goes out and he come back in and he goes, 'Oh, it's 2 o'clock now. I'm having my lunch. Do you want to write that down too?' (PW daughter)

## **Researched information**

Some participants described feeling frustrated at the lack of clear explanations from health professionals, and turned to the internet to find the information they needed.

They used long words and didn't explain and so I would try and remember what it was and write it down and then look it up on Google on the laptop the older kids gave me every night. (PW wife)

But that's another thing the internet was good for, is the medication, and the side effects, yeah, and how all her medications, all the stuff she was taking, would affect yeah whatever else she was taking. So it was easier to figure out what was wrong or what medicines were good for her and what wasn't. (PW daughter)

## **Read written information**

Patients and whānau were asked what information they received from services, how that information was communicated to them, and whether any resources were used to support communication. Most of the patients and whānau did not report that they received information from written resources. This health literacy practice was mentioned by only two whānau, and the second whānau only read the information in retrospect.

## **Dispensed medicines (including using syringe drivers and nasogastric tubes)**

Whānau also talked about the demands placed on them around specialist care. The first quote illustrates the problem-solving abilities of one whānau when the health system did not provide the support required. The second highlights how whānau could be overwhelmed with the level of care they needed to provide but with the right support this could be achieved.

He developed a chest infection and it got so bad he would be in agony and we'd be calling [the GP] on the phone saying, 'Should we be calling the ambulance, should we do something?' and he's like 'Well give some paracetamol' ... In the end we got the ambulance ... We took him up to the hospital and during that process we got in contact with the Asthma Foundation and got him a nebuliser ... we did this ourselves. Not through the hospital, or [the GP], not through anyone. (PW wife and step daughter)

I told her I was really nervous about it 'cause ... I didn't know what I was doing and then all of a sudden I've got this big responsibility on her meds. And I didn't want to – but she [nurse] taught me and then she got me to do it and I did it ... I didn't know if it was still going to be easy when I had to do it once we were home. But I seemed to know what I was doing plus I talked to other people plus the nurse, so I obviously knew ... it was like five minutes training, but I asked to stay in there for the day just to see, just to watch and make sure. (PW daughter)

## **Advocated on behalf of patient, with health professionals and health care providers**

Whānau also reported on some occasions it was necessary to act as an advocate. Sometimes this was because the patient was too sick or too afraid to advocate for themselves; in other cases advocacy was required to negotiate the health care system.

I had to stay with [her] in hospital, 'cause she didn't trust any doctors or nurses. And then one day she just didn't want to have bloods and they took it that she gave up on all her medication, but it was just at that one time she didn't want them ... so we had to kind of negotiate times and stuff like that, yeah ... We tried negotiating with dieticians too, way back, to try and get a menu developed for our families that runs within the budget – but no one would really come to the party. (PW cousin)

## **Interpreted unspoken messages**

Patients and whānau interpret messages that are not written down or explicitly stated by health professionals. In this first quote, the whānau used the proposed appointment date as an indication of life expectancy when they felt otherwise uninformed about when death might occur.

She [allied health worker] said she was gonna come and see mum on the Wednesday and I thought, oh, you must think she's still gonna be alive on Wednesday, geez that's promising. (PW daughter)

Health care professionals discussed their understanding of non-verbal cues from patients and whānau, and how they adapted their practice accordingly.

You have patients who are reluctant to take any medication at all. I certainly have that conversation with patients about pain and how it makes them feel alive ... I'll ask if they've used the medication and if it's still sitting there not being used, then I explore really why it's not being used and if there are anxieties about actually picking up the bottle and using it. (GP BoP)

In the following exchange, a daughter illustrates the importance of understanding non-verbal cues.

**Interviewer:** How do you know when she didn't understand stuff or when did you know you had to explain things?

**Participant:** Because she just used to sit there and smile. [laughs] And agree. Cause she didn't know. (PW daughter)

These quotes may indicate barriers in achieving health literacy, or a lack of skill on the part of health professionals in transmitting or understanding information when in dialogue with patients.

# Barriers

This study identified barriers experienced by patients and whānau, and reported by health professionals, while navigating the palliative care system. These included patient/ whānau factors and also factors external to whānau (generated by health professionals, palliative care service providers or the palliative care system itself) which directly interfered with whānau building their health literacy skills around palliative care.

## Low health literacy among patients and whānau

It was very common to hear that patients and whānau refused inpatient hospice care.

They wanted her to go to hospice, and for her in her mind was no, hospice is the last place that you're ready to go out. So she'd never go there. (PW cousin)

But to take them into hospice, they prefer not to. They prefer to look after them at home. That is what I'm trying to say here. Nine times out of ten ... [the whānau] would prefer to take them home and look after them, not go in to hospice. (Māori health professional Auckland)

Participants noted that patient and whānau misconceptions about palliative care and hospice impacted on their access to services. In particular, believing that palliative care is primarily delivered inside a hospice or hospital as opposed to in the community and that to accept palliative care was to accept that death was imminent.

Māori look at it in that way that this is the last stop and until one can get that message across, that is not the last stop but it's a place where one can be sort of – in Māori we call it manaaki – one can be helped. (Hospice, Kaumātua Auckland)

Several participants described patient and whānau beliefs that the purpose of hospice care was to hasten death. This was particularly the case when morphine was being administered or the dosage increased through a syringe driver for the first time.

You are very blessed if you can speak to them and tell them that the morphine in the syringe driver is just taking over from what the patient has been taking, and we're not trying to increase it and we're not certainly trying to hurry the procedure, but that the cancer or the illness is just progressing ... I guess unpacking some of their thoughts and beliefs, and trying to reframe it, but sometimes those beliefs are so deeply set. (Hospice BoP)

According to health professionals, reasons for avoiding palliative care included stigma and a lack of accurate information about cost and what was involved.

I think there's more of that stigma attached to palliative care services than there is a GP, and a GP is a very normal thing to go and see versus palliative care. You're automatically identifying yourself as being someone who's dying or someone who's in a different zone to everyone else. (FG Māori health service BoP)

I don't think people realise that it is a free service and people living in poverty would be thinking, like, I can't go there because it is going to cost me money. (Hospice Auckland)

I think that hospice itself, regardless of culture, is not well advertised, it is not [on TV] ... That [awareness] really needs to be addressed because anybody can come to us ... If they know about our services long before they are needed, they will know where to come when they are needed and they don't need to get a GP referral. (Hospice Auckland)

Comments indicated that for whānau who were initially reluctant, concerns were allayed once in hospice care.

He reluctantly went to the hospice. And they were wonderful in there. It's a beautiful place. (PW daughter)

And we have a big family, like lots of grandchildren and stuff – like they didn't mind us all being there ... You didn't feel like that, oh, you're not allowed to go up yet because it's blah, blah, blah time. (PW daughter)

This included a fear of hospice as 'the place to die'.

I remember wheeling in a Māori lady one day ... she was so frightened, really frightened ... I stopped the wheelchair and whipped round the front and said, 'Are you really as frightened as you look?' and she said, 'Yes I am; this is a place you come to die'. She brought the conversation up again when she saw me the next time and said, 'This is the best thing that we ever did. I really did think this was a place to come and die and now I know better' ... sometimes it's breaking that initial perception. (FG Hospice BoP)

## Poor information and late access

Sometimes going to palliative care was just too complicated. Patients were confused by the amount of information that was often inconsistent or incomprehensible, were too ill to have the energy to do something new and/or had insufficient time to build relationships of trust with new health professionals. This latter point is likely a reflection of late access due, for example, to late referrals.

It didn't help that the physios came in before that and the OT department came in after that to put some things in his house. He was buggered and he got mixed up about who was who ... the process of that was too much; he didn't even understand the language. (Māori health service BoP)

If you've gone to the same GP your whole life, to suddenly change and trust a new medical professional takes a long time. You see that with the oncologist. It takes a long time to build up a relationship with an oncologist. (F Māori health service BoP)

## Health system culture

Among all the health professionals and key informants, there was a clear perception that Hospice, the Cancer Society, and the wider health care system in general are Pākehā organisations: 'white, female and middle-class'.

We are very white middle class. You go around the whole staff, every department; that's who we are. (FG Hospice Auckland)

There's a perception that – the Cancer Society's a very good example of this. A white middle-class organisation who won't understand me, who won't try to understand me, who don't want to understand me. (FG Māori health service BoP)

Comments indicated that a lack of Māori presence within palliative care settings was a cultural barrier to access. Health professionals expressed the view that Māori communities and whānau do not have confidence in the capacity of hospice and other palliative care providers to deliver culturally competent care.

Coming into this building, it is not very welcoming. There is nothing that they can recognise that makes them feel that this is a place where they can get the proper care that their culture, their way of thinking and doing things; it doesn't look like they are going to get it in this building. (FG Hospice Auckland)

In any situation like dying, respect is a paramount thing, well with anybody I think, and with Māori they simply think that unless they [hospice] are Māori and they know Māori protocol and procedures, that they just are not aware of how Māori do things. (FG Hospice Auckland)

[Hospice is a] Pākehā service. There's always that reluctance to get involved in the first instance ... That imbalance that will always be there I guess until you see a Māori face to that organisation ... (KI Māori health professional BoP)

Processes and environments that acknowledge a Māori worldview were seen as largely absent from many palliative care services. For example, Māori cultural preferences to express reciprocity in the relationship with providers were not accommodated and attendance at groups was controlled by the service provider.

I think if it was an open house type thing, and let people know that, then you can just drop in for a cup of tea, instead of having to belong to a group ... And you see hospice gets everything. They get baking done for them ... Well you know, when I was growing up, we had to take a plate, whether it be a bread and a butter, and that's the thing. I think hospice has got to let them bring what they want to bring, instead of saying, 'Oh no, no, it's all right, they've got it all here'. That's not the issue. The issue is this is something I brought to share. (PW husband)

## **Workforce composition**

Health professionals expressed concern about the lack of a representative workforce. Comments indicated that Māori staff were either not recruited or were not viewed as intrinsically important to the service.

Interestingly enough, we have a process where we have a Chinese liaison person who meets all Chinese patients. We don't ask them [the patients]; the nurse comes as a shared visit. And we have looked at why is it that we do that with all Chinese patients, but we don't do that with other cultures. Perhaps the nurses aren't introducing [the kaiāwhina – support staff] – well because it is very hard to introduce someone who they've never met before. (FG Hospice Auckland)

Well definitely for us it would be lovely to [have] someone that worked for us that was Māori. It would be nice to have a Māori nurse ... We've been asking for it for a very long time and obviously it all just comes back to money. (FG Hospice BoP)

I think one of the barriers is that our workforce is not culturally diverse enough in palliative care ... I think that we should be doing some sort of purposeful recruitment, because I think our workforce lacks cultural diversity. (FG Hospital-based service Auckland)

## **Racism**

Some focus group comments indicated individual racism, and a lack of appreciation of the structural barriers to Māori access to health care was also apparent in some comments.

I think part of it is we believe we have a lovely place here but for them it's not like their home, it's too clean, it's too – they sometimes get embarrassed coming to a place that they don't perceive, I don't like to say worthy of, but it's different and we see it, and we have it set out nicely and they find sometimes Māori people, until they get here and once they're here they love it, but it's just different for them. (FG Hospice BoP)

Here it is beautiful and pretty and perfect. On one level you could argue that it's designed for neat, tidy little tiny modular families rather than great whānau and so forth, and that's something that we've talked about here. We struggle. We don't really have the facilities ... Some of my colleagues find it extremely difficult to manage those – the numbers of folks that can happen. (FG Hospice BoP)

I think there is a difference for Māori ... I think health literacy for everyone's really important ... But for Māori sometimes I think it's ignorance of wanting to know, by not going to the doctor hence late presentations – the fear of what is, yeah. (FG Hospice BoP)

Focus group comments also indicated structural racism. That is the low level of Māori staff in hospices (as discussed above) and a paucity of ethnicity data within the sector, with some palliative care organisations not collecting ethnicity data as per census guidelines (see further comments below).

## **Ethnicity data quality and use**

Participants' comments indicated problems with ethnicity data collection, quality and use within the palliative care system.

I can't identify sometimes whether these people [patients and whānau] are Māori or not ... I don't get that information because it's not in our access sheet. (Hospice Auckland)

## **Communication**

Poor communication by health professionals was identified as a key barrier to navigating palliative care. Generally these barriers related to failing to communicate fully with whānau and a lack of acknowledgment of the considerable knowledge and expertise about the patient which whānau had developed through providing their continuous intimate care.

So we were trying to get [the doctor] to – don't talk to us like we're idiots – talk to us and explain to us what you're looking at. (PW wife and step-daughter)

He [specialist doctor] always just told us. There's no conversation. (PW daughter)

When we [moved to another hospital] my understanding was that he was going into the intensive care unit. I didn't realise it at the time but I do now know that because he had a superbug my husband was never going to be admitted to intensive care. But no one told me that – no one told me anything ... It was only later I realised that ... because they thought he was going to die they didn't do anything about [his infection]. (PW wife)

Health professionals commonly expressed the view that their colleagues in non-palliative care settings such as hospital wards, specialist services, and primary care avoided having 'hard conversations' with patients and whānau about the change in focus from treatment to palliation. This created situations where patients and whānau were poorly prepared for palliative care.

# Facilitators

## Advocacy and navigation

A common theme that emerged was the importance of effective advocacy/navigation to address some of the health literacy and other access barriers. While advocacy was discussed previously as a health literacy practice involving utilising whānau and friends, this section relates to a specific function provided by palliative care services. Called variously a navigator, kaiāwhina, or an extension of an existing role such as a nurse or social worker, these roles provide advocacy and system navigation and were reported to have impacted substantially on the quality of care for whānau.

... I was trying to take notes and then she [the navigator] just took my book ... so I could listen, she did all the notes for us and I really appreciated that ... always like keeping a step ahead of us. Like she knew what questions we didn't know to ask, and she knew that soon we would be needing certain services, and she would make sure that contact either had been made by herself to set up contact – so that they would contact us or she would give us the information and we would contact them ... (PW wife and step daughter)

We support whānau in terms of navigating their options in a way that maintains their mana. And in a way that provides an opportunity to whānau to actually look at what are the choices that they make. And part of that ... is actually ensuring that information is delivered in such a way that they can comprehend, they can apply those options to their worldview, and to their whānau context and what's actually happening. (FG Māori health service Auckland)

Attending appointments with patients and whānau formed a key part of advocacy, ensuring that information was effectively communicated because:

...people feel overwhelmingly intimidated by health professionals and the language that's being used and may not really understand what's going on. (FG Hospital-based service Auckland)

Advocacy extended to accessing social support through, for example, Work and Income appointments, and intervening when schools became concerned about a child's absence during the final stages of a whānau member's life.

