



Māori health literacy and communication in palliative care: Kaumātua-led models



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Waikato District Health Board



Mihi/Karakia

He Inoi

E te Atua Kaha Rawa

Te matapuna o te aroha me te rangimārie

Tenei te inoi atu ki a Koe

Kia whakanohohia Tōu Wairua Tapu ki roto ki te hinengaro

*Me te ngakau o tēnā me tēnā, me tēnā kia puawai ai, kia whai hua ai, hei
aha?*

Hei oranga a wairua, a ngakau mo te hunga kaumātua

Tukua mai tēnei e Ihowa i runga anō i te ingoa

A Tāu Tama a Ihu Karaiti

Amine

Prayer

Almighty Father, source of love and peace.

*Our prayer for your Holy Spirit to be immersed into this plan, in particular
the thoughts, ideas and aspirations it contains.*

To give it protection against the ignorant.

But rather allow its message to enter the minds and hearts of all who read it.

Our humble prayer is that with your blessing it will develop and blossom.

*Into a meaningful plan that will in turn enhance the physical and spiritual
wellbeing of kaumātua who access our services. We ask this in the name of*

Your Son Jesus Christ,

Amen

*Ko te mōhiotanga me te mātauranga kei te kaumātua,
engari ko te maramatanga kei te roanga a ōna ra*

*Understanding and knowledge is with the elder, but
wisdom comes with the length of his days.*

nā Matua Beau Haereroa

Whakapuakitanga—Foreword from the Board of Trustees

When the palliative care research project was first raised with the Trustees of the Rauawaawa Kaumātua Charitable Trust there were mixed reactions, because of the different experiences that each has had with palliative care. The trustees were nevertheless united in their confidence that the completion of the research could only have positive outcomes for our organisation and, more importantly, for those we serve. The trustees are honoured to be associated with so many distinguished people who are experts in palliative care and associated fields who have contributed.

The last journey is never the same for any person who takes it. How it turns out is based on a number of factors that must be sorted by the person and their whānau to determine the outcome they desire. The trustees are confident that this research will help whānau to understand the many complex issues and to make informed choices about the options available to them.

We have no doubt that satisfactory outcomes can only be achieved with the combined effort of many people ‘doing their best.’ The story that follows illustrates the intertwining of endeavours by many good people trying to do their best. The story also touches on many of the issues mentioned in the research.

A patient (and her whānau) was told by her doctor that she was terminally ill and could pass away in days, maybe weeks, perhaps months. She had an aneurism in her stomach that was growing and would eventually start to press on her vital organs and cause the organs to fail. The aneurism could not be operated on because of possible damage to vital organs. This advice to whānau automatically triggered a series of events which required the whānau to choose a palliative care provider. The whānau, because of past experience caring for their mother/grandmother, chose the hospice. This started a relationship between the whānau and the hospice workers that the whānau described as ‘really good’.

Because of the clear and precise way the doctor at the hospital had described the nature of the illness, the whānau were also able to develop a care strategy that they thought would be beneficial for their loved one. The whānau kept a daily diary so that they could ask the hospice workers and the doctor any questions. Whānau members kept a daily vigil. From day one the whānau concluded that they would protect their loved ones stomach by minimising any movement to it that could affect the aneurism. This seemed to work because instead of days she lasted three months. One day a new member of the hospice team came to wash the patient, and accidentally moved her more robustly than usual. Within days the person died. Although the whānau speculated that the more robust handling may have contributed to the passing of their loved one, they were only grateful that they had had their loved one for all that extra time. They were also immensely grateful for the help given by hospice workers, who were mostly volunteers that had given up their time to help.

Thank you to the research team for your tremendous effort, participants for your willingness to share and funders for making this research possible.

Tonga Kelly

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Ngā Mihi—Acknowledgements

The Rauawaawa Kaumātua Charitable Trust (hereafter Rauawaawa) expresses its sincere appreciation to the Ministry of Health and Health Research Council for funding this research. Furthermore, fundamental to the research was the generosity of kaumātua, their whānau members, palliative care kaimahi (workers), Hospice Waikato and the Palliative Care Unit at Waikato Hospital. Their open sharing of experiences and contributions has been central to the outcomes of this research.

Recognition must also be paid to fellow research members of the team who have provided tremendous support, guidance, mentorship, and much appreciated academic and clinical expertise. They are: Professor Linda Tuhiwai Smith, Professor John Oetzel, Dr Mary Simpson, Mr Maui Hudson, at Te Whare Wānanga o Waikato (The University of Waikato); Mrs Mere Balzer, Matua Beau Haereroa Ms Keri Thompson, Ms Rachel McClintock, Ms Arianna Waller, at Te Rūnanga o Kirikiriroa; Dr Peter Kirk, Mrs Kay Berryman, Mr Rawiri Blundell, Mr Wayne Johnstone, Ms Sandi Haggard, at the Waikato District Health Board; and Professor Ross Lawrenson, Mr James Waetford, Ms Veronique Gibbons, at The University of Auckland, Waikato Clinical School.

Last but not least our gratitude is extended to all those who worked diligently behind the scenes prior to and during the research, in particular the Trustees, Kotahitanga Committee, Volunteers and Kaimahi of Rauawaawa. A special note of thanks also goes to Ms Pare Meha, administrator for the project and Whaea Tiwai Iti an invaluable and inspirational Kuia on this research journey. Without the contribution of each and everyone this research would not have been possible and for that we are deeply indebted.

Ngā mihi nunui ki a koutou katoa

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Whakarāpopototanga—Executive Summary

Hei Manaaki ngā Kaumātua or enhancing the quality of life and well-being of kaumātua (elderly people aged over 55) is the vision of Rauawaawa Kaumātua Charitable Trust (hereafter referred to as Rauawaawa). After more than a decade of experience serving kaumātua, the Trustees identified palliative care as an area of high need for involvement, investigation and improvement. This in turn initiated a strong desire to be involved in this research area and provide opportunity for kaumātua voices to be heard.

Purpose/Aims

The central focus of our study was to identify access issues for kaumātua and their whānau in palliative care services, using a health literacy perspective. Health literacy is conceptualised as a multidimensional construct involving functional, technical, interactive, cultural, and critical/advocacy aspects. The **vision** for our study was to develop appropriate models of communication that can be utilised within palliative care services, including practices and interventions that enhance kaumātua and whānau knowledge and experience of palliative care, and improve delivery of those services by clinicians and community health kaimahi (workers). **Our aim** was to identify key communication practices that contribute to Māori health literacy and kaumātua and whānau experiences of end-of-life planning and care, as well as clinicians' and community kaimahi delivery of these services.

Research Design

The overall project was guided by Rauawaawa kaupapa Māori, in combination with kaupapa Māori research approaches. This alignment ensured stakeholder relevance and cultural appropriateness in the research endeavours. The research design included:

1. The establishment of an advisory group and a stakeholder end users group.



2. A systematic review of New Zealand and international literature.
3. Interviews kaumātua, whānau hui (focus groups) and focus groups with palliative health care kaimahi (workers).
4. An analysis of promotional brochures from providers of palliative care services.
5. A document audit of palliative care patients' use of Emergency Departments within Waikato District Health Board.

Ethical approval for this research was granted by the Northern Y Regional Ethics Committee: Reference - NTY 11/08/085 (September 2011). Noting that the ED audit fell under a separate application which was later approved by the same committee: Reference - NTY 11/11/111 (January 2012).

Findings

Literature review

A systematic review of literature from 2004-2011 identified the need for improvement in health literacy for kaumātua/whānau around functional, technical, interactive, and critical literacy. It also identified the need for improvement in health literacy for health care kaimahi and rōpū whakahaere providers around technical, interactive, cultural, and critical literacy.

Interviews with kaumātua

Our goal was to understand the facilitators and barriers to using palliative care from a health literacy perspective. We interviewed 21 kaumātua using interview procedures designed to elicit information in a culturally meaningful manner. The kaumātua interviews identified four core themes (each with subthemes) about the end-of-life journey and the use of palliative care services during this journey:

1. Cultural practices, values, and beliefs illustrating traditional Māori values.
2. Give and take with health care providers.
3. Responsibilities during the end-of-life journey.

4. Balancing the tensions of receiving and providing support during the end-of-life journey.

These themes emphasised the importance of interactive health literacy for kaumātua and whānau and interactive and cultural health literacy of health care kaimahi. Essentially, these areas are ones where health literacy can be improved to enhance the quality of palliative care services and the end-of-life journey.

Whānau Hui

The five whānau hui resulted in four primary themes with subthemes that reveal their complexity:

1. Whānau cultural dimensions of care and communication.
2. Tuitui ngā Tangata Kotahi—People working together: Whānau roles and responsibilities with palliative care.
3. Whanaungatanga: Tētahi ki Tētahi —Whānau communication as creating and maintaining relationships.
4. Me Waihotanga ki ngā Whānau ngā Tupuranga ngā o Mua —Whānau passing on their learning to the next event and next generation.

The analysis showed that problems emerge when either party—whānau and kaumātua or palliative care kaimahi and service—were unable to meet the interactive or cultural health literacy skills of the other. Yet, the *system* and *organisational* culture impacts levels of technical and cultural health literacy. Systems need to change to be able to better meet and develop palliative care ‘kaimahi’, kaumātua and whānau levels of interactive, cultural, and technical (systems) health literacy.

Focus Groups with palliative care kaimahi

The three focus groups identified four primary themes during the analysis process. The four themes centred on:

1. Engaging culture.



2. Engaging whānau.
3. Communicating with kaumātua /whānau.
4. Mahitahi—Care Coordination with other care kaimahi and providers.

The themes emphasise the importance of interactive and cultural health literacy when providing palliative care services for kaumātua and whānau.

Brochure analysis

The analysis revealed two main findings. The first group focused on functional and technical health literacy in terms of the accessibility and relevance of the brochures to kaumātua and their whānau. In short, different writing styles, unexplained medical terms that assumed reader knowledge, and the uneven use of relational devices such as personal pronouns, combined to make the communication process between palliative care provider and audience a mixed experience. The second group of findings centred on cultural health literacy in terms of the use of Māori images and te reo in brochures. While some brochures used Māori words, phrases, and symbols, overall Māori worldviews were absent from most of the brochures. Unintentional mixed messages, contradictions, and notable absences; the use of unnamed landscape; sometimes inappropriate placement of Māori images; along with the unintentional denial of alternative worldviews, would suggest that kaumātua and their whānau would be unlikely to relate culturally to the services offered.

On a positive note, many brochures aimed to connect sensitively with the intended reader and make them feel welcome. In summary, however, the providers would be unlikely to connect with kaumātua, or their whānau using brochures alone.

Emergency departments (ED) document audit

The key finding from this study was that there were no statistically significant differences between attendances at ED by ethnicity. Significantly, the study highlights the role ED provides in caring for palliative care patients and thus



signals that research needs to be undertaken to assess how EDs may be integrated into the service.

Unfortunately there is little from this record-linkage audit that directly informs health literacy issues for kaumātua and their whānau. Three notable points, however, were first, that people over 80 years may be less likely to be referred to palliative care, which suggests potential issues for communicating with very old people, and the possible roles of family or whānau of the very old. Second, palliative care kaimahi need to provide better information and networks for kaumātua to get care outside of the ED, and to better understand the reasons for patients using EDs. Third, palliative care rōpū whakahaere need to critically analyse service use and gaps to better serve patients and their whānau.