## Communication processes

### Generic communication processes

Effective communication was identified as a key facilitator of access to palliative care services. Patients and whānau found the following general communication processes used by health care professionals were effective in supporting them:

- ability to communicate 24/7 with health professionals, to ask questions and have their fears allayed

The good thing about it is that they had this whiteboard and it told you who was on, and like from the social worker right down ... we could talk to any of them about if we had like a question or anything. They were nice ... And the thing about them was that they were quite straight up with you, which was even better ... Even though it was scary, it was still good. (PW daughter)

- established respectful rapport with patients
 

Oh the way she spoke, the way she interacted with us ... she was really lovely, really informative ... He was happy with her. She went right through the medication ... saying that he can increase that whenever; there won't be any problems with it. (PW wife and daughter)
- training provided for carers
 

So the nurses taught T what to do [morphine], which is really good, 'cause it was one-on-one so it was easy for her to understand as well. (PW15 daughter)
- opportunity to have regular meetings with people providing care to patient to discuss progress
 

Once a week you could call a meeting with everybody who's looked after mum and then we can all group together and see what's going on and how's it all going? (PW15 daughter)
- communication book to record what was happening
 

Because they got to read it and note who was coming in to see mum and what were they saying about mum and how she was reacting. Even writing down what she looked like [laughs]. (PW daughter)
- help with predicting future care needs
 

... always like keeping a step ahead of us. Like she knew what questions we didn't know to ask, and she knew that soon we would be needing certain services, and she would make sure that contact either had been made by herself to set up contact – so that they would contact us or she would give us the information and we would contact them ... She was saying, 'Do this now, don't wait till it gets worse, so that you've got a rapport with these people before you need them'. (PW wife and step daughter)

As well, the use of plain speech and demonstrating respect for the knowledge held by whānau was considered important.

Generally whānau participants identified that individual nurses were open and honest and tried to advise whānau of the reality of the situation. Most health care professionals said they would answer questions if asked, but some were not always proactive in giving information, particularly if they assessed the patient and whānau were not ready to hear it.

I would only ever tell someone what they wanted, if they were asking about it. They say in hospice that you have to be really careful, you can't just throw all the information at people ... Our nurses are really good at not forcing information that they don't want. Lots of people don't want to know everything about it. They just want to know what they want to know. (FG Hospice Auckland)

Some health professionals described their process for ensuring patients and whānau would feel able to access information and support.

I want them to feel that there's an open door and that they will use the phone ... I will follow that up a few days later with a phone call just to say how are things going, we met the other day, again just to make sure that they know that I'm really open to that level of communication. The most important thing in a doctor/patient relationship is that you can communicate and let people know that there's an ability to communicate. (FG GP BoP)

I always explain, ‘Come with your questions, don’t hesitate. If you’re too whakamā [ashamed or embarrassed] give them to me and I’ll ask them’ ... we’ll stay afterwards because the whānau usually come, ‘Now what did that doctor mean?’ or they usually come back asking me questions. And that’s good too, because that’s what we want. (KI Māori health professional Auckland)

## **Cultural competency and communication**

Participants identified a number of concepts that underpinned culturally competent communication for Māori – wairuatanga, whanaungatanga, kanohi ki te kanohi, whānau knowledge sharing knowledge, and ‘by Māori for Māori’.

Wairuatanga or spirituality is a dimension of care that is fundamental to whānau engagement, and therefore should be able to be integrated within clinical settings. At times, there may be tensions between spiritual beliefs and conventional medical practices. In terms of communication, it is important that health professionals acknowledge Māori spiritual beliefs.

So we have conventional medicine and treatment, rongoā [Māori traditional medicine], tohunga [experts in various fields], karakia and mirimiri [massage]. I think the nurses know that when it comes to that palliative care time for their patients, that they are there to sit and karakia with them, provide them what they want and to know what it is they want and to understand the process and I think that is where it is, Māori for Māori. (KI Māori manager BoP)

It’s a completely different point of view, and a specific perspective that I’m thinking here ... Dealing with pain, for instance, you are obliged to put up with that pain, because it’s been given to you by God and trying to circumvent that by taking pain relief is trying to circumvent God and therefore we don’t do that. And that’s just something that from a spiritual point of view and a health practical point of view – that’s a very hard concept for us [nurses] to go along with, or even understand. So there you’ve got a spiritual divide. And you’re asking them to understand information from a practical point of view and scientific point of view, and that’s just not where they’re coming from at all. (FG Māori health service BoP)

Whanaungatanga, a Māori process of strengthening relationships, was identified as a foundation for effective communication. Two specific dimensions were discussed. The first was the initial process of becoming known to one another and developing trust, which takes time and underpins the acceptability and cultural safety of service delivery. The second aspect was the nature of the development of an ongoing relationship between the patient and whānau, and health professionals.

We go along and introduce ourselves and talk about them, where they come from, where we come from, so that we can get a trust formed and then we take it from there ... That can be two or three visits before they talk about cancer. (FG Māori health service BoP)

Once you are in with them from the heart you are bonding with them ... it is from heart to heart ... you take into account the protocol. Their practices, need to think about the family in general ... know how we have to live through this with that person and then once you can get that trust, you know, get them to trust you. (FG Māori health service BoP)

Kanohi ki te kanohi (face-to-face) communication, which requires time and effort, was identified as being of particular importance for effective communication with whānau.

It [kanohi ki te kanohi] takes more time, it does take more effort ... but there are better outcomes. It adds more to the quality of the information – it just does. (FG Māori health professionals BoP)

The value of informal whānau knowledge sharing was highlighted. Comments indicated that within whānau information about palliative care is shared, and this has the potential to enhance the value of information and improve palliative care knowledge and experiences.

I can think of a couple of stories or incidences where people have come in and said, ‘Wow, this [hospice service] is much better than I thought it was going to be, I’ll tell the rest of my family now’. Or you can see the wider family coming to us and saying, ‘This is way different. Yes, now that we’ve seen it with our own eyes we can tell the rest of our whānau’ and we get that kind of comment all the time. (FG Hospice BoP)

Palliative care provided ‘by Māori for Māori’ enabled a different level of engagement with patients and whānau. Participants agreed that there was a:

... cultural divide ... care is better managed by Māori for Māori ... So much of what we do is about relationships, and if ... they’ve got the relationship with [Māori], you’ve got that conduit. (KI GP BoP)

Comments indicated that there is a level of comfort and connection that can be achieved within a shared culture that may not be achieved in cross-cultural palliative care relationships. Some participants noted the value of te reo (Māori language) in supporting engagement.

Sometimes you hear, ‘I wish there were more Māori nurses’, ‘I wish there were Māori’ ... for Māori sometimes there’s just a look and it’s an understanding that words cannot say and you just, I don’t know, have that connection. (FG Hospice focus group BoP)

There is something that Māori nurses have for Māori and it is something we find it really difficult to articulate. It is I suppose just an X-factor – it is a cultural thing and our Māori patients feel this too, like they always say to me, where are you from? There is something that non-Māori nurses, they don’t have that X-factor ... it is wonderful to be able to speak Māori to a Māori nurse fluently and they love that. (KI: Māori manager BoP)

There’s a wairua in the reo that you can feel, and even if you’re not conversing in it but looking at two people conversing, you can still feel that. When people feel that, they move because they can feel it. So you can see or hear things, but it’s different when you feel it eh. (FG Māori health professionals BoP)

Whānau connections between providers and recipients of care did, however, at times need to be managed.

For myself as Māori, some [patients] are family and I’ve had to say several times that what’s said between you and I stays here ... And that conversation I have to have quite often ... that’s the other side of Māori. (FG Hospice)

## Summary

Māori entry into palliative care took many forms, from self-referral through to specialist referrals. Some whānau experienced significant difficulties with access to appropriate care. Whānau and health professionals reported that when referrals occurred very late in the illness process, the patients, whānau and service providers did not have time to engage (including becoming comfortable with providers), negotiate health literacy demands, have their needs met (eg, support and equipment), or make arrangements for a preferred death experience.

Reasons for late referrals and/or use included poor access to information about palliative care for patients and their whānau, leading to misconceptions that entering palliative care was synonymous with accepting imminent death, and that hospice might hasten death.

The health literacy demands associated with palliative care were acknowledged to be wide-ranging and complex. Whānau were negotiating the acquisition of new knowledge and skills within a context of shock, grief and loss. Whānau who participated in this study demonstrated a high level of health literacy practices. Those practices included finding and understanding information, navigating the health care system by utilising friends and resource people, and keeping written records of their experiences. Whānau were often faced with complex health care systems and barriers from health professionals and provider organisations, which may have at times undermined the effectiveness of their health literacy practices. Barriers influencing health literacy in palliative care settings included the quality and context of information transmitted by health professionals, cultural considerations including the view of hospice and the Cancer Society as 'Pākehā' organisations, and the lack of a representative workforce.

Many health care professionals demonstrated an understanding of what was required to achieve health literacy and reduce health literacy demands, but there was little evidence of organisations taking a systematic approach to addressing these issues. Health care professionals also experienced systems barriers to improving their health literacy practice.

Health literacy-related facilitators of Māori access to palliative care were identified. The value of advocacy and navigation roles within palliative care services in overcoming some of the health literacy and other access barriers was highlighted. Effective communication with patients and whānau was a critical facilitator. For whānau participants effective communication involved plain speech, respect for the knowledge held by whānau, and culturally competent communication processes. Those processes included putting into practice Māori concepts such as whanaungatanga and kano ki te kano. As well, acknowledging the importance of wairuatanga and the use of 'by Māori for Māori' approaches that involved Māori health professionals and service providers, contributed to effective communication for patients and whānau.

---

# Research findings – Waikato region

This chapter reports on research findings from the Waikato region only.

## Findings from kaumātua interviews

This section presents findings from interviews with kaumātua. The findings are presented according to the four main overlapping themes identified:

- cultural factors
- communication
- responsibilities during the end-of-life journey
- support for whānau.

### Cultural factors

Cultural factors were identified as playing a central role in participants' experiences of palliative care. Key factors were cultural practices related to death and dying, whānau involvement in care and the integration of culture into palliative care.

#### Cultural practices relating to death and dying

Participants identified a number of whānau cultural practices during the process of dying and recognised that quality palliative care involves meeting both medical and spiritual needs.

Sometimes you know it's not just about medicine. You know, it's about the wairua.  
(Miriamā)

Cultural practices identified often involved strengthening interpersonal relationships (including spiritually) between the person dying and whānau members, and between whānau members. There was a strong resolve among whānau to be at the dying person's bedside at all times to support them. Waiata and karakia (prayers or incantations) were identified as key practices that enable the loved one to move onto the next journey and for supporting whānau connections on a spiritual level.

#### Whānau involvement in care

The desire to be close to whānau, marae (customary Māori community centre) and ancestral lands was identified by some participants as reasons why some Māori remain at home and do not use palliative care.

... it's different ... I suppose to having whānau around you. I'd, I'd say my mother probably would just deteriorate if she was in a [hospital]. (Aroha)

Interviewees noted the importance of palliative care clinical settings that are able to physically accommodate whānau.

They [the hospice] cared for us; they encourage us all come; bring all your family in; you can sleep here; we have the beds ... There's the kitchen there ... they attended to us. They were kind, we felt at home. (Mere)

I'd like to see is that the whānau can just go in [to the hospice] and be there and help if they [whānau member] need you. (Mere)

A number of participants discussed tapu (sacredness or restrictions) and associated norms, such as those relating to touching the body, as reasons why palliative care services were not accessed.

He was one of those Māori that only his wife touches his body and the nurses – you know. And this is, I think with our Māori people, you find most of them will be like this, especially our men. (Rongomai)

Like the handling of ... male nurses with our wāhine Māori [Māori women]. And you can see the wāhine Māori are, are not happy with it aye. (Moana)

Comments indicated a need to ensure that palliative care settings are able to accommodate whānau involvement in care.

### **Integration of culture into palliative care**

Participants noted the importance of integrating culture into palliative care, including the value of a culturally skilled Māori palliative care workforce (eg, with Māori language competencies). That is, Māori palliative care workers who are able to work in 'a Māori way' consistent with Māori norms.

If it's real tūturu [authentic] Māori from Ngāti Porou or anyone like that then bring them in. (Raina)

We [Māori] have got different ideas of how the services [should be delivered] ... We do expect them [palliative care workers from Māori providers] to sit down and have a talk before you know. You don't get straight into the business ... You know have a kōrero with them; really sit there and talk with them and look like you really are caring. (Anna)

### **Communication**

Effective communication was identified as a key element of quality palliative care. While palliative care workers have a responsibility to develop the competencies that enable them to communicate effectively with Māori, participants also identified ways in which kaumātua and whānau may contribute to enhancing communication.

### **Palliative care workers' responsibilities**

While many interviewees reported positive experiences of palliative care, some participants described low levels of cultural competence and racism.

For me I think the palliative nurses need training on how to deal with our people because they are not user-friendly ... they need education with how to work with Māori people when they are sick. (Pare)

I've found the foreign nurses are better to work with. They can relate to us whereas our own tauiwī [New Zealanders of European extraction] they don't know how to relate to us. (Pare)

You're a Māori, you're ... over 60, you're overweight ... they're not interested. (Hiria)

Kaumātua valued professional support as central to quality palliative care. Interviewees referred to important types of professional support that could only be provided by palliative care workers, as opposed to whānau. This included providing medication and medical care and supporting whānau to develop knowledge and skills required to care for loved ones at home. Provision of services in a caring and compassionate manner was also considered very important.

Provision of clear, honest and timely information to reduce uncertainty and enable whānau to care for their dying loved one was very important to kaumātua.

... no one will tell you the truth. No one will say 'Yup, we know he's dying. We can't give you how long. But we know he's on his ... way out'. (Hiria)

And they [palliative care workers] came in the short time as soon as the doctor rang, they were straight up the hospital. They were there to explain what they [were] there for and what the service is all about; and so if we needed help to liaise with what's going to happen with our mother before we took her home. So we had a quick fast talk with them and they got things moving ... In that short time we just couldn't get over how much they had done and [provided] a lot of information. (Ana)

At the same time, while participants did not want to be protected from the truth, they recognised the uncertainties surrounding how long a person may live and wanted information to be communicated to them in a way that enabled them to maintain hope.

Kaumātua expected that the rights and choices of patients would be respected by palliative care workers. Interviewees related positive experiences of being given options and having their decisions respected. However, some interviewees related negative experiences of poor communication and where basic rights were not respected.