Conclusion: Making Connections

Based on the findings in this report, we developed several communication models that illustrate the ideal approach for enhancing health literacy. The first model offers a health literacy development approach to communication between kaumātua and whānau, and palliative care kaimahi. The second mode represents the specific aspects of communication and health literacy that are important in a particular relationship between two or more of the involved parties: kaumātua, whānau, kaimahi, and rōpū whakahaere. The third model uses the metaphor of the Tōtara to represent the inter-relationships and interdependence between the parties involved in palliative care, including kaumātua, whānau, and palliative care services. Each aspect of Te Tōtara as it relates to communication in palliative care is discussed.

We offer detailed recommendations for kaumātua, whānau, and kaimahi, to improve health literacy in the palliative care pathway. In addition we offer recommendations for palliative care rōpū whakahaere and the wider health sector.

Recommendations for palliative care rōpū whakahaere:

- 1) Wānanga, hui, awheawhe (seminars, meetings, and workshops).



- 2) Whakaruruhau kaumātua, whakaruruhau whānau (peer mentors)
- 3) Improving cultural and technical literacy of brochures
- 4) Cultural Supervision for Palliative Care Kaimahi

Recommendations for the health sector:

- 1) Provide guidelines/standards for rōpū whakahaere
- 2) Resource community health kaimahi

Chapter 1: He Kōrero Whakataki—Introduction

Background to the Research

Hei Manaaki ngā Kaumatua or Enhancing the quality of life and well-being of kaumatua (elderly people aged over 55) is the vision of Rauawaawa Kaumatua Charitable Trust (hereafter referred to as Rauawaawa). After more than a decade of experience serving kaumatua, the Trustees identified palliative care as an area of high need for involvement, investigation and improvement. This in turn initiated a strong desire to be involved in this research area and provide opportunity for kaumatua voices to be heard.

Kaumatua played an integral role throughout the research. Kaumatua were integral to each step of the research process. They guided development of kaupapa-Māori research methods appropriate to kaumatua and the research focus, and supported research activities—that is, project hui, kaumatua interviews, whānau hui, kaimahi (worker) focus groups, the brochure analysis, thematic analysis, models of communication development. Kaumatua also assisted with the review and feedback on all reports.

As an organisation it was obvious that to do justice to such an important kaupapa (focus) as palliative care and health literacy research, Rauawaawa would need to seek skills and expertise from outside of the rūpū whakahaere (organisation). Thus whakawhanaungatanga, or the process of drawing on relationships, was crucial to securing team members for the research project. The partnering organisations and their respective teams are shown in Table 1.1.

Since inception, the basis of engagement with members of our collaborative, multi-partner research team has been consultation, openness, transparency and respect. At the planning stages of the project, the different tasks needing to be

completed and the lead for the task were identified. It was also agreed, however, that lead groups would be supported by other team members if and

Table 1.1: Research Team Membership

Collaborative Research Organisations	Research Team Members
Rauawaawa Kāumatua Charitable Trust	Mrs Rangimahora Reddy Whaea Tiwai Iti
Te Kotahi Research Institute Te Whare Wānanga o Waikato/ The University of Waikato	Professor Linda Tuhiwai Smith Mr Maui Hudson
Management Communication Department Waikato Management School/Te Raupapa Te Whare Wānanga o Waikato The University of Waikato	Professor John Oetzel Dr Mary Simpson
Te Rūnanga o Kirikiriroa	Whaea Mere Balzer Matua Beau Haereroa Ms Keri Thompson Ms Rachel McClintock Ms Arianna Waller
Te Puna Oranga Waikato District Health Board	Mrs Kay Berryman Mr Wayne Johnstone Mr Rawiri Blundell
Palliative Care Unit Waikato District Health Board	Dr Peter Kirk Ms Sandra Haggard
Waikato Clinical School Faculty of Medical and Health Sciences The University of Auckland	Professor Ross Lawrenson Mr James Waetford Ms Veronique Gibbons



when needed. Project hui (meetings) and awheawhe (workshops) were regularly held and feedback was continuously shared with the entire group. The learning and relationships gained over the duration of the project has contributed significantly to capacity development for Rauawaawa staff members and it is hoped that this is also the case for other team members. (Table 1.2 in Appendix 1.1 gives further information on some of the main tasks carried out during the project, the organisations that took the lead, their key supporters and other contributors.)

This research aimed to identify key communication practices and develop communication model/s that contribute to Māori health literacy and Kaumātua and whānau experiences of palliative care, as well as clinicians' and community kaimahi delivery of these services. Our methods included an international literature review, interviews with individual kaumātua, whānau hui (focus groups), palliative care kaimahi focus groups, an analysis of brochures from palliative care providers, and a document audit of those on the palliative care register going through the Emergency Departments of hospitals in the Waikato.

Our team approach to conducting the research and reporting on the findings has resulted in a report that acknowledges varying writing styles and voices throughout. This approach was chosen to ensure the member most skilled in a particular area lead it. Whilst there are differences reflected in the presentation of this report there is unity in its substance. This unity is the result of opportunities to continuously review and provide feedback during the research project.

Introduction to the Palliative Care Context and Research Approach

Palliative care is the care of individuals with life-limiting illnesses; people dying from active, progressive, or other conditions that are not responsive to curative treatment (Minister of Health 2001; Waikato District Health Board

[Waikato DHB] 2008). Such care aims to optimise an individual's quality of life and support the individual's family, whānau, and other caregivers through the illness and after death (Minister of Health 2007). Palliative care encompasses a Te Whare Tapa Whā approach, addressing tinana (physical), whānau (kin/social), hinengaro (mental/emotional) and wairua (spiritual) dimensions of wellbeing (Minister of Health 2001).

The central focus of our study was to identify access issues for kaumātua and their whānau to palliative care services through a health literacy perspective. Kaumātua (Māori elders) are key because 'as carriers of culture, anchors for families, models for lifestyle, bridges to the future, guardians of heritage and role models for younger generations' (Taskforce 2010, p 14) they contribute to whānau (kin) wellbeing, as well as to wider Māori and New Zealand societies (Durie 2003). In addition, kaumātua are the highest at-risk group in terms of the palliative care pathway (Minister of Health 2007) and one of the highest groups with poor health literacy (Minister of Health 2010). Consistent with Kaupapa Māori (Māori philosophy) and whānau values, whānau health literacy is also crucial to the health and wellbeing of kaumātua who are in the palliative care pathway. In light of this, we took a whānau ora approach, including both kaumātua (men and women aged 55 years-plus) and whānau at the core of the research. For this research, whānau refers to people caring for/involved with kaumātua with palliative care needs, and includes rangatahi (youth approx. 16-29years), pakeke (adults approximately 30-49years) and kaumātua (50years-plus).

The vision for our study was to develop appropriate models of communication that could be utilised within palliative care services, including practices and interventions that enhance kaumātua and whānau knowledge and experience of palliative care, and improve delivery of those services by clinicians and kaimahi (community health workers). Our aim was to identify key communication practices that contribute to Māori health literacy and

kaumātua and whānau experiences of end-of-life planning and care, as well as clinicians' and community workers' delivery of these services. We develop this chapter in the following sections:

1. provide a context for this study by exploring the palliative care needs of Māori;
2. introduce health literacy and define it as a multidimensional concept;
3. offer a description of the research approach; and
4. provide an overview of the research methods used to address our aim (with more specific methods in the respective research chapters).

Palliative care needs of Māori

The predictions for ageing of the Māori population (Statistics New Zealand 2008) in conjunction with poor health literacy of Māori (Minister of Health 2010), and needs for improved access to and use of culturally appropriate palliative care raise (Minister of Health 2001) policy, resource, and service delivery implications for kaumātua and whānau. Also, the projected demographic change has implications for current and future cultural profiles and roles of older Māori as kaumātua and leaders (Durie 2003).

Significant health disparities exist between Māori and non-Māori (Blakely et al 2004; Davis et al 2006; Howden-Chapman et al 2000), with the average life expectancy for Māori being 9 years less than that of other New Zealanders (Hefford et al 2005). Associated implications of such disparities include but are not limited to individual, economic, social and cultural costs (Davis et al 2006; Waikato DHB 2007). A recent report (Midland Cancer Network 2009) found that Māori, proportionally, had the highest incidence of lung cancer in the Midland Cancer Network region. In addition, Māori had higher rates of avoidable cancer hospitalisations than non-Māori, and Māori over 65 years had the highest rates overall. Nationally Māori have significantly higher rates of cancer mortality compared with non-Māori (Robson and Harris 2007), but

rates are higher still in the Midland Cancer Network region (Midland Cancer Network 2009). Along with cancer, cardiovascular disease and respiratory disease are the most common causes of death for Māori 65years-plus; Māori have a big burden of illness, with deaths from these diseases being 76% higher than for non-Māori (Robson and Harris 2007). Likewise, Māori rates for chronic life-limiting conditions, such as chronic obstructive pulmonary disease, ischemic heart disease, and complications and deaths from diabetes are significantly higher than for non-Māori (Robson and Harris 2007). Because chronic diseases cause over 80% of adult deaths, and in 70% of cases, decisions are needed for palliative health care (Clark and Daltrey 2010), Advanced Care Planning (ACP), or planning for end-of-life care, is important. Given such statistics, improved access and comprehensive health literacy is critical for kaumātua with palliative care needs and their whānau.

A decade ago, the New Zealand Palliative Care Strategy (Minister of Health 2001) identified 50-70% of people as preferring to die at home; given that more prefer to die at home, there remain implications for palliative care service development. Palliative care in New Zealand has historically focused on people with cancer, in part because the benefits of palliative care for people dying from other conditions went unrecognised (Minister of Health 2001). Further, Māori access to, and utilisation of palliative care support services have been affected by several issues including; uncertainty about what palliative care means and available services; low numbers of Māori palliative care provider organisations; lack of education amongst Māori providers; under-representation of Māori health workers in palliative care; and lack of understanding on behalf of mainstream providers of the whānau model of health and illness and Māori cultural beliefs in providing care for the dying (Waikato DHB 2005). Strategies identified for developing culturally appropriate palliative care services for Māori have included; promoting informal links between local service providers, including between palliative care providers and Māori development organisations (Minister of Health

2001); employing and training staff to enable them to meet the needs of Māori (Minister of Health 2001); and adopting principles of Te Whare Tapa Whā to ensure provision of holistic services (Waikato DHB 2008). However, increased availability of culturally appropriate services has not increased access and utilisation by Māori (Moeke-Maxwell 2010). This lack of utilisation raises questions about continuing barriers including communication dimensions of service delivery and health literacy.

Health literacy

Consistent with well documented conceptualisations, health literacy is a multidimensional concept (Nutbeam 2000; Mogford et al 2011; Pearson and Saunders 2009; Zarcadoolas et al 2005), and concerns communities as well as individuals (Kickbursch 2002). The benefit of this multidimensional approach to health literacy is that it enables a vision of personal and collective empowerment (Nutbeam 2000; Zarcadoolas et al 2005). The five dimensions, functional, technical, interactive, political, and cultural health literacy (Nutbeam 2000; Zarcadoolas et al 2005) are key factors in palliative-care health literacy of kaumātua and whānau, and central to our proposed research framework. Whilst the vast majority of research on health outcomes and health literacy has focused on functional health literacy, recent research has expanded to include these other areas. There is little explicit research on the relationship of interactive, critical, and cultural health literacy to health however the literature shows indicators of their importance in meeting the palliative care needs of kaumātua and their whānau.