We used to think that she was playing up, all the time because we didn't have the information ... It wasn't till after she was gone a few days that we realised [she was having hallucinations in her last days., 'Oh my goodness mum what did we do ...' I understood that we didn't understand 'cause we didn't get that information from the service providers. (Anna)

She was early eighties, but she couldn't see and she couldn't hear ... [they] were gonna operate on her arm. So they starved her all day left her in [the] corner ... Three days in a row they starved her till eight o'clock at night ... So we had the big haka [confrontation] ... everyone ignored her again, the nursing staff ignored her. (Hiria)

Overall, interviewees indicated that palliative care workers need to be culturally competent, provide support in a caring manner, provide clear information that reduces uncertainty and leaves room for hope, and respect the rights and choices of patients and whānau.

## **Kaumātua and whānau**

Some participants identified ways in which kaumātua and whānau may support enhanced communication and more responsive provision by palliative care workers, including through ‘teaching’ workers about Māori culture (eg, through providing advice or making formal solutions-focused complaints).

Like us teaching them don’t sit on the table that’s where we have a kai. (Mere)

Some interviewees considered it important that kaumātua and whānau are assertive in order to ensure they get the information they require and receive care that meets their preferences and expectations.

When we had this big meeting and [we] ... asked them what kind of cancer he had and they wouldn’t [tell]. It was a big fight to get the name of it .... he worked at the wharf. What’s that cancer they get ... it’s [from] some ceiling cement. We thought that had caused it. (Hiria)

Kaumātua noted that, even though it may not come naturally, it is important to ask for help from palliative care professionals.

I think that we as a whānau [many Māori] ... we think of ourselves first to do it [provide care] instead of asking outside the family. (Kei)

These comments reflect kaumātua experiences of low levels of cultural competence among palliative care workers and a desire for high quality services that meet their needs. This is primarily a responsibility of funders and providers of palliative care, as opposed to kaumātua and whānau receiving palliative care. Kaumātua and whānau may, however, encourage culturally competent practices when this does not place an additional burden on them.

## **Responsibilities during the end-of-life journey**

Three key themes were identified regarding the responsibilities and challenges faced by whānau in supporting the end-of-life journey: balancing tino rangatiratanga (autonomy) and tino whanaungatanga (connection), demands of providing care, and maintaining relationships with whānau.

### **Balancing tino rangatiratanga and tino whanaungatanga**

There are challenges in managing the tensions between the competing values of tino rangatiratanga (maintaining the autonomy and self-determination of recipients of palliative care) and tino whanaungatanga (the desire for a deeply connected supportive relationship with whānau).

Interviewees noted that dying kaumātua desire love, support and connection with their whānau while at the same time wanting to maintain their tino rangatiratanga and mana (power and authority).

One participant reflected on how his father had been the head of the family for a long time and was always respected and listened to. However, when he was dying he was being told what to do and not being allowed to do things for himself. He therefore lost his tino rangatiratanga and his mana was diminished.

Yeah don’t take away my rights and as long as we still got it up here [have intellectual capacity]. (Mere)

Another participant expressed an expectation that as a whānau carer she would be kept informed of her family member's condition by health professionals.

As a family member who's looking after my, my tūroro, my patient. I would like to have been told that prior to the patient being told. Sometimes the patients tell the doctors, 'Don't tell your whānau'. (Moana)

Advance planning, which may be as simple as a conversation expressing preferences for care or completing a power of attorney, helps to address these tensions if there is a later need for palliative care.

The idea would be to have the conversation [about palliative care] openly with your children. Now have your conversation with your children now and include your mokopuna [grandchildren]. (Hine)

### **Demands of providing care**

Participants noted that individuals receiving palliative care did not want to burden whānau, whereas whānau wanted to help their loved one and fulfil their responsibility to provide care (including emotional support).

I went through that quite a few times at night; I looked after him because he had to go to the bathroom a lot. He had a bag and I said anytime you want to get up you wake me up he says, 'But I don't like it [waking you] dear'. That's when I would hear him; he would get up with his bag and then he would be pretty slow and I could hear him walking to the bathroom. (Roimata)

Participants described emotional challenges for both the dying and their whānau. One participant talked about caring for her husband, whose emotional state changed during the end-of-life journey. However, she was happy to accommodate his emotional states as he had been a good husband throughout their life together.

Because he couldn't remember anything and that was it. I had to be careful sometimes [because he would get angry], and he was loving and caring at other times, you know he was one fellow and then he was the other one. (Roimata)

Participants, particularly women, discussed the substantial demands of providing care and putting the needs of the dying person above their own. However, they did not consider this to be a burden.

And because she was who she was, the place became invaded with visitors and because she was so involved with Māori Women's Welfare League and all of those other things, people kept coming. My whole time was to keep the house turning over and seeing to her needs. (Hine)

'Cause that's your, it's your whānau, you just do it aye. (Kei)

However, providing care was particularly demanding for those who did not have support or felt culturally isolated.

... that time it was hard for me. I had to look after her and go to work and during the lunch break I had to run back home give her something to eat and run back to work and keep in contact with her ... So it was tough going those years. (Hemi)

He was diagnosed with having um cancer in the stomach lining, and um for about three months all I did was cry. What am I gonna do? Where am I gonna go to? Because I was in a Pākehā environment; there's no help for, for me anywhere. (Rongomai)

Comments indicated that low health literacy at times leads to whānau shouldering extra responsibilities and financial burdens.

If I only knew two years before that it was only after I had put in a new shower block for the housing. I had to pay \$1500 to have it fit in and I didn't tell my doctor about it. And he only just found out about it and he said, 'Oh, I could have got that done for you for nothing'. And we didn't realise there was stuff that we could get her to awahi [care for] her. So if we had been educated on, on what facilities could've been used to awahi her. It would've made it so much easier for us. (Hemi)

### **Maintaining relationships**

During the palliative care period whānau spend a lot of time together and may reconnect as whānau, even when previously relationships may have been strained. At the same time, however, there may be challenges in maintaining positive whānau relationships when conflicts arise regarding or during the end-of-life journey. Participants referred to conflicts as a result of unresolved anger and frustration that had built up over time, for example, in relation to decisions that had been made or a sense of exclusion.

We get built up with all sorts of things and so we start lashing out at each other and that happened to our family it wasn't good ... Well we ended up in a big row like nearly a fist fight. (Mere)

And I've always looked at myself why didn't I do something when she was going through all of that. If I had thought about it earlier on or a year before – you know, changing our doctor ... my kids even said that 'It's your fault'. (Hemi)

### **Support for whānau**

The participants identified the need for emotional support from within the whānau, from health care workers, and from employers and community organisations.

Participants noted that often forgotten in the end-of-life journey are the emotional support needs of whānau and the effort required to maintain positive whānau relationships. It is important for whānau to address their own emotional needs, especially given the tendency to focus on others during the end-of-life journey. The ongoing need for support for whānau after the death of a loved one was also noted.

It's wrong to assume that when the eyes are closed that it's finished. And I would love to see ... that somewhere is the ability to sit like this and then be able to take out or share out those feelings that have been building up. It's okay. It's all right to feel like that. (Hine)

Participants reported that the best health care workers are those who can deliver care that is inclusive of emotional support.

The kids said to him [doctor], 'Oh it's Dad's fault'. And he was really very angry and he turned around and he called all the kids together. And he said 'Don't you kids blame your dad on what's happened'. ... He rang me two days after and said, 'I want to see you if it's possible'. ... He came to counsel me and he said. 'Don't you ever blame yourself'. That was the best thing. (Hemi)

Community organisations were identified as an important source of emotional support and also practical support, such as assisting whānau to navigate palliative care pathways.

[a community organisation] is where I can come and tangi [mourn, weep] and share my journey and know that I'm safe ... We need special people to have that empathy to share that kind of feeling with. (Hine)

... every Tuesday, from 9 'til 10, they [community organisation] would come in. A whole group of them would come in and waiata to him. (Miriama)

Participants also referred to support provided by their employers through paid or unpaid leave to provide care for their loved one.

I was lucky that the company that I was working for allowed me to go to the hospital with full pay just to look after her so I was lucky in that sense. (Hemi)

## Summary of findings as they relate to health literacy

Table 5 below makes explicit links between the themes derived from interviews with kaumātua and health literacy.

**Table 5: Kaumātua interview themes and health literacy**

Theme	Subtheme	Examples of areas of health literacy (HL)	Description
Cultural factors	Practices relating to death and dying	Kaumātua and whānau cultural factors	Cultural practices that reinforce whānau connections and spirituality provide insight into what is important at the end of life.
	Whānau involvement in care	Workers' cultural factors	Palliative care settings able to accommodate whānau involvement in care, including in terms of physical space and workforce cultural competence.
	Integration of culture into palliative care	Workers' cultural factors	Capacity to accommodate Māori cultural preferences. Culturally competent Māori workers facilitate service access.
Communication	Palliative care workers responsibilities	Workers' technical and cultural factors	Workers are culturally competent, caring, provide clear information, and respect whānau rights and decisions.
	Kaumātua and whānau	Kaumātua and whānau interactive HL	Where able, kaumātua and whānau may encourage the cultural competence of workers.
Responsibilities during the end-of-life journey	Tino rangatiratanga and tino whanaungatanga	Kaumātua and whānau interactive HL	Balancing the need to maintain kaumātua mana and self-determination, and connection with whānau.
	Demands of care	Workers' interactive HL	Recognition that provision of care is demanding for whānau.
	Maintaining whānau relationships	Whānau interactive HL	Whānau need to negotiate the tensions that occur among whānau members during the end-of-life journey (eg, managing conflict).
Support for whānau	Emotional and other support from whānau, workers, community organisations, and employers	Whānau interactive HL, Workers' interactive HL, Organisations' interactive HL and cultural factors	Whānau need to access emotional and/or other support from the wider whānau, palliative care workers, community organisations and employers. These parties in turn are a critical source of support.

# Findings from whānau hui

This section presents findings from the five hui with whānau in the Waikato region. The findings are presented according to the four overlapping key themes that emerged:

- cultural factors
- whānau involvement in care
- communication and relationships with providers
- knowledge transfer.

## Cultural factors

Cultural factors highlighted in focus group discussions were spirituality and specifically the role of karakia and waiata, and providing space for tikanga and whānau functioning.

### Spirituality and the role of karakia and waiata

Whānau talked freely about the last days and hours spent with a dying whānau member or friend as a spiritual experience. They specifically discussed the importance of waiata and karakia (prayer and incantation) in managing pain and facilitating the dying person's spiritual journey.

Waiata served a spiritual purpose for the dying person and for their whānau and other support people. Waiata were uplifting and emotionally supportive, and spiritually enriching. Some whānau described how the dying person preferred to rely on waiata for pain management rather than medication; they wanted to be present and lucid with their whānau during their last days and hours.

Karakia were used in whānau care for the dying, particularly when close to death, to protect the person on their journey to the next world and to connect them to ancestors. The connections between the material and spiritual worlds have great significance to Māori and are normalised.

When you go up to the hospital you are constantly praying, because you know there are people there, his tūpuna [ancestors] are coming to get him. (Wahine)

It is important for palliative care workers to recognise and work with Māori understandings and expressions of spirituality.

### Providing space for tikanga Māori and whānau functioning

In one focus group, tikanga (cultural protocols) and meanings of whānau were discussed.

Tikanga was discussed in terms of its meaning in varied situations, and how different tikanga relate to one another. The group talked about the ways in which iwi, churches and other organisations influence expectations and practices, and also how individuals had a say in what happened to them as they were dying and after death. These issues impact on whānau roles and responsibilities and have implications for palliative care services.

Participants noted that palliative care organisations have their own protocols which are different from tikanga Māori (Māori protocols). Further, that it is necessary for whānau to be proactive and take the lead if they want tikanga integrated into the care of their loved ones.

... you can't change that tikanga up there [at the hospital] because it is not ours. You can take the tikanga with you, but you are explaining it from the offset that this is what we want to do. This is how we want to provide care for our loved one and usually they will adhere to your wishes. (Wahine)

Participants discussed the importance of respecting the requests of the dying person, even in situations where their wishes may not be consistent with tikanga Māori.

The concept of whānau was explicitly discussed within the focus groups. Kin connections were noted as especially significant, but other relationships were also important. In some groups, whānau was taken to mean those with close and immediate relationships, but in others whānau included broader networks of support, such as church or kaumātua groups. A distinction was made between whānau as a broad support network and immediate whānau who need to be kept informed about care.

Should the whānau know? Of course ... When we talk about whānau with loved ones in hospital, we are talking about immediate, not second cousins or somebody down the line. (Tane)

Whānau is a big, huge world. It's not just our immediate whānau. Um today it's [community organisations] – becomes part of my dad's whānau because he [goes there] and does all these activities on a Friday. So our little whānau's expanded to that and then again, it's like the hospital, the hospice and our extended whānau. (Wahine)

The challenge is for workers to consider what can be done in the clinical setting in particular to enable whānau to function as a support network and integrate tikanga into care. Palliative care workers need to be able to not only accept Māori worldviews but to also make 'cultural space' for kaumātua and their whānau to fulfil their cultural obligations.

## **Whānau involvement in care**

The right of whānau to actively participate in caring for their dying kin was emphasised, including the involvement of younger whānau members (eg, mokopuna/rangatahi). It was noted that people should be enabled to choose the ways in which they will be cared for physically, culturally and spiritually. Hui participants expressed their desire to provide most care, but with support (when requested) from palliative care workers. While home care was favoured, when it was not possible, whānau wanted to be involved with care in hospice or hospital settings. The following subsections discuss enablers and barriers to whānau involvement in palliative care.

### **Enablers of whānau involvement in care**

Two multifaceted enablers of whānau involvement in care were identified by hui participants: mahitahi (coordination) and tautoko (advocacy).

Two dimensions of mahitahi were discussed: coordination within whānau and coordination between whānau and palliative care workers. Hui participants discussed coordination strategies they had employed to facilitate communication within the whānau such as holding regular whānau meetings and using communication books so that everyone had the opportunity to be kept up to date.

We kept a diary, a journal through all our whānau things, day-to-day on the minute sort of thing. Any medication, anything that was done is in the book. We still have those books today and we still do those things. (Tane)

Some whānau set up systems to coordinate sharing tasks within the whānau, such as a roster, and to best draw on the strengths of individual whānau members.

We had a roster that had about ... fifteen of us that included the brothers and sisters, our children and some of our in-laws ... every time a new person came on, that book was there for that person to read up on. (Wahine)

Close relationships with providers enabled whānau to access services and resources and coordinate provider and whānau contributions to providing care. Hui participants highlighted the positive outcomes for whānau and the person being cared for as a result of coordination.

The transition from hospital to home [pause] well there were really good things put in place before she came out ... we had to adjust some things and we had to get things that she could hold on to ... pull herself with up with ... there is a whole list of things that I wouldn't've even known. (Wahine)

Tautoko as described by participants, included advocacy to access services and resources as well as emotional, spiritual and cultural support. That advocacy may come from palliative care and other organisations as well as from members of the wider whānau. The following comments highlight various aspects of tautoko that are linked to dimensions of health literacy – interactive health literacy, technical health literacy and cultural competency respectively.

If the whānau weren't up to Pākehā language, you needed an advocate; somebody from the family who could carry the weight of the kōrero [the talk] who could understand the kōrero and could share the kōrero. (Wahine)

[The nurse from this agency] has got direct links and she's wonderful ... she doesn't give up she is like a pit-bull: 'I'm going to talk to somebody about this and they're going to give me an answer'. She becomes the advocate; she's like between the whānau and hospital – those tertiary services. (Wahine)

When you are going through a palliative care type scenario for people who are close to their death, somebody who is not immediate whānau, but somebody is there to help the whānau to look after your loved one as well. Just so you are able to answer those questions or ask those questions. (Wahine)

It was apparent from hui discussions that those whānau who had interactive health literacy (eg, knowledge of palliative care and equipment) and networks (eg, other agencies, advocacy services, whānau connections) were better able to navigate the system and access resources and services. The advantages of learning about palliative care before it is needed were also expressed.

The findings in this section suggest that whānau with interactive health literacy skills and culturally competent palliative care workers are able to work well together. Further, the support of an advocate helps whānau to navigate the palliative care pathways in order to get care that meets their needs.

### **Barriers to whānau involvement in care**

Barriers to whānau involvement in palliative care were identified within the whānau and within the palliative care service, particularly regarding whānau and palliative care workers' expectations of one another's roles.

Within whānau, the most common barrier related to access to information. That is, not knowing how to ask for help (eg who to ask for help and what to ask for) or a reluctance to ask for help which may result in stress and feeling overwhelmed.

We think we can do it all ourselves. And so we go away and we do all these things ourselves then next minute we're like pulling our hair out because we're stressed and we don't have enough time to go and spend with our own families ... we've taken on that whole work load ourselves ... We need to get that help. (Wahine)

Participants also expressed concern that information and services were not readily forthcoming, and whānau needed to be assertive in order to access information and care.

But it was frustrating that you always had to ask the doctors and the nurses. That they would not come and say to you, 'We have this service for you if that is what you would like done'. (Wahine)

I had to go to the nursing staff and say, 'You need to come and explain to us what's happening'. So, I think they just need reminding. It's not that they – you know, don't want the family to know. It's just they are not aware that this person is not capable of passing the message on, so to speak. (Wahine)

Another more commonly identified concern was that clinical staff did not listen to whānau wishes to provide care for their family member. This was a barrier not only to whānau involvement in providing care, but also to kaumātua receiving the best quality care.

... we wanted to do that [provide personal care] wait on her 24 hours but they [clinical staff] wouldn't let us and there was only one nurse [who was helpful] and she was a night nurse, only one nurse who had done palliative care prior to working in the hospital. (Wahine)

Discussions in focus groups highlighted differing expectations between palliative care workers and whānau as to who will provide care and how whānau roles in the care process may be accommodated in palliative care settings. This highlights the need for higher levels of interactive and cultural competency within palliative care organisations and systems.

## **Communication and relationships with providers**

Participants identified a role for whānau in facilitating communication between the individual receiving palliative care and clinicians. They also identified the importance of kaumātua and whānau building relationships with palliative care and other support services prior to the need for palliative care.

### **Whānau as facilitators of kaumātua–clinician communication**

In order to maintain their dignity and mana throughout the palliative care process, those receiving care and their whānau need to understand palliative care information. Hui participants expressed a need to understand what was happening in terms of palliative care so that they could provide explanations to kaumātua receiving care and other whānau members. Participants indicated that it is important that whānau are present when kaumātua receive information about their care, so that whānau as support people are kept informed and are able to help kaumātua to understand information.

But when they talk to the Pākehā, it's like ... the wording and everything is ... quite difficult for them [kaumātua]. So if they didn't understand, we were there to get them through that. (Wahine)

When my mother got diagnosed, the whole lot of us went to every single appointment that she had. And from that, we got explained in detail what was the process, what was gonna happen, how it was gonna work and what facilities were available ... And we wouldn't leave until they [parents] knew exactly what was happening. (Wahine)

At the same time, they emphasised the role of whānau in supporting kaumātua to maintain their tino rangatiratanga, to respect their right to be included in all discussions and make decisions. They noted the balance required between kaumātua and whānau needs and respect for kaumātua during any communication.

### **Relationships with providers**

Several participants mentioned the value of familiar and long-standing relationships with community organisations (other than palliative care providers). The trust within existing relationships enabled community organisations to provide support and enhance understandings of the palliative care process during an uncertain and stressful period.

‘Cause like, they [kaumātua] don’t like being changed around; gotta go here for this, gotta go here for that. So they’re already getting that support here [through a community organisation] in a lot of other avenues. You know is it something that we may need to look at going into the future? Having that care provided [by a community rōpū whakahaere [coordinating group]] because you’ve already got that relationship. (Wahine)

... they [community organisation] could see what was going on around me that yeah ‘cause I was too focused and shocked and disbelieved, so it was good to hear them say things ‘cause I believed what they said – I didn’t quite believe what the nurse said – ‘cause they were people I knew and were familiar with. (Wahine)

Whānau highlighted the need for flexibility to use community services with whom kaumātua already have existing relationships and the value of kaumātua building relationships with palliative care services before they are required.

... if you sort of introduce them [palliative care services] a lot earlier and have that building of the relationship and ... [kaumātua] feeling confident with them. I think it would have been fine when the time came to using [palliative care services]. (Wahine)

### **Knowledge transfer**

The theme of knowledge transfer is concerned with how palliative care learnings can be shared within and between whānau in order to improve future palliative care experiences.

As previously discussed in relation to mahitahi strategies, whānau learning may involve sharing care experiences at the time through whānau meetings and use of communication books. There may also be opportunities to learn as a whānau through reflecting on palliative care experiences.

We all meet again, all congregate, the whole family. We turn up at the person’s house, that had passed away, and then we sit and we reminisce ... The good and the bad, things that have happened, this thing happened right through and everybody’s learning together. (Wahine)

Learnings may be used to inform whānau planning for potential future palliative care needs.

I’ve got things in place because when my husband died, everything was left on me and my two children ... I told them [my children] what I wanted, where I want to go, how I want to go up there, so there’s nothing left for them. I’ve got a fund that they can access; get their hands on it within 48 hours. (Wahine)

But maybe next time, we need to be a bit more smarter and not just help for the care of our dad but help for the care of ourselves. [If] we don’t care about ourselves, then we’re not gonna give the care to our dad. (Wahine)

Learnings were also shared with wider whānau experiencing palliative care.

Because we've been through that journey we're also helping our own whānau. Last year ... a nephew got sick. He was in palliative care, his wife looked after him [and] we were there to support them. (Wahine)

Comments also indicated an awareness of the value of experiential learning for younger generations in order to prepare them for their future role in providing palliative care.

One day when I get old, I would like my children to care for me because I know that when it's time for my mum to go, I want to step up as well. So I think that is a very intricate part of being Māori, is allowing your children to be around that so that they can learn. They cannot understand why, when they see their grandfather in hospital and have been told by the doctors in the hospital that they are going to get better when in reality they're not ... You don't understand straight off, but as you embrace that, you begin to acknowledge and accept that it is just part of our culture. (Wahine)

## Summary of findings as they relate to health literacy

Table 6 below makes explicit the links between the themes derived from whānau hui and health literacy.

**Table 6: Whānau hui themes and health literacy**

Theme	Subtheme	Examples of areas of health literacy (HL)	Description
Cultural factors	Spirituality, role of karakia and waiata Tikanga and whānau functioning	Palliative care workers' cultural competency	Culturally competent palliative care workers who accept Māori worldviews and make space for the expression of cultural beliefs and values within palliative care settings. This includes the integration of tikanga into care and enabling whānau to function as a network of support.
Whānau involvement in care	Enablers – mahitahi (coordination) and tautoko (advocacy)	Interactive HL Workers' cultural competency	Culturally competent workers support whānau to improve their internal communication, coordinate whānau care tasks and use whānau strengths in providing care. Whānau use advocates in navigating palliative care pathways.
	Barriers – access to information, differing expectations	Whānau functional, technical and interactive HL Workers' interactive HL and cultural competency	Advocacy for kaumātua and whānau offered when workers lack cultural competence skills, or when kaumātua and whānau lack the confidence, or the functional/technical/interactive health literacy skills to navigate the system.
Whānau communication and relationships with providers	Whānau facilitate communication	Whānau technical and interactive HL Workers' interactive HL and cultural competency	Whānau keep informed and help kaumātua understand information. Workers help whānau understand information, processes and practices and their implications.
	Building relationships prior to need	Whānau interactive and political HL	Whānau build knowledge of palliative care and relationships with support agencies and palliative care services before the need arises.
Knowledge transfer		Whānau functional, technical and interactive HL	Palliative care knowledge transfer within and between whānau. This includes an intergenerational dimension with purposeful sharing of learnings with younger generations to build future capacity.

# Findings from focus groups with palliative care workers

This section presents findings from three focus groups with palliative care workers in the Waikato region. The findings are presented according to the four overlapping key themes that emerged:

- cultural factors
- engaging whānau
- communication
- coordinating care.

## Cultural factors

According to palliative care workers, culture is an important factor in providing services to kaumātua and whānau. Three main cultural factors relating to providing care for kaumātua and whānau were identified through focus groups: cultural competency<sup>2</sup> of palliative care workers, provision of navigation support for whānau by Māori staff community members and avoiding over-generalisation.

### Cultural competency of palliative care workers

Some participants expressed concerns at their own low levels of cultural competence and wanted to know more about Māori culture and what they could do better to meet the needs of Māori.

... I've struggled with in the past is what do Māori want from us? ... And I know I have approached the Māori management team ... and all that was forthcoming was the tikanga booklet which gives me some general perspective but doesn't sort of help me understand what Māori would like when they're looking at the journey of end-of-life care. What's specific to them? What would be important? Like I know a Catholic might want their last rites or they might want communion or a blessing or something like that. What do Māori want? I don't know. (Hospital)

Some participants noted that in clinical settings care was not always culturally appropriate and consistent with tikanga.

You know like I've gone to see them and there's a urinal sitting on their tray where there food is. (Community)

They've got feet on their pillows to elevate their feet. (Community)

According to participants, the expression of cultural sensitivity is important in the provision of quality palliative care for kaumātua. This includes respect for culture, effective cross-cultural communication and working in partnership with Māori. Working in a respectful way may include correct pronunciation of Māori names, being non-judgemental with regard to Māori use of tohunga or rongoā (traditional Māori medicines), following basic Māori protocols (removing shoes when entering Māori homes where appropriate), understanding and allowing for Māori beliefs such as in relation to tapu, and negotiating acceptable compromises between cultural preferences and what services may offer.

<sup>2</sup> The term 'cultural literacy' was used in the original Waikato research report but is not a commonly used term. The Ministry of Health views what was described as cultural literacy as 'cultural competency'. Cultural competency is a commonly used term in the sector.

Some [patients] will say ‘I’m using some Māori traditional medicine as well’ or ‘I’m going to see a Māori spiritualist’ or something like that. There’s no stigmatisation on our side. That’s fine for that to happen in conjunction to what we offer. And to make them feel comfortable that that’s acceptable to us. (Hospital)

According to participants, palliative care may be a good option for kaumātua when it is delivered in a culturally competent way, and all palliative care workers (particularly community workers) endorsed the need to increase cultural competence among the workforce. This not only requires cultural competence training for the palliative care workforce, but that workers must put those learnings into practice in palliative care settings.

### **Provision of navigation support for whānau by Māori staff and community members**

Māori health care workers and Māori community members may provide a source of expertise in relation to, for example, tikanga and the ability to interpret and express Māori values (eg, aroha [love], manaakitanga [caring] and kotahitanga [unity]) in palliative care settings. This type of cultural support was identified as important in enabling palliative care workers to meet the cultural needs of kaumātua and whānau.

Cultural liaisons have varied levels of involvement and roles in palliative care settings, such as advocacy in hospitals and the provision of cultural support and training for hospice clinicians. Participants described experiences of practical support provided by cultural liaisons.

So we talked about [whānau] coming and finding out what support there was. And I said [palliative care worker to whānau member] if there are any other siblings or anybody else, ‘You’re very welcome too’. And a couple of days later she rang up and she said, ‘We would like to come’. And I said, ‘How many, so I can put the jug on’ ... and she said, ‘There will be about 21 of us’. How do I do that? ... I don’t know what to do. So we got a hold of [the kaumātua we work with] and he came with me when the family came, so that he could do the proper welcome and everything. And afterwards, he did the debrief with me as to the good and the bad, because I didn’t get it all. Because I didn’t realise they wanted me to tell the whole family that he was going to die. Which was really quite hard, you know, when you’re not prepared for that. (Hospice)

### **Avoiding over-generalisation**

Finally, most participants cautioned against overgeneralising to all Māori, as Māori are not a homogenous group. They recommended respecting and supporting cultural practices but not assuming that all Māori want the same thing or have the same perspectives, preferences and needs.

### **Engaging whānau**

Engagement with whānau in the palliative care process is of critical importance.

I think what distinguishes the Māori from the general patients that we see are their large families and the need for their families, the whānau, to be involved. (Hospital)

... bringing the family in and having the family participate in that journey with you ... (Community)

Participants expressed their desire to help patients and whānau maintain control, reach the best decisions about palliative care given their own unique situations and have their particular needs met.

I think it's about meeting families where they are [group in agreement]. We are going into their lives ... making sure they've still got some control. But each family we visit, it's about assessing what they want and what they need, isn't it? Not what we might think they need. (Hospice)

The importance of palliative care services having physical space to facilitate whānau engagement was noted, such as accommodation for whānau at hospices. Participants commented that in engaging with whānau there are limits, particularly where very large whānau were involved, such as the numbers who are able to stay at a hospice. They also highlighted the value of a spokesperson as the main point of contact for workers.

I had to say to them we need to elect a spokesperson because what was happening was all the whānau members were like, 'Oh no, we're going to do this and we're going to do that' ... So it was really about putting those strategies into place for the family. (Community)

## **Communication**

Effective communication was identified as the key to enabling kaumātua and whānau to effectively navigate the palliative care decision-making process and services. Core elements of good communication identified by participants were building relationships, listening and working collaboratively with the patient and whānau to meet their needs, and addressing functional health literacy.

### **Building relationships**

Participants emphasised the importance of whakawhanaungatanga, or building relationships with kaumātua and whānau. Further, that those relationships are best built through taking time, not rushing and communicating in respectful ways. Relationships should also be built with Māori community organisations that work with and support kaumātua and whānau to facilitate broad support and access to palliative care.