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 (Kickbusch et al 2005; Ratzan and Parker 2000). By way of comparison, functional health literacy is a significant problem in the United

States with 47% of Americans not reading at a high school level (Young 2004) and health literacy identified as contributing to health care costs estimated at \$73 billion (Kickbusch et al 2005). Similarly, a recent New Zealand report (Minister of Health 2010) found that on average, New Zealanders have poor health literacy skills and therefore, insufficient skills to cope with the demands of typical health literacy. Māori, however, have significantly poorer health literacy skills than non-Māori, and across all age groups, have fewer with good health literacy and more with poor health literacy than non-Māori. Further, Māori aged 50-65years, had the lowest health literacy scores (Minister of Health 2010). International research has found that low functional health literacy is associated with lower knowledge about diseases, lower health status, lower health service utilisation, and higher service utilisation costs (Baker et al 1998; Berkman et al 2011; Kalichman et al 2000; Lindau et al 2002). This would suggest that poor health literacy of Māori is a contributing factor to health disparities in life-limiting diseases, and poor access to, and utilisation of palliative care services.

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 (Zarcodallas et al 2005). The literature does not directly address the technical literacy of Māori, but technical literacy is closely associated with functional literacy. Further, there is some evidence that suggests that many Māori do not understand what is involved in palliative care (Minister of Health 2001). In contrast, health care kaimahi have a high level of understanding of technical terms and yet there appears to be mixed ability to be able to explain those terms to patients.

Interactive health literacy concerns 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).



With regard to elders 65years and over, low reading comprehension and cognitive abilities have been found to independently predict mortality and therefore, have implications for communication strategies of health organisations and workers (Baker et al 2008). This includes not only communication with kaumātua, but also their whānau. Family and friends have been found to play important roles in health literacy in end-of-life decisions. One study showed that many people aged 50years-plus, preferred to rely on family, or friends, to use their personal judgment over documented care plans when the time came to make decisions (Sudore et al 2008). This study also found that these older people contemplated and discussed their care plans with family or friends rather than with clinicians, but that those who talked with family/friends were more likely to talk through these issues with clinicians. Another study revealed that clinicians' processes in communicating diagnosis and prognosis affected how palliative care patients perceived information (Kirk et al 2004), which would suggest that the interactive communicative skills of clinicians are as important to patient health literacy as the patient's communication skills and those of their family or whānau.

Political health literacy is 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). For instance, from a whānau ora perspective (Taskforce 2010), access to palliative care is not enough; kaumātua, whānau, and Māori communities need to be able to assess if services' meet their needs, and communicate to palliative care rōpū whakahaere (provider organisations) in ways that enable them to respond positively.

Cultural health literacy concerns collective beliefs, customs, world-view and social identity that guide engagement with, interpretations of, and actions



associated with health information and issues (Zarcadoolas et al 2005). The Whānau Ora principle of ‘Ngā Kaupapa Tuku Iho’ (Taskforce 2010, p 22), Te Ao Māori kaupapa, tikanga (world view, values, beliefs, obligations, responsibilities, and protocols), constitute cultural health literacy of Māori. In the context of palliative care needs, cultural health literacy is the knowledge, skill and capacity of palliative care providers, clinicians and health kaimahi, to convey health information and practise in ways that take account of, and engage with, cultural understandings of kaumātua and whānau. Such issues are illustrated in research that identifies factors that contribute to communication experiences between kaumātua and organisational representatives (Richardson and Zorn 2012).

Research overview

A whānau ora and Kaupapa Māori research approach (Taskforce 2010) to palliative care access, from a health literacy perspective, offers kaumātua and whānau opportunities to assess roles and expectations of each other, enables intergenerational transfer, and supports empowering interactions between generations, thereby preparing future generations.

Whānau Ora is distinctive because it recognises a collective entity, endorses a group capacity for self-determination, has an intergenerational dynamic, is built on a Māori cultural foundation, asserts a positive role for whānau within society and can be applied across a wide range of social and economic sectors. (Taskforce 2010 p 30)

A whānau ora research approach that foregrounds the needs of kaumātua within the whānau has ‘transformative potential’ (Taskforce 2010 p 62) in its capacity to build intergenerational knowledge, enhance whānau capability and resilience, and strengthen cultural capacity for collective action.

Further, Kaupapa Māori lies at the heart of this study, and actions, methods, and processes consistent with kaupapa Māori will be promoted and enacted in our Whānau Ora located research design. The goal of this project was to advance knowledge that will enhance functional, technical interactive, political, and cultural health literacy (Nutbeam 2000) in palliative care of kaumātua and whānau. The key research steps for this project are:

1. Establish an advisory group;
2. Review New Zealand and international literature that identifies key issues in health literacy in palliative care involving kaumātua and their whānau;
3. Perform interviews with kaumātua who have experience with palliative care; Hold interviews with whānau about their experiences and perceptions of palliative care;
4. Conduct interviews with palliative care kaimahi about appropriate communication and care of kaumātua and their whānau.
5. Complete an analysis of brochures used for palliative care;
6. Conduct an Emergency Department Audit.

The advisory board was used to provide oversight and direction to our research and ensure we were following a whānau ora and kaupapa Māori approach. The advisory board consisted of kaumātua and kaimahi associated with Rauawaawa Kaumātua Charitable Trust (primarily board members). The role of this group was to ensure the cultural integrity or tikanga of research, by providing oversight, guidance, and input into all the research methodology, procedures, data-collection processes, and analysis that the research team undertook.

As a result of this research, we developed communication models to capture key aspects of the palliative care pathway that can enhance health literacy of kaumātua, whānau, kaimahi, and rōpū whakahaere and also the access and



utilisation of services. Further, we identify specific recommendations from the data and also summarise some general recommendations to facilitate the achievement of concrete goals. We present these models and recommendations in Chapter 9.

Preview Report Structure

A preview of the work undertaken to meet the aims of this research is included in each chapter outlined below:

Chapter 2, Literature Review, provides a systematic review of literature related to palliative care and health literacy in indigenous communities around the world. It included review of literature pertaining to the 2004 – 2011 period and resulted in 59 articles (identified as relevant) being utilised.

Chapter 3, He Whakaritenga—Research Approach, discusses the kaupapa Māori approach used and highlights it as that aligning with the way in which Rauawaawa operates on a daily basis.

Chapter 4, Whai Whakaaro o Ngā Kaumātua —The Hopes and Thoughts of Kaumātua, captures thoughts of 21 kaumātua from individual interviews. The chapter details the resulting four core themes (each with subthemes) about the end-of-life journey and the use of palliative care services during this journey.

Chapter 5, Whai Whakaaro o Ngā Whānau—The Hopes and Thoughts of Whānau, captures thoughts of 33 whānau who participated in one of the five whānau hui/focus groups. The chapter details the resulting four core themes (each with subthemes) that helped gain an understanding of the facilitators and barriers to whānau using palliative care from a health literacy perspective.

Chapter 6, Whai Whakaaro o Ngā Kaimahi— The Hopes and Thoughts of Palliative Care Workers, presents the thoughts of 21 palliative care kaimahi



from three focus groups held with hospital, hospice, and community kaimahi. The chapter details the resulting four core themes (each with subthemes) that helped gain an understanding of the interactive and cultural health literacy factors associated with delivering high quality care to kaumātua and whānau from a palliative care kaimahi perspective.

Chapter 7, *Kei Whea Ngā Mohiotanga?—A Cultural-Discursive and Health Literacy Analysis of Palliative Care Brochures*, discusses the results of an analysis of 99 brochures from various New Zealand palliative care providers. The chapter details the two main findings related to functional, technical, and cultural health literacy.

Chapter 8, *The Use of Emergency Departments by Palliative Care Patients: A Document Audit*, reports on the study of palliative care patients using Emergency departments (ED), in the Waikato DHB catchment zone for a 12 month period between 1 November 2010 and 31 October 2011.

Chapter 9, *Making Connections: Models of Communication and Health Literacy in Palliative Care of Kaumātua and their Whānau*, presents and discusses three models of communication for enhancing health literacy based on the findings in this report.

Please note the convention for using Māori terms in this report is that for the first use in a chapter, the kupu Māori will follow with the English word in brackets. In addition, the rārangi (glossary) of kupu Māori—English is in Appendix 1.2. We adopted the stylistic convention of italicising participant quotes so that they could be easily distinguished from our text. We did this to honour the words of the kaumātua, whānau, and kaimahi who contributed so willingly to the research.

Chapter 2: Arotakenga Mātātuhi—Literature Review

Introduction

The literature review set the context for the project and explained the purpose of the research. With that context and general purpose in mind, the current chapter describes the literature review we conducted to guide the larger research project. Our purpose in completing this literature review comprised each of the following objectives.

1. To identify the current research findings about communication and health literacy around palliative care for Māori and particularly kaumātua (older Māori).
2. To identify the communication and health literacy factors that facilitate and inhibit the utilisation of palliative services for Māori and particularly kaumātua.
3. To use the current findings to frame and guide the research proposed in this project. We define kaumātua as Māori who are 55 years or older. In sum, we want to know what current research exists around this topic and use it to make sure the research added to the literature.

We conducted a systematic review to accomplish these specific purposes.

This chapter is organised in three sections: methods for the systematic review; findings of the review in terms of descriptive information about the study and also a synthesis of the findings using a model of health service utilisation and health literacy; and discussion of the findings in terms of the quality of extant research and areas for future research.

Methods

We conducted a systematic review of the literature regarding palliative care, health literacy, and indigenous communities from 2004 to 2011. We deemed the eight year period was sufficient to provide a recent and comprehensive examination of the literature. The search supported this decision in terms of finding enough relevant research articles. In addition, we assumed that we

would uncover some systematic reviews that would provide indicators of key themes from years not included in the search, which was also true. The systematic review was conducted following the preferred reporting items of systematic reviews and meta-analysis (PRISMA; Moher et al 2009) guidelines.

Search Terms and Data Bases

The search was completed with Library search, which is a tool that includes major databases such as ProQuest 5000, EBSCO, Emerald, Scopus, PubMed, and Medline. Search terms included various combinations of the following:

1. 'palliative care', 'end-of-life care', 'chronic care', 'palliative health services';
2. 'Māori', 'indigenous', 'Aboriginal', 'First Nations', 'American Indian', and 'Native American'; and
3. 'health literacy'.

Health literacy was only included along with terms in group 1 (except that it was paired with Māori in the 2 terms), while the terms in groups 1 and 2 were combined with each other and also with health literacy.