We get a lot of referrals, the Palliative Care team do, directly from the iwi health team kaimahi because we have worked hard to build those relationships with them. (Community)

Relationship boundaries can become blurred over time when palliative care workers, in particular Māori community health workers, become part of the close support network for kaumātua who may not have whānau nearby.

### **Listening and working collaboratively**

Participants noted the importance of listening carefully to patients and whānau to understand their needs and then working with them to determine the best course of action. Participants explained that they need to work hard to make sure they understand patients' true wishes, and sometimes listening includes further exploring issues to ensure that needs are being addressed. As well, participants indicated that listening also includes being aware of non-verbal cues, as patients and whānau do not always express their views or needs directly.

Palliative care workers have a support role but ultimately patients and whānau should maintain control and make the decisions about their care, including whether or not to use palliative care services. However, patients and whānau are not always aware of how to 'lead' decision-making about palliative care, and workers may need to ask questions and provide some direction. Patient and whānau decisions should be respected by palliative care workers.

## **Addressing functional health literacy**

Community health workers explained that functional health literacy is key to providing quality services and yet many kaumātua and whānau do not understand basic palliative care information (eg, terminology or service options).

... there are some Māori families coming here that have said that they haven't heard much about hospice and they are very surprised that hospice existed. (Hospice)

Hospital participants commented that some Māori patients and whānau were not aware of the specific services they offer and which services would best cater to their needs. As well, there are misconceptions about medical services, for example concerning medication like morphine and antipsychotics.

The participants noted that they need to use clear and simple language, have information on who to contact for palliative care (including after hours), and provide information resources that are appropriate for whānau. Community health workers also noted that they are able to serve as advocates for kaumātua to improve health literacy. Comments indicated that this is necessary as kaumātua are often reluctant to share their concerns as they do not want to cause inconvenience.

Asking questions and offering information was identified as a way for palliative care workers to help kaumātua and whānau to increase functional health literacy. One participant noted the value of palliative care workers providing information to kaumātua through hui and prior to needing palliative care.

## **Coordinating care**

The nature of palliative care means that all participants work with other palliative care workers, such as district nurses and general practitioners, and provider organisations in the delivery of coordinated services. By the time patients and whānau enter palliative care they have already engaged with other providers and built relationships.

Comments indicated that there is potential for improved communication and collaboration between services, and better use of existing resources.

Community health workers provide psychosocial support and coordinate with hospice and hospital services to facilitate access for kaumātua to the full spectrum of palliative care services. They indicated that at times they step outside their roles to provide support where there are gaps in service provision to meet basic needs, such as cleaning and shopping.

Some community health workers expressed frustration at the under-resourcing of their services and that they are not always treated as equal partners in the coordination and provision of palliative care. Several discussed experiences where they felt diminished either because they did not have a clinical background or because they were Māori.

... I've worked ... in a so-called team of professionals, clinical professionals. But because I wasn't qualified in a clinical context there was no way that I could be a part of both my ... team let alone be accepted as I interfaced with different services. I just simply felt I just wasn't taken seriously enough. Just 'so-and-so' helping out 'Aunty what's-her-name today' ... And I experienced that for two years. (Community)

... I know a lot of qualified Māori that are still not accepted as professionals yet they have the qualification. So there's only one common denominator I can see and again, it comes back to colour of your skin ... (Community)

These participants felt that their contributions were not valued by colleagues to the same extent as those of medical professionals, and this undermined teamwork in the provision of care.

Coordinating care at times involves challenging other agencies and the status quo.

I think sometimes that the hospital, some of the departments, make the decision that a patient is going to go into a rest home. But it's not discussed with the whānau and the patient themselves and we often go in there and need to speak to the people involved and work it through ... 'in the home situation this is what's needed' or what can be provided and ultimately it becomes a choice [for patients and whānau]. (Hospital)

## Summary of findings as they relate to health literacy

Table 7 below provides a summary of the themes that emerged from the data, and examples of how they relate to health literacy.

**Table 7: Palliative care worker focus group themes and health literacy**

Theme	Subtheme	Examples of areas of health literacy (HL)	Description
Cultural factors	Low cultural competence Interest in learning	Workers' cultural competency	Interest in developing cultural competence to better meet Māori needs. Expression of cultural competence through respect for tikanga, effective cross-cultural communication and working in partnership with Māori.
	Cultural liaisons	Workers' cultural competency	Value of cultural liaisons in improving service delivery through direct support and training for workers.
	Avoid over-generalisation	Workers' interactive HL	Communication to identify the specific needs of kaumātua and whānau rather than stereotyping.
Engage whānau		Workers' interactive HL and cultural competency	Effective engagement with whānau to provide quality care.
Communication	Building relationships	Workers' interactive HL	Take time to build trust. Also build relationships with Māori community organisations. Community health workers provide emotional support.
	Listening and collaborating	Workers' interactive HL	Using communication skills and working collaboratively to meet the needs of kaumātua and whānau. Respect their decisions.
	Addressing functional HL	Community workers' technical and political HL	Use simple language and provide appropriate information resources including key contacts. Community workers as advocates to support health literacy.
Coordinating care		Interactive HL between workers Workers' political HL	Work together to meet the needs of kaumātua and whānau, and respect the role of community health workers. Challenge the status quo if necessary in order to meet needs.

---

# Findings from analysis of palliative care written resources

Both projects undertook an analysis of palliative care written resources to investigate the capacity of those resources to convey messages to Māori patients and their whānau, and the findings are combined in this chapter. The analysis carried out by the Waikato research team placed particular emphasis on the effectiveness of written resources for kaumātua. Overall findings are grouped according to dimensions of health literacy (functional, technical and cultural) and how the value of written resources may be maximised.

## Functional and technical health literacy

The first group of findings centred on functional and technical health literacy in terms of the accessibility of written material. Overall, both research projects found that a number of factors combined to reduce the accessibility of information contained in written resources. Factors identified in the projects included:

- readability levels (high scores indicating documents were hard to read)
- mixed writing styles and the use of formal language and structures
- difficult vocabulary, including unexplained medical and other terms that assumed reader knowledge
- large blocks of text and lack of white space
- the mixed use of relational devices such as personal pronouns.

The Auckland and Bay of Plenty report noted that some resources had good headings and subheadings which assisted in navigating the text to find particular information.

The recommended average length for a sentence is 15 to 20 words, with anything longer having no more than three pieces of information (Plain English Campaign 2001). The Waikato report found that writing styles ranged widely from some using short active sentences to others using complex, wordy sentences and paragraphs. An extremely poor example was a 72-word sentence that referred to five topics and four organisations, as well as contractual relationships. The complexity was a barrier to comprehension. In contrast, some brochures were able to tackle difficult topics, such as morphine and medication, using short, active sentences that were easy to read and understand.

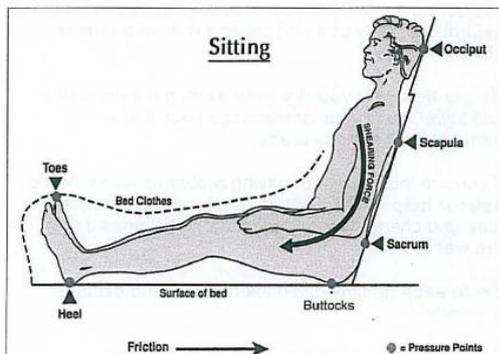
Both research reports identified the use of medical and technical terms in a way that assumed reader understanding of palliative care and related services. A number of terms such as complementary therapies, psychosocial, terminal patients and respiratory, were used without explanation. The Waikato report gave examples of terms such as subcutaneous, cardiopulmonary resuscitation and intravenous being explained in some brochures but not others. The Auckland and Bay of Plenty report identified terms that were conceptual or required whānau to infer meaning – for example, integrity, respect, ‘circles of support’ and ‘practical matters’. According to the Waikato project team, findings suggest that resources were created

from the service providers' knowledge base, rather than being oriented towards readers' worldview, experience and knowledge.

The Waikato project report noted that few brochures included diagrams. However, when presented clearly, kaumātua found diagrams helpful as they did with Figure 1 below.

**Figure 1: Example of diagram – managing pressure areas**

When sitting



**Advice:**

- Try and relieve pressure every 15 minutes. Take the weight off your bottom by leaning forward while pushing up with your arms or roll from buttock cheek to buttock cheek.
- You may need a special cushion to help relieve the pressure.
- Avoid sitting in the same position for prolonged periods.

Source: Prevention of Pressure Areas, Hospice Taranaki

According to the Auckland and Bay of Plenty report, sometimes the audience and the purpose of the resource were clear. In other resources, they were implied or absent. The report noted that a number of hospices provided 'communication books', for example, to facilitate clear communication processes by enabling all health care professionals, patients and their whānau to write notes and questions in one place. One had a sticker on the front cover with the 24-hour contact numbers for the staff. None of the books included examples of how whānau could use the communication book.

The report also noted that some services provided a lot of information to whānau all at one time (in a folder or envelope) and it was hard for whānau to see the relevance of much of this information, such as a Work and Income pamphlet where the first service offered is to assist people to get into work, or a pamphlet about eye donation. One hospice had a welcome letter that explained to whānau how they could use the information in the folder. Although this letter could be improved, it was a good example of helping a reader to understand other material they are given. Other services also had letters but these did not provide a guide to the content of other material so were evaluated as being redundant.

According to the report, often different types of documents (eg, information and instructions) were combined without making it clear when there was a transition from one type to the other. For example, a text might start off providing information and then move to giving instructions.

The Auckland and Bay of Plenty research team found that consent forms were particularly difficult to understand. Some of the forms contained information about services the hospice did not provide, including information about social services and enduring power of attorney.

# Cultural competency

Cultural competency was examined in terms of the use of te reo Māori and Māori imagery. Very limited use of te reo, unintentional mixed messages, contradictions and notable absences; the use of unnamed landscape and stock images; sometimes inappropriate placement of Māori images; and the unintentional denial of alternative worldviews, would suggest that Māori patients and their whānau would be unlikely to relate culturally to the services offered.

## Use of te reo Māori

The Waikato project report noted that almost all of the written resources they analysed were in English, with most including no more than single- or two-word Māori phrases. Only 2 of the 99 brochures analysed by the group were written in Māori and both were provided by the same organisation. An additional two brochures used both English and Māori, and three brochures included waiata and/or whakatauki in Māori.

## Māori images: mixed messages, contradictions and notable absences

The Waikato research report provided an analysis of images contained in the brochures, and their findings are contained in this section. On the whole, most of the images were mainstream-oriented with few Māori images or symbols. For instance, palliative care and dying were often associated with autumn, sunsets and journeys. Butterflies also featured, along with pleasure-boats on the water. Findings indicated that these images were not understood or relevant to Māori perspectives of palliative care and dying. Kaumātua participants in hui questioned the use of butterflies; one group asked: 'How long does a butterfly live?'

Notably absent were images and symbols that communicate directly with Māori. Figure 2 contains a sample of the relatively few images and symbols that appeared. The koru (spiral shape of unfurling fern frond) and pounamu (New Zealand greenstone) resonated deeply with kaumātua.

**Figure 2: Symbols used in the brochures**



Sources: Arohanui Hospice (carving); North Shore Hospice (side panel); Otago Community Hospice (other images).

Kaumātua expressed concern when words and images did not support each other's message and meaning. One example was the use of family/whānau in the brochure text, but the main image was of older Pākehā-looking women. This is in contrast to brochures that used images of multi-generational and Māori whānau groups. In another example a brochure cover read 'Carer support and respite care' and these words appeared over an image of a bed with green leaves on top of a white bedspread (see Figure 2). Kaumātua saw the image as meaning death and therefore contradicting the message of 'care and ... support'. In a third example, the image was not seen as appropriate to the content of the brochure: A comic aeroplane appeared on the front cover with the words 'Taking Control'. For kaumātua, this image did not convey respect for the topic.

Images of landscapes were sometimes used, including mountains, surf beaches, gardens and parks. Bodies of water such as lakes or the sea were used mostly in brochures about what to expect when someone is dying, grief and bereavement. Some images were clearly photos of local places (eg, Whakatāne and Whāingaroa), but others could be anywhere – a waterfall, a sunset over water or mountains. Very few pictures had captions. Captions about landscapes and images would help to link a palliative care provider with the local area. Whakapapa is genealogy in both place and time and therefore inherent to whanaungatanga (eg, Mead 2003; Tate 2010). Therefore, identifying pictures of localities in the brochures is important. Images of identifiable local landscapes and features communicate more than service information; they help to connect people of the local area and 'ground' the service for the reader.

Kaumātua noted that Māori images were not always used correctly and that there were iwi differences in how images could be used. There were also examples of Māori images of symbolic and spiritual significance such as pounamu being presented beside frivolous mainstream images such as a clip art butterfly. As well, Figure 2 shows a panel used incorrectly because it did not go from edge to edge to signal 'eternity'. Instead it was boxed-in within the frame of the brochure.

## **Unintentional denial of alternative worldviews**

The Waikato report noted that some brochures used 'we' in a broad way to talk about 'we' as in greater humanity and the human experience. For instance 'What happens as we are dying?' According to the report, this assumes some universal worldview relating to death and dying. While there may be common processes and events, there will also be differences that are not able to be adequately acknowledged within brief written resources. For instance, written resources tended to focus on the physical and practical dimensions of dying, with the exclusion of spiritual dimensions, which may have high priority for some audiences. Generally, written resources were infused with mainstream voices and values.

A specific instance of exclusion of Māori worldviews was found in a brochure on grief. In a list of possible effects of grief was 'hallucinating seeing or hearing loved one'. From a medical perspective this may make sense, but it denies any worldview that accepts that spirits of the deceased may visit the living.

The Auckland and Bay of Plenty study found that few publications referred to Māori values and concepts.

# Enhancing the value of written resources

Absorbing new or complex information takes time, and can be affected by emotional state, vulnerability following diagnosis, and being in unfamiliar environments such as hospitals (Friedman and Hoffman-Goetz 2006). Therefore, according to the Waikato report, if written resources are used to inform patients and whānau about palliative care, it is important that they are able to ‘speak to’ Māori. If the wairuatanga is not right, Māori audiences may not continue to read even if the text is understandable. Palliative care organisations need to consult with Māori with appropriate cultural expertise, such as knowledgeable kaumātua, in designing informational material. That is, co-create material that best enables palliative care providers to communicate in ways that are most likely to elicit positive responses from patients and their whānau.

Written resources are often used to support other forms of communication (Manning and Dickens 2006). The Waikato report noted that reading information cannot be expected to replace sense-making that takes place in face-to-face communication, ongoing conversations, and retrospective reflection. The value of written resources is maximised when palliative care workers sit down with whānau and explain their use and relevance –as opposed to just giving the brochures to them. The Auckland and Bay of Plenty research report emphasised that the efficacy of written resources relied on the quality of the relationship between the patient and whānau and the health professional, which needs to be characterised by effective communication.