We briefly explain the rationale for including the search terms. We began with a search of 'palliative care', 'health literacy', and 'Māori' which resulted in one article. Thus, we needed to expand the search terms to include enough relevant articles. We then examined the terms without regard to any particular cultural group. At this point, we found nearly 500 articles each in searches such as 'health literacy' and 'palliative health services' or 'health literacy' and 'palliative care.' Combining all of the possible search terms was going to yield too many articles to effectively sort, review, and synthesise. Thus, we decided to consider other indigenous cultures around the world because there are some parallels with Māori (eg, colonisation, similar health and socio-economic outcomes). We assumed that this expansion would yield sufficient numbers of articles and also involve some cultural similarities in the

populations, although certainly there are cultural differences among indigenous communities. We identified a total of 571 abstracts using these search strategies.

Search Process

There was a three step process for reviewing articles for the systematic review (see Figure 2.1). First, abstracts of the articles identified with the search terms were reviewed using inclusion and exclusion criteria. There were three groups of inclusion criteria.

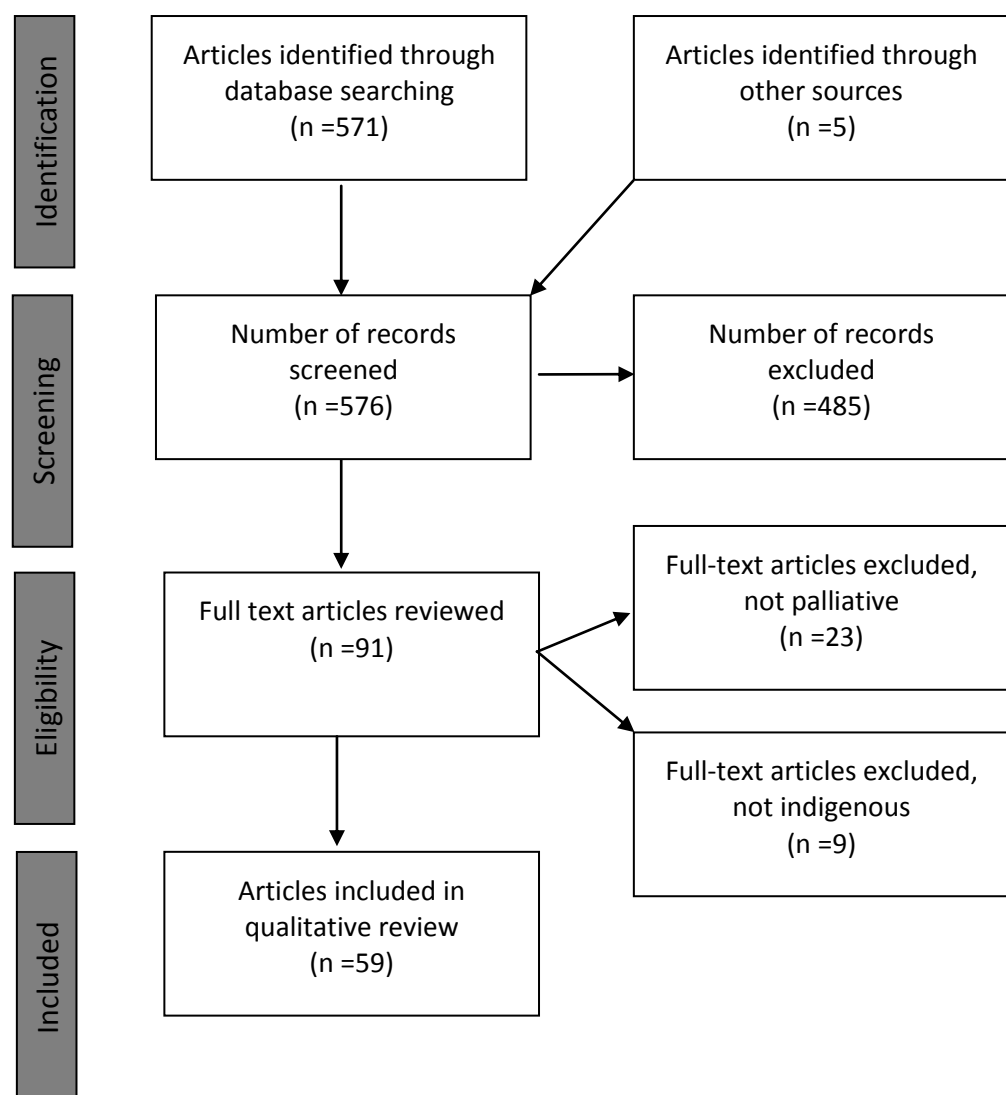
1. One or more of the following demographic characteristics: indigenous community or cultural minority or low socio economic status/underserved, rural.
2. Discussion of health communication, health literacy, or service delivery.
3. One or more of the following conditions: end-of-life, palliative, long-term, or chronic.

The exclusion criteria were those that focused on; specific medical treatments (eg, use of opioids); acute life-threatening condition; and health promotion/prevention. We included abstracts that met two of the three inclusion criteria in order to ensure a sufficient sample of articles. During this first stage, it became apparent that the number of articles was over 200 and beyond the scope of the systematic review. Thus, we required that all three criteria had to be met during the second stage. After removing duplicates, there were 86 abstracts.

Finally, during the final stage, we reviewed the specific articles against the inclusion criteria and excluded articles that did not have an indigenous population or did not include end-of-life or palliative care. During this stage, nine articles were removed because they did not have an indigenous population and 23 articles were removed because they did not focus on palliative care. We identified 56 articles that met all three inclusion criteria.

In addition, peers provided us with five articles/reports that also met the inclusion criteria resulting in a total of 59 articles/reports. One exception is that we did include three articles/reports that focused on models of care for Māori even though they did not focus on palliative care. Given the relevance to other facets of the project (eg, health literacy and service models), they remained in the database. Figure 2.1 provides a flow chart of the search process.

Figure 2.1: Flow chart of the search process.



Findings

The findings are organised around two sections. First, we present the summary of the types of articles and provide a brief evaluation of the body of literature. Second, we organise the themes of the extant literature in terms of a general model of health services that emphasises communication and health literacy components.

Summary of the Literature

Table 2.1 presents the types of articles uncovered in the literature review and the location where the studies were conducted. The table illustrates that 44 percent of the articles were data-based studies (both qualitative and quantitative approaches to data collection) and another 29 percent were editorials/arguments about effective approaches to care. Another 10 percent

Table 2.1: Summary of Articles in the Systematic Review

Type of Study	Location					Total
	New Zealand	United States	Canada	Australia	Other/Not Specified/Multiple	
Empirical Study	5	3	2	13	3	26
Systematic Review	0	1	0	2	3	6
Case Presentation	1	1	2	1	1	6
Editorial/Argument	2	2	3	5	5	17
Models of care for Māori	4	0	0	0	0	4
Total	12	7	7	21	12	59

were narratives reviews of the literature and another 10 percent were case presentations. In terms of location, Australia was the most prevalent with 36 percent of the articles, while New Zealand had 20 percent, and the United States and Canada had 12 percent each. Twelve of the articles were in other locations or had a non-specified or multi-locale.

The vast majority of the studies were qualitative in nature. This is not surprising given the infancy of this area of research. Qualitative research is a strong approach when exploring the nature of the topic and when not a lot is known or the issues are anecdotal. The quality of the individual studies is good to excellent given the purpose of the study and the questions asked. In addition, there were a number of editorials and case studies illustrating the experiences of practitioners. There is no longitudinal research and there is limited research examining statistical models of factors that might be associated with quality of care. Further, there are no specific evaluation studies of models of palliative care, although there are arguments about what the nature of that care should look like. In summary, the research demonstrates an underexplored topic with limited empirically-supported information about the effective approaches to palliative care and health literacy in indigenous communities. In fact, the number of studies is inflated, however, by the fact that seven of the articles came from a single data base of 72 interviews (McGrath 2007, 2010; McGrath Holewa et al 2006; McGrath Ogilvie et al 2005; McGrath Patton et al 2006; McGrath and Phillips 20082006and her colleagues). This is not a criticism of those authors, but simply recognition that the 59 articles are not completely unique.

Organising Model for the Literature

Within health services research, a leading model examining health and health seeking is the behavioural model (Andersen 1995). Gelberg et al (2000) developed this model to include a focus on vulnerable populations. The

model suggests that health service utilisation for a population is a function of a predisposition by people to use services, factors that enable or impede such use, and people's need for care. Predisposition includes demographic factors, health beliefs, social structures that lead to people's perception of usefulness of health services. Enabling (or impeding) factors are family and community resources that encourage or discourage service utilisation (eg, social support, stigma, income). Need focuses on perceived or actual health. These three factors influence the health behaviours in a population and include personal health practices and health-seeking behaviour. The outcomes from those behaviours then influence our future predispositions, enabling conditions, need, and health behaviours. The model is meant to be general so that it can be adapted to a specific population. Further, the model is meant to explain the behaviour of a particular population and thus it does not consider the interactive features of patients with medical care givers. This limitation is something we addressed by adapting the model.

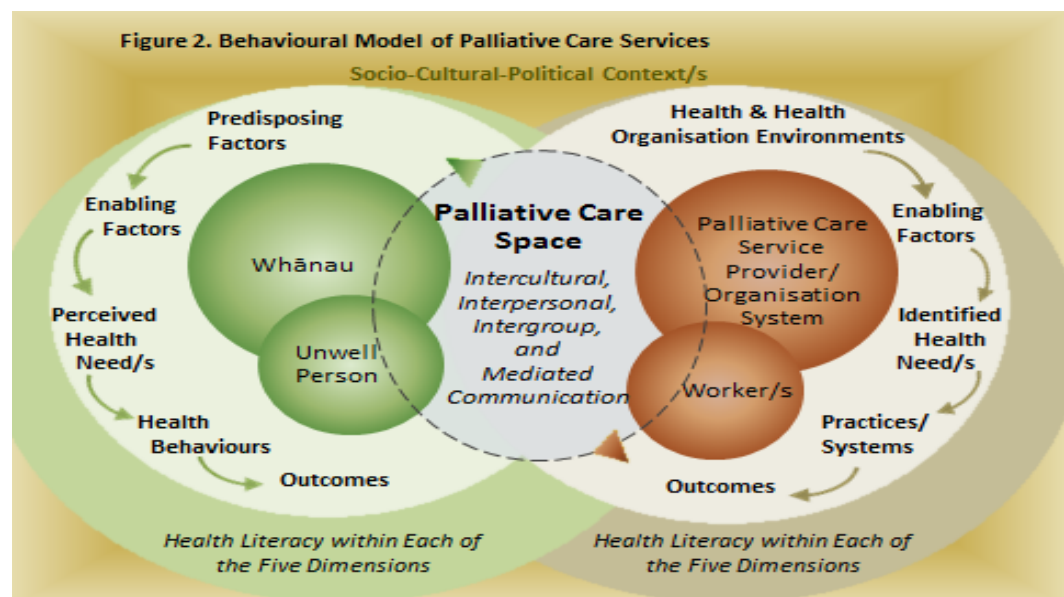
The revised model identifies a 'palliative care space' in which un-well patients and their relations (ie, kaumātua and their whānau) seek support and palliative care services, and rōpū whakahaere (provider organisations) and their kaimahi (care-staff) offer/deliver those services. We frame the 'palliative care space' as the space in which the various individuals and groups negotiate various needs. These include the needs of the un-well kaumātua and his or her whānau, as well as the possibilities for, and limits of, services the provider/rōpū whakahaere can offer. There is a range of communication forms that may take place: intercultural (eg, including rōpū whakahaere culture); interpersonal (eg, face-to-face, phone); intergroup (eg, between service providers), and mediated (eg, print, web-pages). Further, we adapt Gelberg et al's (2000) original model to incorporate provider/rōpū whakahaere systems perspectives. This enables the evaluation of systems as well as individual performances of those (ie, employees) who assess, offer,

and deliver palliative care services. Finally, the proposed model incorporates five dimensions of health literacy:

1. Functional literacy.
2. Interactive/ interpersonal literacy.
3. Technical/science literacy.
4. Cultural literacy.
5. Civic or political health literacy (Nutbeam 2000; Zarcadoolas et al 2005).

In applying these dimensions to the seekers/users of palliative care, as well as rōpū whakahaere and kaimahi that provide those services, the model is further located within a communicative framework. The model is presented in Figure 2.2 and we used it to organise the literature. Specifically, the literature for each component is briefly synthesised with exemplar studies reviewed in more detail.

Figure 2.2: Behavioural Model of Palliative Care Services



Predisposing Factors

Predisposing factors included demographic characteristics, health beliefs, and historical context. A systematic review of the literature identified demographic characteristics of adult patients that were associated with lower

utilisation of community palliative care services (ie, not hospitalisation; Walshe et al 2009). Walshe et al conducted a search of databases from around the world from 1997 to 2008 to identify whether there were inequities in service utilisation for palliative care. They identified 48 studies that met their search criteria of adult patients with a comparison group. They found that the following groups were less likely to use community palliative care services. These groups were those who were:

1. Older;
2. lower socioeconomic status;
3. male;
4. not married;
5. ethnic minority populations (including indigenous);
6. without cancer; and
7. without a home carer.

Walshe et al noted that the studies did not identify reasons for variable access or examine complexities of service utilisation.

Several studies address health beliefs. In some cases, a lack of knowledge of palliative care services by patients limits utilisation (Sullivan et al 2003). Additionally, there is belief of many providers, and also some empirical evidence, that indigenous patients prefer to die at home and thus only want palliative services in the home (DeCourtney et al 2010; Kelly and O'Driscoll 2004; McGrath 2007; Sullivan et al 2003). Some attribute this to a fear of hospitals (Falleni 2004). For example, McGrath (2007) interviewed 72 people in Australia including indigenous patients, indigenous caregivers, and health care kaimahi (both indigenous and not) about the documented wishes about place of dying. She found that there was a clear statement of the wish of Aboriginal people from rural areas to die at home connected to land and family. Lawrenson et al (2010) examined rural general practitioners' perspective of the needs of Māori patients receiving palliative care. They surveyed 186 GPs and found that nearly 62 percent of Māori patients died in

their homes as opposed to other locations; this is compared to 46.5 percent of all palliative care patients. The reason for this difference was not identified.

Two studies considered the importance of risk and protective factors of health for kaumātua, particularly around cultural issues. Waldon (2004) examined the health and attitudes of 429 kaumātua, all at least 60 years old. He found that better health was associated with active participation and affiliation with culture, home ownership, and higher incomes. Kēpa (2011) explored attitudes of nearly 270 kaumātua aged 80-90 years. She found that 87.7 percent of participants reported that language and culture were moderately to very important to well-being (including health). In addition, 76.9 percent said their iwi (tribe) was moderately to very important to well-being. While these studies did not directly examine use of palliative care, they do demonstrate the importance of language and culture for health.

Finally, the negative historical context was identified as a factor for low service utilisation. The colonial history of indigenous cultures has created distrust for mainstream institutions including health providers (Durie 2011; Sullivan et al 2003).

Enabling and Impeding Factors

Enabling and impeding factors for palliative care services were not strongly addressed in the literature. The importance of being close to family and having family involved in the decision-making process was documented as important (DeCourtney et al 2010; McGrath 2007; Sullivan et al 2003). For example, DeCourtney et al (2010) conducted six focus groups with 84 elders in six Alaskan Aboriginal communities. The authors found three themes. Elders talked about the:

1. 'Normalness' of dying and culturally appropriate practices around dying.
2. Importance of caring for those who are dying at home.

3. Importance of involving family in the decision-making process about the nature of the care.

If the family connection is maintained then family becomes an enabling factor for seeking services. If it cannot be maintained, it is an impeding factor. For example, Shahid et al (2011) conducted 30 in-depth interviews with indigenous Australians suffering from cancer. They found that displacement from family and having a lack of support persons were barriers to care raised by participants.

Older patients and palliative care recipients also report a concern for the burden placed on their whānau and/or caregivers (DeCourtney et al 2010; Gysels et al 2011; Harding and Higginson 2005). Gysels et al completed a systematic review of the literature on palliative care services in sub-Saharan Africa. The authors identified 51 articles that included qualitative research on the topic. They found that the burden of end-of-life care is high for caregivers and includes physical, emotional, and social aspects. In many cases, this burden was complex because of the various roles that caregivers have. Further, studies identified the need for caregivers to have training, support, and tools to properly care for the dying. Thus, the needs of caregivers are often overlooked in the palliative care process and yet it appears to be a critical factor for enabling/impeding utilisation of palliative care.

Need

The need for palliative care was not directly investigated in the articles included. Almost all of the published studies included rationale for studying palliative care in terms of an ageing population and resulting health problems. There was frequent mention of the health inequities in general. However, there were no direct surveys of specific need for palliative care. This is not surprising given the temporary nature of palliative care and thus it is difficult to identify a concrete need. Instead, the focus in the studies was the perceived need for palliative care and whether palliative care services will help (Waikato DHB 2005).

Health-Seeking Behaviours

The literature addresses a variety of issues related to health-seeking behaviours. In fact, this aspect of the palliative care model is the most researched. The palliative care space of health seeking includes patient perspectives, health care worker perspectives, the health care system constraints, and the communication between patient and health care kaimahi.

Patient perspectives.

From the patient perspective, the focus in research is about barriers to seeking care. Some of these barriers are communication related, which are discussed below. Others of these focus on value differences (Chattopadhyouy and Simon 2008; Johnstone and Kamitsaki 2009). For example, Johnstone and Kamitsaki (2009) argued that end-of-life care and advanced planning is challenging as there are often core value differences between cultural minority (including indigenous) communities and mainstream health care. For example, decision-making authority in the health care setting lies with the individual, while in many minority communities it lies with the family. Additionally, advanced planning is seen by mainstream health care kaimahi as a tool to respect patient choices and to help avoid conflict in the family; in contrast, some minority communities see it as a tool that is paternalistic and denies control and choice for patients and particularly family members.

Health care kaimahi perspectives.

Four studies examined the perspective of health care kaimahi specifically (Castleden et al 2010; Kumar et al 2009; Marshall et al 2011; Sheward et al 2011). In general, these studies find that staff members have a difficult job that places an emotional burden on them, some challenges to communication with patients and also some work constraints that limit their ability to do their job well. However, they also find that there is some positive communication with other care kaimahi and also patients. For example, Sheward et al (2011) surveyed 179 staff members providing palliative care for patients and their

whānau in an acute care setting. The authors identified, through a thematic analysis of written text, several themes: the reality of care (difficult and involving emotional labour, but they try their best), positive team dynamic, importance of needing knowledge and education, and environmental and rōpū whakahaere factors (workload, time constraints, continuity of care, staff skill mix, space, privacy, and resources). There were delays in recognising dying and challenges in how to communicate diagnoses resulting in delayed decision making. There was also an absence of well documented plans and guidelines.

Similarly, Marshall et al (2011) explored staff perceptions of providing palliative care for patients and their whānau in an aged residential care setting. The authors surveyed 61 providers and found that respondents had high confidence regarding their care of the dying including aspects of communication and teamwork. Further, written comments were analysed thematically and six themes identified: the naturalness of dying; the character of care (extraordinary effort—individualised care); care relationships; emotional response; knowledge; and the rōpū whakahaere environment (lack of time and staff shortages). Also, they found that self-reported communication with dying patients is strong, but communication with whānau and other staff members was not as strong.

System constraints.

A number of studies examine limitations within the palliative care system that likely serve as barriers to health-seeking behaviour. For example, Sullivan et al (2003) conducted a multi-staged analysis of palliative care services to aboriginal people in Australia. They included a survey questionnaire of 83 agencies to identify what palliative care services were available. Then they conducted fieldwork in 18 locations that focused on one of two components:

1. places with high aboriginal populations, but little known about the needs and services (regional needs analysis) and



2. places that had reports of providing good practice of palliative care (good practice studies).

Their research identified a number of barriers to seeking palliative care including the following: negative past experiences with the health care system, lack of Aboriginal and Torres Strait Islander staff in mainstream services, lack of support at the time of referral including the lack of involvement of cultural kaitautoko (advocates) in discharge planning, the cost, and perceived cost, of palliative care, and negative attitudes and perceived attitudes of mainstream service providers that provide services to clients at home.

Another key barrier is the incongruence between the health care system and the indigenous culture. Muircroft et al (2010) discussed the challenges for Māori in the palliative care process. The authors described the health disparities in cancer outcomes experienced by Māori, compared to non-Māori. Further, the authors advocated for a tailored palliative care health service system that includes a focus on language, culture, and traditions. Specifically, they reviewed the Whare Tapa Whā model (eg, Rochford 2004), which includes four sides: wairua (spiritual aspects), hinengaro (mind and thought), tinana (physical aspects), and whānau (family/community aspects). They argued that the holistic perspective offered by this model would provide a more effective palliative care structure than the model currently in place. Such a model is consistent with indigenous communities around the world including Canada (Clarke and Holtslander 2010; Hanson 2010; St. Pierre-Hansen et al 2010), the United States (Arenella et al 2010), and Australia (McGrath 2010).

In sum, the literature identifies the following constraints:

1. uneven/lack of services (Kitzes and Berger 2004; McDermott et al 2008; McGrath Patton et al 2006b; Phillips et al 2006);
2. lack of referral (Sullivan et al 2003);



3. lack of integrated care (Phillips et al 2006; Sullivan et al 2003);
4. lack of indigenous health kaimahi (Shahid et al 2008; Sullivan et al 2003; Willis et al 2011);
5. not having peer-to-peer resources (Castleden et al 2010);
6. non-cancer diagnoses get limited specialised care (Rosenwax and McNamara 2006);
7. not having social/public health system capacity (Street 2007) and
8. not having culturally appropriate services (Muircroft et al 2010; Shahid et al 2008; Sullivan et al 2003; To and Boughey 2010).

These system constraints create challenges that impact effective service care provision and also the communication between patients and health care kaimahi.

Communication between patients and health care kaimahi.

Communication is a critical component of all health care service provision. Effective communication, including both verbal and nonverbal components, is essential to patient-provider relationships and results in higher patient satisfaction, treatment adherence, and better patient health outcomes (Wagner et al 2002). In the literature, a number of studies identified the importance of communication for effective palliative care services (Lawrenson et al 2010; McGrath et al 2005; Sullivan et al 2003). For example, Lawrenson et al's (2010) study of rural GPs in New Zealand found that the greatest need when dealing with Māori palliative care patients is good communication. Good communication was especially needed for when a large whānau was involved.

A number of communication challenges were identified as barriers, or at least obstacles, to effective care. They included:

1. Communication style differences of indigenous patients and health care kaimahi (Gysels et al 2011; Kemp 2005; Prior 2006; Sullivan et al 2003).