## Summary

Overall findings from both research projects indicated that there were multiple problems with written resources for patients and whānau used in palliative care, relating to their accessibility and cultural relevance. Providers would be unlikely to connect with patients and their whānau using written resources alone. Given cultural preferences for face-to-face communication, questions remain about the role brochures play in informing patients and their whānau about palliative care services and influencing decisions.

The value of written resources would be maximised if they were used to support culturally relevant communication by health professionals. That is, where written resources are used face-to-face by health professionals who take their time to explain palliative care to patients and whānau and where whānau may use the resources for later reflection.

---

# Discussion and recommendations

Health literacy is a concept that lies at the centre of the complex and evolving relationships between the health system, health organisations, health professionals and patients and whānau (Workbase 2013). It is a broad concept that is understood as an interaction between the individual capacities of patients, whānau, palliative care workers and the health care environment (Institute of Medicine 2004; Kickbusch et al 2005; Nutbeam 2008; Rudd et al 2007). For patients and whānau, health literacy is a skill set used in health contexts to obtain, process and understand health information. For health professionals, health literacy is about their ability to communicate health information and build skills and knowledge. For health organisations, health literacy is about the appropriateness of the health information and services they provide for patients and their whānau as well as the organisational systems and processes to support health professionals to build health literacy.

## Māori access to palliative care services

In both studies research participants expressed a desire for accessible palliative care services. Access to palliative care services concerns not only service utilisation, but gaining entry into and through services, and timeliness and quality in terms of how services are used (processes) and what is achieved (outcomes) (Cormack et al 2005). The Auckland and Bay of Plenty project found that Māori entry into palliative care took many forms, from self-referral through to specialist referrals. Difficulties with access were identified in both studies as issues for patients and whānau. Late entry was a particular concern identified in the Auckland and Bay of Plenty report.

Health literacy is a function of the demands placed on the patient and whānau by the health care system (eg, the complexity of access to services) as well as by the patient's disease processes (Sudore et al 2009) and associated intensive physical health care needs. According to the Auckland and Bay of Plenty study, these demands include the knowledge and task components of the disease management focus of medicines, patient care and the wider focus of navigating the palliative care system. Findings from both studies indicate that these demands are amplified in the emotional environment of palliative care, with whānau negotiating the acquisition of new knowledge and skills within a context of shock, grief and loss. In discussing issues for Māori and their whānau in accessing palliative care, this report takes a broad view in considering health system factors, health organisation factors and patient and whānau factors.

# Māori health literacy in palliative care

A systematic review of health literacy identified that it can be a mediator of ethnic disparities in health outcomes (Berkman et al 2011). Despite evidence of low health literacy among Māori generally (Minister of Health 2010), whānau who participated in these research projects used complex health literacy practices (actions to meet health literacy demands). These practices utilised a range of literacy and numeracy skills and included critical thinking and decision-making. The health literacy practices used included seeking out and utilising whānau and friends for information and support as well as advocacy on behalf of patients with health professionals and health care providers, and keeping written records and communication books. Waikato research participants also held regular whānau meetings and established systems to coordinate tasks. Other health literacy practices identified in the Auckland and Bay of Plenty report were researching information, especially on the internet, and dispensing medicines (including using syringe drivers and naso-gastric tubes). These health literacy practices were used in spite of significant barriers that were often related to a lack of effective communication in palliative care.

These findings appear at odds with evidence of low levels of health literacy among Māori generally. However, as suggested in the Auckland and Bay of Plenty report, explanations of this could include that people receiving palliative care may be more motivated by the diagnosis of life-limiting illness to develop health literacy. This suggestion is consistent with both adult education principles (Knowles et al 2005) and adult literacy studies (Sticht et al 1987). An alternative explanation supported by data in both research projects is that patients and their whānau had help and support in their journey to develop health literacy skills, such as through the utilisation of the expertise of wider whānau members or friends. This provided one way of 'working around' barriers and obstacles posed either by the system itself or by organisations or people working within the system.

## Factors influencing Māori access to palliative care from a health literacy perspective

Many health care professionals demonstrated an understanding of what was required to reduce health literacy demands and achieve health literacy. The Auckland and Bay of Plenty report identified that some health professionals were individually working with patients and whānau to build their health literacy. However, health care professionals experienced systems barriers to improving their practice in the area of health literacy, and there was little evidence of palliative care service providers using systemic approaches to reducing health literacy demands (DeWalt et al 2011). There is a growing appreciation that health literacy does not focus solely on individual skill (Institute of Medicine 2004), so reducing health literacy demands needs to be an active, purposeful process driven by the health care organisation (Rudd 2013) and including a systems-level focus.

Health system, health organisation and individual and whānau factors influencing Māori access to palliative care from a health literacy perspective are discussed below. Health system factors relate to the health system as a whole, rather than to the characteristics of individual services. Health organisation factors relate to specific health organisations and services. The focus within these first two categories, from a health literacy perspective, is on reducing the health literacy demands imposed by systems, organisations and services. Patient and whānau factors operate at the level of the person and their whānau. The focus at this level is on factors that influence the achievement of health literacy among individuals and whānau so they are able to manage health literacy demands. Some factors may be expressed as a barrier or a facilitator, such as health

professional cultural competence – low workforce cultural competence is a barrier to Māori access to palliative care, while high workforce cultural competence is a facilitator.

## **Health system factors**

This research indicated that the health system makes health literacy demands on Māori patients and whānau trying to obtain access to palliative care services. Health system factors identified in the research that contribute to the extent of health literacy demands and influence access to palliative care services are:

- the focus of the palliative care system
- coordination
- the palliative care workforce
- availability of quality information
- the quality of ethnicity data.

### **Focus of the palliative care system**

Participants in both research projects indicated that the palliative care system has a total population focus and is generally perceived as ‘Pākehā’. There is a lack of Māori presence within most services and relatively few efforts throughout the system to accommodate Māori cultural values and preferences. This undermines Māori confidence in the ability of hospice and other palliative care service providers to deliver culturally competent care that will meet their needs. Findings from this research indicated a need to integrate culture into palliative care services. The Auckland and Bay of Plenty research showed that many health professionals demonstrated a level of helplessness about effecting changes within the system that would benefit Māori.

Research findings indicate that whānau involvement in palliative care is critical, including in hospice and hospital settings. A whānau-oriented approach is not, however, embedded within the palliative care system. Differences in expectations of whānau versus health professionals as to the role of whānau in the provision of care were identified as problematic in the Waikato report. Also, according to both reports, in palliative care settings there were difficulties with physical space and other resources for accommodating whānau.

Inequities in access to specialist palliative care services in rural areas have been acknowledged as a concern in the literature (Minister of Health 2001). This may impact on the many Māori who live in rural areas or return to their rohe (tribal homeland) when terminally ill (Lawrenson et al 2010). The geographical location of specialist services may also impact on the capacity for whānau involvement in care.

Findings from the research projects indicated a need to address individual and institutional racism. This was apparent given prejudiced attitudes of some health professionals and a lack of empathy, poor access to quality ethnicity data within palliative care, and low levels of Māori representation within the workforce.

### **Coordination**

Palliative care is delivered by multiple providers and multidisciplinary teams; therefore, enhancing coordination is important to enable quality care. For example, improved coordination between providers may help to address late entry into palliative care for Māori. The Auckland and Bay of Plenty project found that late referrals when death was imminent were a particular concern. Often there was insufficient time for patients and whānau to develop relationships with providers, to become familiar and comfortable with facilities and services, to

negotiate health literacy demands, have needs for support and equipment met, or make arrangements for the patient's preferred death experience.

According to the Waikato report, long-standing relationships of trust with Māori community organisations made these organisations important sources of support, particularly for kaumātua who valued familiarity. Further, Māori workers based with Māori community organisations and Māori health providers were identified as a key source of cultural support. Their contribution as part of multidisciplinary networks of palliative care providers should be respected and resourced given that they provide necessary cultural expertise that is limited within the wider palliative care workforce.

### **Palliative care workforce**

The research found preferences among patients and whānau for 'by Māori for Māori' approaches to service delivery that involved provision by Māori, and enabled enhanced communication. However, there is long-standing and enduring under-representation of Māori in the palliative care workforce. Participants also commonly expressed concerns at the low levels of cultural competence of the palliative care workforce. In combination these factors undermine confidence among patients and whānau in the capacity of the workforce to deliver quality palliative care for Māori that meets their palliative care needs.

### **Availability of quality information**

Health literacy in palliative care settings is influenced by the availability of quality information, that is, information that is specifically designed to meet the needs of Māori, including kaumātua. There were multiple problems with written resources for patients and whānau used in palliative care, relating to their accessibility (eg, how easy or difficult they were to understand) and cultural relevance. The Waikato research report suggests that what is required are high-quality, Māori-specific written resources about palliative care and palliative care services that are co-created with Māori.

Given cultural preferences for face-to-face communication, questions remain about the role written resources play in informing patients and their whānau about palliative care services and influencing decisions. The value of written resources would be maximised if they were used to support culturally relevant communication by health professionals. That is, when written resources are used face-to-face by health professionals who take their time to explain palliative care to patients and whānau and when whānau may use the resources for later reflection.

The findings of both research projects indicate that the combination of culturally relevant communication processes along with high-quality written resources specially targeting Māori may be an important contributor to improving health literacy.

### **Quality of ethnicity data**

As yet there is no systematic analysis, monitoring and reporting of palliative care data by ethnicity that enables clear understandings of Māori palliative care needs and issues, in order to inform policy, planning and action. Comments from participants in the Auckland and Bay of Plenty project indicated that quality ethnicity data is not routinely available to inform practice.

## Health organisation factors

At the organisational level, research findings indicated a low level of commitment from palliative care organisations to building Māori health literacy. The following organisational factors were identified that influence the level of health literacy demands on Māori patients and whānau trying to access palliative care services:

- the quality of health care professionals' communication
- health literacy of health professionals
- workforce cultural competency
- provision of Māori-specific health literacy roles.

## Health professionals' health literacy and effective communication

For health professionals, health literacy is about their ability to effectively communicate health information to patients and whānau, and thereby provide education that builds health literacy knowledge and skills among Māori. Providing education is a fundamental health professional intervention that is ideally both empowering and culturally sensitive for those in hospice and other end-of-life care settings (Cagle and Kovacs 2009). However, many health professionals are likely to have been taught to provide education in a 'top-down' fashion (with the health professional as the powerful expert) that bears little resemblance to the principles of adult education (including shared collaborative knowledge) that form the foundation of health literacy (Nutbeam 2008).

In both research projects patients and whānau expressed the importance of clear, honest and timely information to reduce uncertainty and enable whānau to care for their dying loved one. However, they related experiences of poor communication. A recent New Zealand study identified patients' and families' dissatisfaction with the quality and type of information provided, understanding of language used, ways of being informed about patient's condition, poor communication of 'bad news', staff lacking the skills to have these difficult conversations, staff not available to provide updates, and being reactive rather than proactive around providing information (Robinson et al 2013). The experiences of patients and whānau across the two research projects were consistent with these examples of poor communication, and concerns were expressed across both projects that full information was not forthcoming. In addition the Auckland and Bay of Plenty project documented concerns at the lack of acknowledgment of the considerable knowledge and expertise about the patient which whānau had developed through providing their continuous intimate care.

A survey of New Zealand GPs identified the need to involve whānau in the management of Māori patients needing palliative care by identifying the key people within the family (Lawrenson et al 2010). Findings from the Auckland and Bay of Plenty project indicated that non-Māori health care professionals perceived that having a single spokesperson for whānau was preferred by patients and their whānau. However, this approach increased the responsibility and workload for that person, and had the potential to create problems for them. Whānau caregivers discussed how stressful and difficult it could be to be the 'identified person'.

A New Zealand study found that a traditional Māori belief system about the inevitability of death made conversations about end-of-life care less difficult for staff (Bellamy and Gott 2013). Despite this, findings from the Auckland and Bay of Plenty regions study found that (with the exception of specialist palliative care workers) health professionals managing patients' conditions struggle to discuss with patients and whānau a transition from active treatment to palliative care. The capability of health professionals to have these discussions impacts on the health literacy of patients and whānau. When those conversations were avoided or unclear, whānau reported feeling overwhelmed and under-informed about their options and how to help

their family member. This finding highlights the need to understand how to teach and support health professionals to work with people who have life-limiting illnesses, particularly at the point where active treatment changes to palliative care. Data contained in the Waikato report supported these findings.

Effective communication greatly enhanced the whānau experience of palliative care. Whānau identified aspects of good communication practices in palliative care settings, which assisted them in providing optimal support to their loved ones. Patients and whānau respondents in both projects found the following communication processes used by health care professionals were effective in supporting them:

- ability to communicate with health professionals when required (eg, 24/7), to ask questions and have their fears allayed
- full communication from health professionals
- practical training provided for whānau caregivers to support their knowledge and skill development
- establishing respectful rapport and relationships with patients, including respect for the knowledge whānau already held
- use of plain speech
- communication books to record what was happening
- culturally competent communication processes, including putting into practice Māori concepts such as whanaungatanga and kanohi ki te kanohi.

In addition, participants in the Auckland and Bay of Plenty research identified the following factors:

- supporting oral communication with quality written resources, and taking the time to explain written material (health professionals indicated difficulties in finding time to discuss resources)
- ‘front-loading’ time, described by health professionals as ensuring that when patients are first referred, relationships are actively created to support effective learning environments
- opportunity to have regular meetings with those providing care to patient to discuss progress
- help with predicting future care needs.

For kaumātua and whānau respondents in the Waikato project, effective communication also involved collaborative ways of working with whānau.

### **Workforce cultural competency**

The health literacy of Māori patients and whānau is influenced by the cultural competence of the palliative care workforce, particularly given that it underpins effective cross-cultural communication. The research projects, and particularly the Waikato study, highlighted the importance of integrating culture into palliative care, central to which is the requirement for a culturally competent palliative care workforce. That is, palliative care workers who are able to support whānau involvement in care and the integration of Māori cultural beliefs, values, preferences and practices into care. Culturally competent palliative care workers make the space for whānau to fulfil their cultural responsibilities in clinical settings, an issue which is of particular significance for end-of-life care.

Generally, research findings indicate low levels of cultural competence among the palliative care workforce, with examples from the Waikato project including lack of understanding of Māori cultural preferences for end-of-life care and culturally inappropriate practices (eg, inappropriate placement of urinals and use of pillows). Biased attitudes, uninformed beliefs and discriminatory stereotyping were also indicated in both reports. Health professionals acknowledged the need to increase their cultural competence and expressed a willingness to develop knowledge and skills in that area. Some participants in the Waikato study indicated perceptions of a lack of clear pathways for health professionals to develop their cultural competence.