2. Different norms for communication behaviours such as eye contact and not using the name of the deceased (Brooke 2011; McGrath and Phillips 2008).
3. Not displaying a proper respect for colonial histories (Sullivan et al 2003).
4. The experience of racism/racist communication (Hampton et al 2010).

There were also a number of suggestions provided for communication. These suggestions are primarily noted in editorials or discussion sections rather than being directly researched. These included the following:

1. Building trust and good relationships through good communication (Sullivan et al 2003).
2. The need for health care kaimahi to provide coaching/facilitating decision making rather than being authoritarian (Sullivan et al 2003).
3. Taking advantage of opportunities for mutual learning (McGrath Holewa et al 2006).
4. The importance of telling the truth and providing open communication when making diagnoses (Kumar et al 2009).

Despite the identification of communication issues, this research suffers from a lack of specificity and in-depth examination. For example, good communication is a nice idea, but the literature does not provide concrete description of what good communication looks like. There is also a lack of research on the specific communication issues that are involved in the process. The exception to this limitation is McGrath et al's (2005) study. Their study examined communication difficulties faced by health care kaimahi and indigenous patients in a palliative care setting. A total of 72 interviews were conducted. Participants emphasised communication facilitators and difficulties in the patient-provider interaction. The key message is that the right story needs to be told to the right person(s). Challenges to this message include sharing difficult news, cultural shyness

and insensitivity, information being taken literally, Western medical concepts, and language barriers.

Outcomes.

The outcomes of palliative care were not usually examined directly in the articles. Outcomes usually included having a good death or being satisfied with the services received. For example, Gysels et al's (2011) systematic review found that having a good death was important. Further, one of the factors that related to having a good death was not dying of disease with stigma such as HIV/AIDS.

In addition, a dying person's journey is deemed a 'good death' if the services provided fit with health beliefs, particularly in terms of who provides care and where that care is provided. Hampton et al (2010) described the process of dying and shared what five First Nations elders revealed during interviews. The elders were asked what they wanted to tell health care kaimahi and the following themes were identified.

1. The naturalness of dying.
2. The need to call together the community and be with family (including the need for space in the hospital).
3. The importance of being with the dying person to provide (and receive) comfort and energy.
4. The importance of following appropriate protocols immediately following death and in the days following.

Similarly, McGrath Patton et al (2006) conducted 72 qualitative interviews with consumers and health care kaimahi and found that the lack of respite services limited patients' ability to have a good death, which included staying at home and being connected to family and land. The lack of respite services also inhibited carers to fulfil their caring duties appropriately and put undue stress on carers (physical, emotional, and economic).

Discussion

The adapted behavioural model of palliative health services provides a comprehensive examination of the issues related to health seeking for indigenous communities. It serves to identify what has been identified and what further research is needed. This section is organised around the two areas of health literacy and issues needing further investigation.

Health Literacy

Health literacy is the ability of individuals and communities to acquire, process, and utilise basic health information and services and to also navigate health systems for positive health outcomes. It serves as a useful construct for applying the research to illustrate where improvements in literacy appear to be needed.

Table 2.2: Areas of health literacy in palliative care to be improved

Type of Health Literacy	Patients/Whānau	Health care Kaimahi/ Health care System
Functional	Δ	*
Technical	Δ	Δ
Interactive	Δ	Δ
Cultural	*	Δ
Political	Δ	Δ

*= area of competence; Δ= area for improvement

Consistent with well documented conceptualisations health literacy is a multidimensional concept, and concerns communities as well as individuals (Nutbeam 2000; Roter 2000; Zarcadoolas et al 2005). The benefit of this multidimensional approach to health literacy is that it enables a vision of personal and collective empowerment. The five dimensions (functional, technical, interactive, cultural, and political health literacy) are key factors in palliative-care health literacy of kaumātua and whānau along with that of

providers. This subsection describes the five types of health literacy and uses the literature review to identify where developments in health literacy are needed (see Table 2.2 for a summary).

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. The extant literature suggests that Māori in general have low levels of functional health literacy around palliative care. Functional literacy is not an issue for health care kaimahi given their high levels of formal education.

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. The literature does not directly address the technical literacy of Māori, but technical literacy is closely associated with functional literacy. Further, there is some evidence that suggests that many Māori do not understand what is involved in palliative care. In contrast, health care kaimahi have a high level of understanding of technical terms and yet there appears to be mixed ability to be able to explain those terms to patients.

Communicative or *interactive health literacy* concerns 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. The literature suggests that some patients have difficulty initiating conversations about palliative care and also that some health care kaimahi have challenges interacting with patients, particularly when there are

cultural differences between the interactants. As interaction is co-constructed, this area is something that both patients and health care kaimahi can enhance.

Cultural health literacy concerns collective beliefs, customs, world-view and social identity that guide engagement with, interpretations of, and actions associated with health information and issues. Indigenous communities have high levels of cultural health literacy when it comes to their own cultural communities. In contrast, the literature clearly identifies that health care kaimahi from other cultures desire more training and understanding about cultural issues with indigenous communities.

Political health literacy is 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. It also involves civic/political engagement to change policies and mobilise people. The literature does discuss the need to develop capacity in the system and in communities for addressing palliative care.

Areas for Further Exploration

As the literature to date is in its initial stage, there are a number of areas that need further exploration in order to develop effective models of palliative care for indigenous communities in general and Māori in particular. First, the importance of communication is recognised. However, specific aspects of communication are understudied. We do not know what constitutes good (bad) communication between patients and health care kaimahi. We do not know what constitutes good communication between whānau and health care kaimahi. We do not know the different types of communication channels (face-to-face, mediated, etc.) that are most effective in this process. We do not know the best types of messages that are used to inform patients and their whānau about palliative care.

Second, whānau/carer perspectives are limited. It is clear that patients recognise the importance of carers for functional, cultural, spiritual and relational reasons. However, these perspectives have not made their way into the literature. We do not know how whānau and kaumātua negotiate palliative care and advanced planning. We do not know how whānau give and receive support to and from each other during this process. We do not know how whānau interact with health care kaimahi.

Third, the importance of health literacy in this process is not well known. Above, we identified areas for improving health literacy for both patients/whānau and health care kaimahi. However, these have not been directly researched; when referenced, studies focus only on functional literacy. Thus, further confirmation is needed whether these areas are important in the palliative care process.

Summary

In summary, this review of literature identifies key issues around predisposing, enabling, need, health seeking, and outcomes in the palliative care process. In particular, there is a strong need to examine what we call the ‘palliative care space’, which includes the interactions among and between whānau, patients, health care kaimahi, and the health care system/rōpū whakahaere. In this space, communication is a key concept and one that is understudied. Taking an indigenous, Māori-centred research approach to interviews with kaumātua, whānau, and health care kaimahi appears to be a strong approach for better understanding how to enhance the health literacy of all parties and thus strengthen palliative care service delivery. In this manner, effective communication models of palliative care can be created.

Chapter 3: He Whakaritenga—Research Approach

This chapter outlines the research approach taken by the team in the project. The Rauawaawa Kaumātua Charitable Trust (Rauawaawa) led the project with kaupapa Māori at the heart of the organisation. The Trust brought together a diverse research team to do justice to such an important kaupapa (focus) as palliative care and health literacy research. The team included researchers with academic, clinical, community, and kaupapa Māori expertise. The basis of engagement with members of our research team since inception has been consultation, openness, transparency and respect. This has been demonstrated in the regular project hui, training workshops (eg, cultural, CBPR, thematic analysis) and joint presentations since the launch of the research. In addition, team acknowledgement of each member's expertise was evident in their leading the project at different times during the research. Acknowledgment of our cultural differences, and the strengths this brought to the project, was addressed through our project hui, training workshops, planning and conduct of research processes. Moreover, the presence and availability of kaumātua leadership at the operational and advisory levels of the project enhanced team focus and research goals.

Rauawaawa's own brand of kaupapa Māori, combined with the diverse mix of team members, necessitated using mutually agreeable procedures and activities that would assist the team to achieve the purpose of the research. Therefore, the key principles underpinning the approach and the specific research processes used are detailed below. We begin with discussing kaupapa Māori approaches from both Rauawaawa and research positions. This is followed by the team's use of Community Based Participatory Research (CBPR), research design, and procedural steps taken in the research process.

Kaupapa Māori Approach: Rauawaawa and Research

Rauawaawa is a ‘by kaumātua for kaumātua organisation’ with its purpose (Hei Manaaki Ngā Kaumātua; to enhance the health and wellbeing of Kaumātua), people (kaumātua, elder Māori), processes (eg, karakia, waiata, whakawhanaungatanga, kai, koha) and place (Te Puna o te Ora, combining to demonstrate its own unique version of kaupapa Māori. This is also heavily influenced by the Tainui rohe (area) Rauawaawa operates in, those it seeks to serve and those that govern and lead the organisation.

In research, a kaupapa Māori approach is a culturally appropriate methodology to research in the local context. Kaupapa Māori has emerged as a significant feature in Māori development (Mane 2009) and as an academically relevant discourse theory and praxis (Smith 1997). A kaupapa Māori approach normalises Māori worldviews and practises (Kennedy and Cram 2010). This approach insists that all of the researchers must be respectful of Te Tiriti o Waitangi and the rangatiratanga of local hapū, iwi, and Māori communities (Tuhiwai-Smith 1999). The key concepts of this approach are the recognition, validity, and legitimacy of Māori as indigenous peoples (Mane 2009).

The use of Kaupapa Māori within this research was congruent with Rauawaawa values and principles of whakawhanaungatanga, manaakitanga, wairuatanga, tino rangatiratanga, and aroha. The organisation recognises that Kaumātua respond positively to culturally sensitive and holistic protocols. A whānau ora and Kaupapa Māori research approach (Taskforce 2010) to palliative care access, from a health literacy perspective, offers kaumātua and whānau opportunities to assess roles and expectations of each other, enables intergenerational transfer, and supports empowering interactions between generations, thereby preparing future generations.



Whānau Ora is distinctive because it recognises a collective entity, endorses a group capacity for self-determination, has an intergenerational dynamic, is built on a Māori cultural foundation, asserts a positive role for whānau within society and can be applied across a wide range of social and economic sectors.

(Taskforce 2010 p 30)

A whānau ora research approach that foregrounds the needs of kaumātua within the whānau has ‘transformative potential’ (Taskforce 2010 p 62) in its capacity to build intergenerational knowledge, enhance whānau capability and resilience, and strengthen cultural capacity for collective action.

Whilst recognising the need to conduct all aspects of research in a culturally appropriate way, kaupapa Māori methodology does not exclude other cultural traditions and approaches. This is not a definitive statement about kaupapa Māori research, but rather it is an outline of the key concepts that underpinned this project. The greatest strength of utilising this approach is that Māori are able to define the processes used and conduct the research in a culturally appropriate manner, with the eventual outcomes targeting Māori whānau, hapū and iwi. This was an important factor, given the aim and objectives of this project.

Community-based participatory research (CBPR)

One of the strengths of the non Māori researchers within this research team included their understanding of community-based participatory research (CBPR). A CBPR approach lends itself well to the Māori-centred paradigm that guided the kaupapa Māori research approach and processes utilised throughout this research project. With the increasing recognition in the past decade of the importance of community partnership in research to reduce health disparities, Community-based participatory research (CBPR) has moved to centre stage as a significant advance in the approach to research

with indigenous communities and other historically marginalised communities (Israel et al 2005; Smith-Morris 2007). The CBPR literature from indigenous communities has helped set the standard for community voice, ownership and control, in opposition to the historical acculturative force of medicine and public health research (Manson 2004; Wallerstein and Minkler 2008). CBPR is a collaborative approach that equitably involves partners in the research process and recognises the unique strengths that each partner brings (Oetzel et al 2007). Wallerstein and Duran (2006) maintained that ‘CBPR is not simply a community outreach strategy but represents a systematic effort to incorporate community participation and decision making, local theories of aetiology and change, and community practices into the research effort’ (p 13). CBPR begins with a research topic of importance to a community, with a key aim being the combining of knowledge and action for social change, such as addressing health issues (Duran et al 2005; Hall 2001), such as palliative access issues through health literacy for kaumātua and whānau.

Empirically supported interventions developed in dominant culture settings do not necessarily translate into practice sites of indigenous communities (Duran and Walters; 2004; Persaud and Mamdani 2006). Culturally supported or centred interventions fit within the values and social service systems of local communities, support cultural revitalisation, and remain highly utilised and sustained over time (Mane 2009; Tuhiwai-Smith 1999;). CBPR offers a valuable means for integrating a hybrid decolonising approach to knowledge and to co-developed interventions by a) translating and testing the core components of empirically supported interventions with communities, while also b) integrating culturally supported interventions in order to enhance the translation and sustainability within a local context.

Qualitative Research Design

Specific aspects of qualitative methods were utilised to conduct this research. Qualitative methods lent themselves well to the intentions of the project, and complemented the Rauawaawa, kaupapa Māori, and CBPR approaches. The presumptions of a qualitative method are that it must provide a holistic contextual portrayal; use a thematic content analysis (Braun and Clarke 2004; Owen 1984 ; focus on in-depth, open-ended interviewing or discussions and personal observations; and give emphasis to the uniqueness and diversity of peoples' experiences and beliefs (2002). Like the kaupapa Māori approach, this is not a definitive statement about qualitative research design. It is an outline of the key concepts that assisted in the completion of the project.

Specific practices of a qualitative method which were utilised included:

- face-to-face interviews to discuss the topic area;
- focus group interviews to obtain thoughts, views and opinions from a collective group;
- open-ended questions and prompts to generate discussion;
- analysis of discussion information using key themes;
- recognition of the context of information during analysis;
- an in-depth analysis of key themes through key categories; and
- a narrative reporting style.

Consistent with Kaupapa Māori and whānau values, whānau health literacy is also crucial to the health and wellbeing of kaumātua who are in the palliative care pathway. In light of this, we took a whānau ora approach, including both kaumātua (men and women aged 55 years-plus) and whānau at the core of the research. For this research, whānau refers to people caring for/involved with kaumātua with palliative care needs, and includes rangatahi (youth approx. 16-29years), pakeke (adults approximately 30-49years) and kaumātua (50years-plus).



Key Research Steps

This section describes the key research phases of the project. They are establishing the advisory board; gaining ethical approval; completing the literature review; recruiting participants; collecting and analysing data.

Advisory Group Established

The advisory board, which was also a stakeholder end-users group, was used to provide oversight and direction to our research and ensure we were following a whānau ora and Kaupapa Māori approach. The advisory board consisted of kaumātua associated with Rauawaawa Kaumātua Charitable Trust (primarily board members). The role of this group was to ensure the cultural integrity or tikanga of research, by providing oversight, guidance, and input into all the research methodology, procedures, data-collection processes, and analysis that the research team undertook.

Ethical Approval

Ethical approval for the qualitative component of this research was sought from the Northern Y-Regional Ethics Committee based in Kirikiriroa (Hamilton). Ethical approval was granted for the project in September 2011 (Reference - NTY 11/08/085). Ethical approval for the Emergency Department Audit was sought from and granted separately from the Northern Y Regional Ethics Committee in January 2012 (Reference - NTY 11/11/111).

Literature Review

As outlined in the previous chapter, in order to understand the subject area and in preparation for data collection, a systematic review of literature was undertaken. The literature review was integrated within the research methodology, as it provided the ability to fully investigate the breadth of information already written in relation to palliative care and health literacy in indigenous communities around the world. It also enabled clarification of the

topic, provided important contextual understanding of the issues being explored, was the basis by which questions were formulated for data collection, and lead to the development of a revised model of communication in palliative care relevant for kaumātua and whānau Māori.

Recruiting Participants

Kaumātua, whānau, and kaimahi (worker) participants were identified and contacted through the established networks of Rauawaawa and members of the research team (particularly in the palliative care kaimahi group). Kaimahi from the hospital and hospice were recruited through existing relationships between Rauawaawa kaimahi and trustees, research team member professional relationships and other networks.

Kaumātua and whānau participants were first contacted by a kuia member of the research team who was known to many of those who later agreed to participate. She initially contacted them by phone or face to face, at which time they were given preliminary information about the purpose of the study and invited to participate in the research project. A follow up visit was made for those who wanted to discuss the research further after reading their preliminary information. Established relationships and trust were central to creating a positive situation for kaumātua to fully engage in the research and share their intimate experiences willingly and openly.

Data Collection Methods and Preparation

Overall, the data collection phases for this research project comprised of 21 interviews with kaumātua, five hui/focus groups with whānau, three focus groups with palliative care kaimahi, a cultural-discursive and health literacy analysis of brochures from providers of palliative care services, and a document audit of emergency departments in Waikato. The research team considered it essential to develop research processes grounded in kaupapa Māori that were engaging to kaumātua, whānau, kaimahi, and responsive to



their needs considering the sensitive nature of palliative care. In consultation with the advisory group and key members within the research team, the eventual research process was developed.

Once kaumātua had agreed to participate, a time suitable to participants were organised and an individual interview schedule formulated which saw a few days where a team of researchers were paired so that concurrent interviews in the morning and afternoon were able to be held. This was made possible through the commitment and co-operation of research team members, the size of the Rauawaawa complex and the flexibility of kaumātua participants.

For individual kaumātua interviews the respective sessions were first welcomed as a group by a kaumātua lead member of the research team in te reo Māori and English. This initial group process involved karakia, mihi, kai, whakawhanaungatanga, introduction of the project, participation consent confirmation, project ethics discussion and permitted time for the participants to ask the researchers questions. Following this, each individual accompanied by two researchers went together to their respective room for their interview.

Two researchers were purposefully chosen to ensure that respect for the kaumātua through maintaining uninterrupted attention with at least one person for the duration of sharing of their palliative care story. This meant that in most sessions one interviewer would take the lead, ensure that dialogue was maintained so that the other interviewer could be more of a supporter, operate the voice recorder (provided participant consent had been given), ensure paper work was signed off and take notes as necessary. Interviews generally ran from one to one-and-a-half hours, after which each group returned to the larger group to engage in a debriefing session termed ‘whakawhitiwhiti whakaaro’ by our lead kaumātua on the team Matua Beau Haereroa. At the close of this session, the group shared in a kai whilst the afternoon group of participants were welcomed to join in and whakawhanaungatanga with



researchers and the earlier participants. A similar process then followed for the afternoon group of participants.

All the focus groups were opened, conducted, and concluded in a similar manner. Two researchers led each focus group and the only exception was that due to whānau work commitments times had to be worked around whānau availability. In the case of palliative care kaimahi the same situation arose except the venue was changed to best suit their needs. Kaupapa Māori protocols were used (eg, karakia before and after hui, whakawhanaungatanga, koha and kai), except in the case of the hospital and hospice palliative care kaimahi. The reason for this was that time was restricted for the participants, and it suited them better to hold the focus group at their workplace.

All of the research tools were developed to be kaumātua friendly (ie, large font) such as the participant information sheets, participant consent forms, and open-ended questionnaires with prompts. The research team designed all information sheets and consent forms using te reo Māori and English to offer choices to participants. In addition our kaumātua member was present to facilitate an interview in te reo Māori in case participants requested it.

As mentioned earlier, before the interviews and focus groups started the participants formally consented to participate in the project by signing a 'Consent to Participate' form. This assured them of their anonymity so that they would not be able to be identified in any way in the final report nor in the dissemination of findings.

In acknowledgement of their time and participation, all kaumātua who participated in the interviews received a koha as an acknowledgement of their time and contribution to the project. They were not informed of the koha prior to discussions, and it was only disclosed to participants after the interview, hui/focus group had taken place. For internal accountability purposes an

acknowledgement of receipt form was signed and dated by participants when they received their koha.

One of the critical observations concerned how kaumātua were appreciative of being engaged in the research, even in an area as sensitive as palliative care. We believe the familiarity of the environment, its people and the commitment to Tikanga Māori were important contributors to this outcome. Of particular note is the significance to kaumātua in reducing the introduction of too many new and unknown factors, creating time for whanaungatanga with those about to interview them and the sharing of kai prior to and after the conduct of research with them. Both of these processes increased the time for conversations to be had, relationships to be formed and developed without the pressure of a certain kaupapa to discuss. Moreover, each interview, hui/focus group involved two researchers; with at least one, and often two Māori. This enabled us to accord the sensitive topic of palliative care with a respectful, age appropriate and culturally sensitive resource intensive approach. Such an approach ensured that the participants were supported along the journey of data gathering. This approach also facilitated cultural sharing and learning for our Māori and non-Māori research pairs, and research experience sharing and learning for our mature and younger research pairs. Important to note is that research pairs were changed continuously to ensure sharing and learning opportunities were maximised across our group.

As mentioned earlier, the involvement of faces and environments familiar to kaumātua participants was helpful to allaying fears about research. Tikanga and the opportunity to use te reo Māori when and where they were able to allowed a sense of cultural safety, as did the opportunity to be included in the group introductory and ‘whakawhitiwhiti whakaaro’ sessions.

Data Analysis Methods

The kaumātua interviews, whānau hui/focus groups, and kaimahi focus group transcripts were analysed using a thematic analysis and the method of constant comparison (Boyatzis 1998; Braun and Clark 2004; Owen 1984). Thematic analysis is ‘searching across a data set . . . to find patterns of meaning’ (Braun and Clarke 2006 p 86). In this part of the study this meant searching across the kaumātua interview transcripts to identify patterns of meaning, or themes. A theme is a ‘set of cognitive schema [rather] than a limited range of interpretation that are used to conceptualize and constitute relationships’ (Owen 1984 p 274). Themes were identified based on three criteria: recurrence, repetition, and forcefulness. Recurrence is when there is a minimum of two mentions of a particular idea that represents the same meaning, regardless of the words used. Repetition is as repeated words, phrases, or sentences. The difference between these two criteria is the repetition of specific wording (ie, repetition) rather than the general idea (ie, recurrence). The last criterion is forcefulness; the emphasis of certain points because of intensity, dramatic pauses, crying and other verbal or nonverbal qualifiers to illustrate intensity (eg, stating anger).