### **Māori-specific navigator roles**

A common theme from the research projects was the importance of a specific advocacy/navigator function provided by palliative care services to support Māori patients and whānau to address access barriers. These roles are variously described as a navigator, kaiāwhina, or as an extension of an existing role such as a nurse or social worker. The roles provide advocacy and systems navigation and have the potential to improve health literacy and reduce health literacy demands for patients and whānau. These roles have been successfully put in place in a range of New Zealand health care settings (Dohan and Schrag 2005; Doolan-Noble et al 2013; Freeman 2006).

### **Patient and whānau factors**

At the patient and whānau level, health literacy, and whānau values, preferences and context were identified as influencing access to care.

### **Levels of health literacy**

Research findings indicated a desire among whānau to understand palliative care and services and to be kept informed about their loved ones' conditions and care options. It was apparent that there was diversity in the levels of health literacy among patients and whānau, ranging from those with very poor health literacy to others who exhibited complex health literacy practices. Findings indicated that low health literacy is a barrier to access to palliative care services, particularly where whānau are still wishing to remain positive (Bellamy and Gott 2013). Conversely, those whānau with higher levels of health literacy were better able to navigate the system and access resources and services.

The Auckland and Bay of Plenty study found that some patients and whānau were reluctant to accept palliative care because of misconceptions that these services were only available as an inpatient, that the purpose of hospice care was to hasten death, and that to accept palliative care was to accept that death was imminent. According to that report, health professionals had stories about helping patients to overcome a fear of hospice as 'the place to die', which were consistent with New Zealand research (Frey et al 2013a). Misconceptions and initial reluctance were often overcome once patients and whānau obtained entry into palliative care, though sometimes late admission meant that insufficient time was left to benefit fully from palliative care and adequately prepare for preferred death experiences.

The perceptions of some health professionals in the Auckland and Bay of Plenty study were that decision-making was easier and more effective when patients and whānau already had some knowledge about palliative care. Some patients and whānau did not know of the existence of palliative care services until they were confronted with a referral. Low levels of health literacy were also apparent in both research projects in terms of the difficulties patients and whānau experienced in understanding palliative care and palliative care services, and in knowing how to ask for help (ie, who and what to ask).

Research findings indicate that the level of health literacy is likely a key factor in whether an individual accepts a referral to palliative care, and that because of current low health literacy many Māori patients and whānau are not well positioned to make informed decisions about entry into palliative care. This is consistent with the literature, with people who have low or marginal health literacy more likely to prefer treatment-focused care than palliative care (Volandes et al 2008). A recent New Zealand study confirms this finding across other population groups in addition to Māori, and recommends public profiling of hospices with education and information provision to strengthen community involvement (Bray and Goodyear-Smith 2013). This indicates that perceptions of Māori preferences to die at home may not take account of the role of a lack of awareness and understanding of palliative care services in driving those decisions. Further, there was no indication in this research that Māori would refuse palliative care for cultural reasons when that care is provided in a culturally competent way.

### **Patient and whānau values, preferences and context**

Health literacy and access to palliative care services may be influenced by the extent to which patient and whānau values and preferences are expressed in palliative care services and the context for palliative care. Cultural factors identified as playing a central role in participants' experiences of palliative care related to death and dying and whānau involvement in care.

Whānau participating in the Waikato project described the last days and hours spent with a dying whānau member or friend as a spiritual experience and emphasised the critical role of tikanga (cultural practices). They specifically discussed the importance of waiata and karakia in managing pain and facilitating the dying person's spiritual journey through making connections between the spiritual and material worlds. These cultural practices were an expression of Māori beliefs and values and often involved strengthening interpersonal relationships (including spiritually) between the person dying and whānau members, and between whānau members.

The free expression of cultural values that enhance wairuatanga (eg, tapu, manaakitanga, aroha, rangatiratanga and whanaungatanga) by patients and whānau was identified as important during the end-of-life journey in the Waikato project. It was also important for whānau to balance the tensions between some of these values, such as maintaining the mana and self-determination of recipients of palliative care while meeting needs for a deeply connected and supportive relationship with whānau.

The right of whānau to actively participate in caring for their dying relations was given strong emphasis in the Waikato report, and this aligned with comments that expressed the high value patients placed on being surrounded by whānau at this time. Participants in both studies emphasised the importance of palliative care services that were able to fully accommodate whānau and therefore enable whānau to function as a practical support network for patients and one another in palliative care settings. In the Waikato report concerns were highlighted around differing expectations between whānau and health professionals as to the role of whānau in palliative care. That is, instances where some clinical staff did not listen to whānau wishes to provide care for their loved one. Participants underlined the value that whānau add in the provision of quality palliative care for Māori, including their role in facilitating communication between individuals receiving palliative care (and their wider whānau) and clinicians, and in palliative care knowledge transfer within and between whānau and in Māori communities.

For some patients and whānau, receiving palliative care may be an impetus to developing health literacy skills. At the same time, according to the Auckland and Bay of Plenty report, it is important to recognise that patients and whānau experiences of shock, grief and loss create emotional environments that may influence whānau health literacy during the end-of-life journey. Absorbing new or complex information takes time, and can be affected by emotional state, vulnerability following diagnosis, and being in unfamiliar environments such as hospitals (Friedman and Hoffman-Goetz 2006). Findings from the Waikato project indicate that there is likely value for kaumātua, other Māori individuals and whānau in building relationships with palliative care providers and other support services prior to the need for palliative care as a mechanism to facilitate access if and when required.

The Auckland and Bay of Plenty report indicated that whānau caregiving was another factor that influenced the emotional climate in which health literacy occurred. The Waikato report noted that for whānau, the role of caregiver, while a responsibility that was willingly accepted, was very demanding. This was particularly the case for those who did not have support due to low health literacy (eg, they were not aware of available financial and other support) and other reasons, and who felt culturally isolated. The end-of-life journey is emotional and while it may reinforce whānau relationships, it may also raise challenges in terms of maintaining positive relationships. Findings indicate that ongoing formal and informal support for whānau during the end-of-life journey and following the death of a loved one are important.

## **Enhancing Māori health literacy in palliative care**

The research projects have identified health system, health organisation and patient and whānau factors that have the potential to influence the achievement of health literacy and access to palliative care for Māori patients and whānau. Findings indicate that key measures to improve Māori health literacy in palliative care and service delivery relate to strengthening a Māori focus and presence, and a whānau orientation within the palliative care system. This should be reflected in:

- the constitution of the workforce (ie, Māori representation)
- coordination between providers, including Māori community organisations
- the availability of quality palliative care information that is tailored to Māori
- quality ethnicity data that is routinely analysed and reported to inform palliative care planning and decision-making
- health professionals that engage in health literacy and cultural competence training that enables them to communicate effectively with Māori and support the integration of Māori culture into palliative care
- specific Māori navigator roles
- palliative care services that reflect the values and preferences of Māori.

These features are consistent with what researchers have argued are interventions needed to ensure organisations have the attributes to be health literate. Those interventions include, from a Māori health literacy and palliative care perspective:

- having Māori health literacy integral to core palliative care organisational values
- integrating Māori health literacy into planning, evaluation and quality improvement
- workforce cultural competence and preparedness
- integrating Māori community and expert input

- meeting the needs of Māori
- using health literacy strategies in communication
- providing easy access to navigate palliative care information and services, through, for example, inclusion of Māori navigator roles
- utilising relevant and easy-to-understand written resources that specifically target Māori
- prior identification of high-risk situations for health literacy
- communicating clearly about costs (adapted from Brach et al 2012).

## Concluding comments

Māori patients and whānau face substantial and complex health literacy demands that are barriers to access to palliative care services. Many of these demands are systemic factors and health care organisation factors, including barriers caused by the low health literacy skills of health professionals such as poor cultural competence and communication. As a matter of priority, action is required to address systemic and organisational health literacy issues that undermine Māori access to palliative care services. This will enable coordinated efforts by palliative care organisations and health professionals to reduce health literacy demands on Māori palliative care patients and their whānau, and help them to build their health literacy. That is, patients and whānau are empowered to build on their existing knowledge and skills to better understand patients' disease processes, palliative care and palliative care services, and use health literacy practices that contribute to self-management.

The achievement of health literacy by palliative care systems, organisations and health professionals will facilitate the realisation of the potential of palliative care for Māori. That is, palliative care that supports whānau, optimises quality of life for patients including the maintenance of their mana, and enables preferred death experiences that give free expression to cultural values and practices relating to death and dying.

## Recommendations

Seven overlapping areas for action are identified below, with associated recommendations:

### Guidelines and standards

- Prioritise the development of health literacy guidelines and standards that will address Māori health literacy priorities.

### Workforce

- Support and resource ongoing training of the palliative care workforce in cultural competence and health literacy (eg, communication skills based on adult learning principles and addressing biased attitudes that impact on interpersonal communication and practice) to ensure their capacity to foster health literacy knowledge and skill among Māori. This should be supported by management systems and processes that make explicit the expectations of culturally competent practice and building health literacy of Māori.
- Provide incentives and funding to encourage Māori palliative care workforce development at all levels and in a variety of roles. This should encompass professional development in health literacy for Māori already in the palliative care workforce, including those based with Māori community organisations.
- Recognise and support the valuable contribution of Māori community organisations to enhancing Māori health literacy and access to palliative care for Māori through adequate and ongoing funding.

## **Resources**

- Encourage and fund the development of high-quality, Māori-specific written resources about palliative care and palliative care services.
- Develop tools to assist services and health professionals to communicate effectively about palliative care with Māori patients and their whānau.
- Use culturally relevant communication processes supported by accessible and relevant written resources in working with Māori patients and their whānau to improve health literacy.

## **Service orientation**

- Palliative care organisations develop meaningful partnerships with iwi and other Māori community organisations.
- Support and encourage Māori participation in palliative care services at the governance level, and ensure Māori expert advice at service policy levels.
- Involve Māori expertise and the range of relevant Māori organisations and providers in multidisciplinary palliative care teams and networks to better enable collective and coordinated ways of working, including coordinated transitions in palliative care.
- Integrate Māori worldviews, values, knowledge and practices into palliative care services to better ensure the cultural competence of services and thereby reduce health literacy demands for Māori.
- Embed a whānau-oriented approach within the palliative care system and services to ensure whānau-centred practice and support whānau involvement in care.
- Develop and evaluate models and resources to support Māori patients and their whānau to meet health literacy demands in palliative care.
- Develop, establish and evaluate Māori health navigator roles to support Māori health literacy in the palliative care context.
- Palliative care organisations provide support and guidance in the use of electronic resources, processes and communication (eg, internet, social media and eHealth) to maximise the benefits for Māori and ensure that the uptake and use of these resources does not lead to inequalities.

## **Monitoring and evaluation**

- Institute systems for the collection of quality ethnicity data in palliative care, and routine monitoring and reporting on Māori palliative care needs and equity of access to palliative care services for Māori (including the timeliness of referrals).

## **Research**

- Support the translational research in priority areas that will influence palliative care provision and health literacy for Māori.

## **Addressing structural barriers**

- Review health literacy demands made on patients and whānau by palliative care systems and services, and where possible reduce the burden of those demands.
- Undertake proactive measures to raise Māori awareness of palliative care services.

---

# Glossary of Māori terms<sup>3</sup>

aroaha	love
awhi	care, support, help
haka	traditional posture dance
hapū	subtribe
hui	meeting, gathering
iwi	tribe
kai	food
kaiāwhina	support staff, supporter, helper
kanohi ki te kanohi	presence and participation, face-to-face
karakia	prayer
kaumātua	elder/s – in some areas, including Waikato, this term refers to male and female elders
kaupapa	subject, topic
kaupapa Māori	a Māori philosophical framework
koha	contribution, gift
kōrero	speak, talk, discuss
koru	spiral shape of unfurling fern frond
kotahitanga	an ethical principle denoting solidarity and the worth of people, unity
kuia	grandmother, female elder
mahitahi	coordination
mana	a principle denoting status, prestige, dignity, autonomy
manaaki	caring, hospitality
manaakitanga	an ethical principle denoting the importance of caring for others
marae	a traditional meeting centre often comprising a formal courtyard, meeting house(s) and a dining house
mihimihi	greetings
mirimiri	traditional Māori form of massage
moko, mokopuna, mokos	grandchild/ren
Pākehā	New Zealander of European descent
pounamu	greenstone
rohe	tribal homeland
rongoā	medicine, Māori traditional medicine
rōpū	group
tapu	sacred, restricted
tautoko	advocacy
Te Ao Māori	the Māori world, as opposed to Te Ao Whānui, the wider world

<sup>3</sup> Definitions are given in the context of this report and may not be generically applicable.

te reo Māori	Māori language
tikanga	Māori process
tino rangatiratanga	self-determination, autonomy
tino whanaungatanga	connection, the desire for a deeply connected supportive relationship with whānau
tohunga	a Māori specialist in a particular field
tūpuna	ancestors
tūrangawaewae	tribal homelands
wahine	woman
wāhine	women
waiata	song, chant
wairua	spirit
wairuatanga	an ethical principle denoting spirituality
wha	four
whakahaere	lead, direct, coordinate
whakamā	ashamed, embarrassed
whakapapa	genealogy
whakawhanaungatanga	building relationships, interconnectedness
whakawhiti whaakaro	group debrief
whānau	family, usually encompassing wider membership than the nuclear family
whanaungatanga	an ethical principle denoting connectedness to Māori collectives

---

# References

- Baker DW, Parker RM, Williams MV, et al. 1998. Health literacy and the risk of hospital admission. *Journal of General Internal Medicine* 13: 791–8.
- Batten L, Clark J, Holdaway M, et al. 2011. Culturally appropriate end-of-life care for Māori: Technical report for Phase 1a: Retrospective chart audit of Liverpool care pathway for the dying patient documentation (HRC 11/027). Palmerston North: Research Centre for Māori Health and Development, Massey University and Palmerston North: Education and Research Unit, Arohanui Hospice.
- Batten L, Holdaway M, LCP Research Team. 2012. Culturally appropriate end-of-life care for Māori: Technical report for Phase 1b: Stakeholders' perspectives of the cultural goals of care in the Liverpool care pathway for the dying patient (HRC 11/027). Palmerston North: Research Centre for Māori Health and Development, Massey University.
- Bellamy G, Gott M. 2013. What are the priorities for developing culturally appropriate palliative and end-of-life care for older people? The views of healthcare staff working in New Zealand. *Health & Social Care in the Community* 21(1): 26–34.
- Berkman N, Sheridan S, Donahue K, et al. 2011. *Health Literacy Interventions and Outcomes: An updated systematic review*. Rockville, MD: Agency for Healthcare Research and Quality.
- Bishop R. 2005. Freeing ourselves from neocolonial domination in research. In NK Denzin and YS Lincoln (eds) *The Sage Handbook of Qualitative Research*. Thousand Oaks, CA: Sage Publications.
- Boyatzis RE. 1998. *Transforming Qualitative Data: Thematic analysis and code development*. Thousand Oaks: Sage.
- Brach C, Keller D, Hernandez CB, et al. 2012. *Ten Attributes of Health Literate Health Care Organizations*. Washington DC: Institute of Medicine, National Academy of Sciences.
- Braun V, Clarke V. 2006. Using thematic analysis in psychology. *Qualitative Research in Psychology* 3(2): 77–101.
- Bray Y, Goodyear-Smith F. 2013. Patient and family perceptions of hospice services: 'I knew they weren't like hospitals'. *Journal of Primary Health Care* 5(3): 206–13.
- Cagle JG, Kovacs PJ. 2009. Education: A complex and empowering social work intervention at the end of life. *Health and Social Work* 34(1): 17–27.
- Canadian Council on Learning. 2008. *Health Literacy in Canada: A healthy understanding 2008*. Ottawa: Canadian Council on Learning.
- Connor SR, Bermedo MCS (eds). 2014. *Global Atlas of Palliative Care at the End of Life*. World Health Organization and Worldwide Palliative Care Alliance.
- Cormack D, Robson B, Purdie G, et al. 2005. *Access to Cancer Services for Māori: A report prepared for the Ministry of Health*. Wellington: Wellington School of Medicine and Health Sciences and Auckland University of Technology.
- Cottle M, Hughes C, Gremillion H. 2013. A community approach to palliative care: embracing indigenous concepts and practices in a hospice setting. *Journal of Systemic Therapies* 32(1): 56–69.
- Cram F, McCreanor T, Smith LT, et al. 2006. Kaupapa Māori research and Pākehā social science: Epistemological tensions in a study of Māori health. *Hulili* 3(1 ): 41–66.

- DeWalt DA, Broucksou KA, Hawk V, et al. 2011. Developing and testing the health literacy universal precautions toolkit. *Nurs Outlook* 59(2): 85–94.
- Dohan D, Schrag D. 2005. Using navigators to improve care of underserved patients: current practices and approaches. *Cancer* 104(4): 848–55.
- Doolan-Noble F, Smith D, Gauld R, et al. 2013. Evolution of a health navigator model of care within a primary care setting: a case study. *Aust Health Rev* 37(4): 523–8.
- Ellershaw J, Wilkinson S. 2011. *Care of the Dying: A pathway to excellence*. Oxford: Oxford University Press.
- European Health Policy Forum. 2005. *Recommendations on Health Information*. Brussels: EU Health Policy Forum.
- Freeman HP. 2006. Patient navigation: a community based strategy to reduce cancer disparities. *J Urban Health* 83(2): 139–41.
- Frey R, Gott M, Bellamy G. 2012. *Understanding Barriers and Facilitators to Hospice Care Services Access in the Totara Hospice South Auckland: Final report to the Totara Hospice South Auckland and Counties Manukau DHB*. Auckland: University of Auckland.
- Frey R, Gott M, Raphael D, et al. 2013a. Where do I go from here? A cultural perspective on challenges to the use of hospice services. *Health and Social Care in the Community* 21(5): 519–29.
- Frey R, Raphael D, Bellamy G, et al. 2013b. Advance care planning for Māori, Pacific and Asian people: the views of New Zealand healthcare professionals. *Health and Social Care in the Community* DOI: 10.1111/hsc.12081.
- Friedman DB, Hoffman-Goetz L. 2006. A systematic review of readability and comprehension instruments used for print and web-based cancer information. *Health Education and Behavior* 33(3): 352–73.
- Gill AM, Whedbee K. 1997. Rhetoric. In TA van Dijk (ed) *Discourse as Structure and Process*. London: Sage: 157–84.
- Institute of Medicine. 2004. In L Nielsen-Bohlman, AM Panzer and DA Kindig DA (eds) *Health Literacy: A prescription to end confusion: Committee on Health Literacy Board on Neuroscience and Behavioral Health*. Washington, DC: The National Academies Press.
- Kalichman S, Benotsch E, Suarez T, et al. 2000. Health literacy and health-related knowledge among persons living with HIV/AIDS. *American Journal of Preventive Medicine* 18: 325–31.
- Kennedy V, Cram F. 2010. Ethics of researching with whānau collectives. *MAI Review* 3: 1–8.
- Kickbusch I. 2002. Health literacy: a search for new categories. *Health Promotion International* 17(1): 1–2.
- Kickbusch I, Wait S, Maag D. 2005. *Navigating Health: The role of health literacy*. London: Alliance for Health and the Future, International Longevity Centre – UK.
- Kickbusch I, Wait S, Maag D. 2006. *Navigating Health: The role of health literacy*. London: Alliance for Health and the Future, International Longevity Centre.
- Kidd J, et al. 2014. *Kia Mau te Kahu Whakamauru: Health literacy in palliative care*. University of Auckland.
- Knight R. 2006. *Literacy is a Health Issue*. Wellington: Pharmacy Guild of New Zealand Inc.
- Knowles MS, Holton EF, Swanson RA. 2005. *The Adult learner: The definitive classic in adult education and human resource development*. Burlington, MA: Elsevier.

- Koh HK, Berwick DM, Clancy CM, et al. 2012. New federal policy initiatives to boost health literacy can help the nation move beyond the cycle of costly 'crisis care'. *Health Affairs* 31(2): 434–43.
- Korhonen M. 2006. *Literacy and Health: The importance of higher level literacy skills: A discussion paper for Inuit communities*. Ottawa: National Aboriginal Health Organisation.
- Lawrenson R, Smyth D, Kara E, et al. 2010. Rural general practitioner perspectives of the needs of Māori patients requiring palliative care. *New Zealand Medical Journal* 123(1315): 30–6.
- Lawrenson R, Waetford J, Gibbons V, et al. 2013. Palliative care patients' use of emergency departments. *Journal of the New Zealand Medical Association* 126(1372): 80–8.
- Lindau ST, Tomori C, Lyons T, et al. 2002. The association of health literacy with cervical cancer prevention knowledge and health behaviors in a multiethnic cohort of women. *American Journal of Obstetrics and Gynecology* 186: 938–43.
- Liu JH. 2005. History and identity: a system of checks and balances. In: JH Liu, T McCreanor, T McIntosh, et al (eds) *New Zealand Identities: Departures and destinations*. Wellington: Victoria University Press: 69–87.
- Manning DL, Dickens C. 2006. Health literacy: more choice, but do cancer patients have the skills to decide? *European Journal of Cancer Care* 15(5): 448–52.
- Mead HM. 2003. *Tikanga Māori: Living by Māori values*. Wellington: Huia Publishers.
- Minister of Health. 2001. *The New Zealand Palliative Care Strategy*. Wellington: Ministry of Health.
- Minister of Health. 2010. *Kōrero mārama: Health literacy and Māori. Results from the 2006 adult literacy and life skills survey*. Wellington: Ministry of Health.
- Minister of Health and Associate Minister of Health. 2002. *He Korowai Oranga: Māori health strategy*. Wellington, Ministry of Health.
- Ministry of Health. 2012. *Rauemi Atawhai: A guide to developing health education resources in New Zealand*. Wellington: Ministry of Health.
- Moeke-Maxwell T, Te Awekotuku N, Nikora L. 2012. Dying to teach us about living. *Hui Whakapiripiri*. Auckland: Ellerslie Event Centre.
- Muircroft W, McKimm J, William L, et al. 2010. A New Zealand perspective on palliative care for Māori. *Journal of Palliative Care* 26(1): 54–8.
- Murtagh FEM, Bausewein C, Verne J, et al. 2013. How many people need palliative care? A study developing and comparing methods for population-based estimates. *Palliative Medicine* 0(0): 4–10.
- Naylor W. 2012. *New Zealand Palliative Care Glossary*. Wellington: Palliative Care Council of New Zealand, Hospice New Zealand and Ministry of Health.
- Nelson Marlborough DHB, Nelson Region Hospice Trust, Marlborough Community Hospice. 2006. *Palliative Care: Improving access to quality services project report*. Nelson, Nelson Marlborough DHB.
- Nutbeam D. 2000. Health literacy as a public health goal: a challenge for contemporary health education and communication strategies into the 21st century. *Health Promotion International* 15(3): 259–67.
- Nutbeam D. 2008. The evolving concept of health literacy. *Social Science and Medicine* 67(12): 2072–8.

- Nutbeam D. 2009. The evolving concept of health literacy: Farewell speech to the University of Sydney. Retrieved 15 September, 2012, from: [http://notes.med.unsw.edu.au/CPHCEWeb.nsf/resources/Don+Nutbeam+farewell/\\$file/Nutbeam+Health+literacy++Sydney+May+2009.pdf](http://notes.med.unsw.edu.au/CPHCEWeb.nsf/resources/Don+Nutbeam+farewell/$file/Nutbeam+Health+literacy++Sydney+May+2009.pdf)
- Oetzel JG, Sanchez C, DeVargas F, et al. 2007. Hispanic women's preferences for breast health information: character types and subjective cultural influences for communication preferences. *Health Communication* 21(1–11).
- Owen WF. 1984. Interpretive themes in relational communication. *Quarterly Journal of Speech* 70: 274–87.
- Palliative Care Council of New Zealand. 2011. *National Health Needs Assessment for Palliative Care: Phase 1 report: Assessment of palliative care need*. Wellington: Palliative Care Council of New Zealand.
- Palliative Care Council of New Zealand. 2013. *National Health Needs Assessment for Palliative Care: Phase 2 report: Palliative care capacity and capability in New Zealand*. Wellington: Palliative Care Council of New Zealand.
- Palliative Care Council of New Zealand. 2014. *Deaths in New Zealand: Regional and ethnic projections 2014–2026*. Wellington: Palliative Care Council of New Zealand.
- Palliative Care Subcommittee: NZ Cancer Treatment Working Party. 2007. *New Zealand Palliative Care: A working definition*. Wellington: NZ Cancer Treatment Working Party.
- Patiki Associates. 2002. *Cancer Control Issues for Māori: A scoping project commissioned by the Cancer Society of New Zealand*. Wellington: Cancer Society of New Zealand.
- Patton MQ. 2002. *Qualitative Research and Evaluation Methods*. Thousand Oaks: Sage Publications.
- Penney L, Fieldhouse W, Kerr S. 2009. *Te hononga a te hekenga o te rā: Connections at the going down of the sun: Improving Māori access to palliative care/tapuhi hunga roku in Te Tai Tokerau*. Kerikeri: Kiwikiwi Research and Evaluation Services.
- Pihama L. 2001. *Tihei Mauri Ora: Honouring our voices*. PhD thesis, University of Auckland.
- Plain English Campaign. 2001. *How to Write Medical Information in Plain English*. From: [www.plainenglish.co.uk](http://www.plainenglish.co.uk)
- Ratzan SC, Parker RM. 2000. Introduction. In CR Seldon, M Zorn, SC Ratzan, et al (eds) *National Library of Medicine Current Bibliographies in Medicine: Health Literacy*. NLM Pub. No. CBM 2000-1. Bethesda, MD: National Institutes of Health, US Department of Health and Human Services.
- Rauawaawa Kaumātua Charitable Trust Research Project Team. 2013. *Māori Health Literacy and Communication in Palliative Care: Kaumātua led models*. Hamilton.
- Robinson JD, Gott M, Ingleton C, et al. 2013. Patient and family experiences of palliative care in hospital: What do we know? An integrative review. *Palliative Medicine* DOI: 10.1177/0269216313487568.
- Rudd R. 2013. Needed action in health literacy. *Journal of Health Psychology* 18(8): 1004–10.
- Rudd R, Anderson JE, Oppenheimer S, et al. 2007. Health literacy: an update of public health and medical literature. In: JP Comings, B Garner, C Smith (eds) *Review of Adult Learning and Literacy*. Mahwah, NJ: Lawrence Erlbaum Associates: 175–203.

- Rudd R, Moeykens B, Colton C. 1999. Health and literacy: a review of the medical and public health literature. In: JP Comings, Garner B, C Smith (eds) *Annual Review of Adult Learning and Literacy*. San Francisco, CA: Jossey-Bass: 158–99.
- Rudd RE, Kirsch IS, Yamamoto K. 2004. *Literacy and Health in America*. Princeton, NJ: ETS Policy Information Center.
- Slater T, Matheson A, Davies C, et al. 2013. 'It's whanaungatanga and all that kind of stuff': Maori cancer patients' experiences of health services. *Journal of Primary Health Care* 5(4): 308–14.
- Sticht TG, Armstrong WB, Hickey DT, et al. 1987. *Cast-off youth: Policy and training methods from the military experience*. New York: Praeger.
- Sudore RL, Landefeld CS, Perez-Stable EJ, et al. 2009. Unraveling the relationship between literacy, language proficiency, and patient–physician communication. *Patient Education and Counselling* 75(3): 398–402.
- Tate HA. 2010. *Towards Some Foundations of a Systematic Māori Theology: He tirohanga anganui ki ētahi kaupapa hōhonu mō te whakapono Māori*. PhD thesis, Melbourne College of Divinity.
- Thomas DR. 2006. A general inductive approach for analyzing qualitative evaluation data. *American Journal of Evaluation* 27(2): 237–46.
- Tuhiwai-Smith L. 2005. On tricky ground: researching the native in the age of uncertainty. In: NK Denzin, YS Lincoln (eds) *The Sage Handbook of Qualitative Research*. Thousand Oaks, CA: Sage Publications: 85–108.
- Volandes AE, Paasche-Orlow M, Gillick MR, et al. 2008. Health literacy not race predicts end-of-life care preferences. *Journal of Palliative Medicine* 11: 554–762.
- Waikato District Health Board. 2005. *Waikato District Health Board Palliative Care Strategy Plan 2005–2010*. Hamilton: Waikato District Health Board.
- Wallerstein N, Duran B. 2006. Using community-based participatory research to address health disparities. *Health Promotion Practice* 7(3): 312–23.
- Workbase. 2013. *Literature Review of Health Literacy Education, Training Tools and Resources for Health Providers*. Auckland: Workbase.
- World Health Organization. 2011. *WHO Definition of Palliative Care*. Retrieved 25 April, 2012, from [www.who.int/cancer/palliative/definition/en/](http://www.who.int/cancer/palliative/definition/en/)
- World Health Organization. 2013. *Strengthening of Palliative Care as a Component of Integrated Treatment Throughout the Life Course*. 134th session, World Health Organization Executive Board. EB134/28.
- Zarcadoolas C, Pleasant A, Greer DS. 2005. Understanding health literacy: an expanded model. *Health Promotion International* 20(2): 195–203.