All analysis was completed by two researchers—one Māori and one Pākehā. We wanted to have a cultural insider and a cultural outsider to analyse the data to provide a level of triangulation of the themes. Specifically, the process began with reading of transcripts and identifying initial codes for the themes. The themes were then reviewed by the research team and shared with participants for validation. We invited individuals to comment on the themes and asked them to critique, change, or clarify certain points.

The initial coding of kaumātua transcripts identified 23 codes for the analysis. We shared this coding list with the entire research team for validation prior to completing the analysis. This meeting led to support for the initial coding list while clarifying the definitions of codes. An analysis was also conducted by



two kuia as a strategy for checking to see if there were differences when a kaumātua lens was applied. The two research analysts continued to code the transcripts and identified eight new codes along with reviewing the existing codes to ensure uniqueness. After the initial coding was completed, the codes were compared to each other and collapsed into themes.

The initial coding of whānau hui transcripts identified seven candidate themes: that is groups of codes that seem to be coherent (Braun and Clarke 2004). The codes were further compared to each other within each of these initial themes, and compared across themes. This resulted in five themes which we shared with the research team for validation. A final code comparison led to the five themes being collapsed into four main themes. Similarly in the initial coding of the kaimahi focus group transcripts, eleven candidate themes were identified. These were shared with the research team for validation and resulted in minimal changes.

Due to the specific nature of the methods used in the brochure analysis and the ED document audit, the details of data collection and data analysis phases are reported in Chapter 7 and Chapter 8 respectively.

Chapter 4: Ngā Tūmanako me Ngā Whakaaro o Ngā Kaumātua — Hopes and Thoughts of Kaumātua

Interviews with kaumātua were a core element of the research. Our goal was to understand the facilitators and barriers to using palliative care perspective from a health literacy perspective. This chapter first describes the participants and the methods for conducting and analysing the interviews. It then discusses the themes identified from the analysis.

Participants

There were 21 participants in the interviews: 5 male and 16 female. Their average age was 68 years and 19 were Māori, 1 Pākehā, and 1 Pasifika person. Of the Māori participants, nine different iwi were reported with three participants not reporting. There were 20 different hapū with seven participants not reporting, and 20 different marae with eight participants not reporting. Thus, the sample drew kaumātua from diverse cultural backgrounds. All of the participants had experience in end-of-life care with a partner, close friend, or whānau member and reflected on these experiences.

Methods

The interview process was designed to be a culturally appropriate process for eliciting kaumātua (Māori elders, men and women) participants' stories. Initially, we had proposed a direct series of questions about palliative care. However, our advisory board and research team members noted that kaumātua like to be engaged in research and interacted within a culturally appropriate manner, particularly in an area as sensitive as palliative care.

As a result, we developed an interview guide that focused on getting kaumātua to tell their own stories about direct and indirect experiences with palliative care. We then developed probing questions around the topics identified during the literature review, such as communication with providers, communication with whānau and facilitators and barriers, to seeking services.

The interview guide was meant to be applied with flexibility and focused on getting kaumātua to tell their stories. See Appendix 4.1 for the interview guide.

Analysis Procedures

Themes

We identified four primary themes during the thematic analysis and verification process (see Chapter 3 for details). In brief, the themes centred on cultural practices, given and take with health care providers, responsibilities during the end-of-life journey, and balancing the tensions of receiving and providing support during the end-of-life journey. Each of these primary themes has parts or subthemes that illustrate the complexity of the themes. We describe each of the themes and subthemes and provide quotes to illustrate the themes, using pseudonyms for the participants. We also identified the aspect of health literacy that is being addressed. So that we can easily identify the themes related to each participant group, the themes emerging from kaumātua interviews are coded 'K' (for kaumātua).

Theme K1: Cultural practices, belief, and values

The first theme identified cultural practices to do with dying, particularly with traditional Māori and kaumātua. This theme included cultural practices around death and dying; cultural norms and practices that limit the utilisation of services; cultural practices that support (or would support) utilisation of services; and situations where culture is not a primary factor in service utilisation.

Subtheme K1a: Cultural practices around death and dying.

Participants identified a number of cultural practices that their whānau engage in during the process of dying. The practices serve as markers of identity and more importantly are about connecting whānau members with the person dying, as well as with each other. They also connect whānau spiritually and physically. These stories are consistent with the Te Whare Tapa Whā model of health care (Durie 2001/2005, p 173) emphasising a holistic perspective of



care. These cultural practices help to provide a context for understanding kaumātua and whānau perspectives about what is important at the end of life.

One of these practices is spending time together and connecting as a whānau. Rona discussed a mate of hers who was dying. Her mate did not have a close relationship with his family over much of his life and he regretted that. However, during the final day, Rona noted,

Well within his family they had become quite close in his last times especially that he had been down. I feel at that time I guess it was good for him that he had gone... I think that at least he had things good with his children he knew his eldest girl and the youngest one..... But yes they were very good and close to one another when it came down to it

Thus, even when there were strained relationships, whānau connection is very important during the last days.

More frequently, kaumātua reported positive relationships with their whānau throughout their lives and the final days were about celebrating that closeness and providing respect to a loved one in not leaving them in the last days. Kohu described her nephew being by the bedside of his wife and stated,

So they would ask Roger, 'Roger what did you have for breakfast this morning?' And Roger would say I had toast. I just had a toast. So they were really only living on toast and a fizzy drink there was no milk and Roger did say, 'We are not worried about us.' They couldn't even leave the bedroom in case she would die. Have you ever had a case like that? They wouldn't, they hardly left her bedside in case she would die.

Thus, the focus was on support for their loved ones and each other rather than on personal needs.

Other cultural practices emphasised spiritual aspects through song and prayer. For example, Raina talked about the importance of waiata (song) and karakia (prayer) during the final days of a loved one dying, *'Well waiata. It helps them go back to those days. You see a smile on their faces sometimes and sometimes the tears come out. ...karakia is most important to me we always did our karakia in Māori.'* Another person, Moana, also noted the importance of prayer in dealing with the challenges of family members fighting during the final days of a loved one dying: *'[A family member] will come back and hurt you; then they look at you; then say come on; then you have karakia and you go.'* Thus, the cultural practices of waiata and karakia helped to connect whānau on a spiritual level and help them recall good times and repair some bad feelings. A final quote from Moana shows how the spirit, the whānau, and the love are all connected together: *'You know, you need, you need to have a whānau to awhi (embrace/connect). And the warmth comes from everyone that's there. You know the wairua (spirit).'* Tikanga (cultural customs, values, and practices) means that the practice of karakia and acknowledgment of wairua (spiritual domain) are deep, and these allow whānau to enable their loved one to move onto the next journey.

Subtheme K1b: Cultural norms/practices that limit service utilisation.

Some interview participants considered cultural norms and practices that limit service utilisation. For example, a number of participants discussed tapu, or what is sacred and identified by strict protocols and prohibitions. One tapu is touch norms for kaumātua. Rongomai discussed her sister's husband and why he chose to die at home without outside help: *'He wouldn't. He was one of those Māori that only his wife touches his body and the nurses—you know you know. And this is, I think with our Māori people, you find most of them will be like this; especially our men.'* Similarly, Kei discussed her experience caring for her father alone: *'I don't think he wanted anyone to touch him; and by only me. I was the only one to bathe him and all that.'* Men were not the only ones who tapu was attributed to. For example, Moana discussed in general why some choose not to use palliative services when she stated, *'Like the handling of ah, of male nurses with our wāhine Māori (female). And you*



can see the wāhine Māori are, are not happy with it aye.’ Thus, tapu specifically related to who can and cannot touch you, limits the seeking of services by some Māori as it is about tikanga, or what is acceptable.

Another cultural practice that limits service utilisation is the desire to be at home—both close to whānau and close to their marae and spiritual connections to the land. For example, Aroha talked about her perspective about hospice or hospital care when her mother was dying: *‘I dunno I’ve got a thing for homes even though they get good care and all that. But it, it’s different, it’s different too. I suppose to having whānau around you. I’d, I’d say my mother probably would just deteriorate if she was in a [hospital].’* Other participants note that their loved ones prefer to die at home. For example, Kohu talked about her niece’s preference to die at home simply to be at home and close to whānau. She noted, *‘Kay was in Hospice and then she went home and she wanted to die at home.’* Thus, the cultural practice of dying at home can limit some service utilisation although a number of participants noted the use of palliative care services in a home environment and how much it was helpful.

Subtheme K1c: Cultural practices that support service utilisation.

Some participants discussed the importance of having cultural practices utilised in the health care provision as a way to improve palliative care services. Much of these conversations focused on the fact that having Māori health care kaimahi (workers) would help with service provision. Rona discussed her experience in palliative care with her mate. She noted,

I guess for me it’s just making sure that for your sickest ones as long as they’re, how do I say?. . . that everything is on time for everything. And as Māori we are able to get our work going for us while we are going through this.

The work she referred to is korero (talking and spending time) with health care kaimahi and te reo Māori (language) to help patients feel like their



culture was respected. However, several participants noted that it is not enough for health care kaimahi to simply be Māori; they have to use cultural practices. For example, Raina discussed the importance of having Māori health care kaimahi who utilise cultural norms, *'If it's real tūturu [authentic] Māori from Ngāti Porou [iwi] or anyone like that then bring them in.'*

Anna discussed her experience with two Māori nurses who did not use Māori cultural practices. She stated:

We have got different ideas of how the services and that as Māori people you know we do. We do expect them to sit down and have a talk before you know. You don't get straight into the business. You know we are different and as long as those ones that are going to give that service under the Māori banner then let's be Māori. Let's do it in a way that we expect it to be done. Don't be too much in a hurry to walk out of the house that sort of thing. You know have a korero with them; really sit there and talk with them and look like you really are caring you know it would be. Yes, I do believe it should be Māori as long as they have got that whole 'it's not about it just being the service provider.'

Thus, having Māori health care kaimahi who support and utilise Māori cultural practices is something many participants said would either enhance the utilisation of, or satisfaction with, palliative care services. Moreover, it would seem that when rōpū whakahaere (provider organisations) promote their services as Māori, then expectations of them are greater than of mainstream services.

Further, several participants noted that having a physical environment that supports cultural practice makes a difference. For example, Mere discussed the environment at a hospice where a family member died. She noted,

She died in the hospice up in Auckland. Now that's where I experience the services in the hospice to the bereaved, and also to us the whānau, excellent. They cared for us; they encourage us all come; bring all your family in; you can sleep here; we have the beds. We have the mattresses. There's the kitchen there. And they, they attended to our girl medication-wise. The doctor came in and they, and they, and they attended to us. They were kind, we felt at home.

Another participant, Huia, stated her desires in a hospice setting:

And um that's what I'd like I'd like to see is that the whānau can just go in and be there and help if they need you. Maybe your whānau can see the ones that are helping in there are doing what your own child would do, you know. They might be happy with that but so long as that there family can come in and just have a look whenever so that they're not tied down all day to look after you.

In sum, having Māori health care kaimahi was identified as helping with service provision. Rōpū whakahaere, whether Māori or mainstream, need to consider their ability to provide such services.

Subtheme K1d: Situations where culture is not a primary factor in service utilisation.

A few participants noted that cultural practices were not a primary factor in service utilisation either because the care was so good or so bad. In these situations, the quality of care was the focus and not the cultural practice. For example, Anna discussed her experience of low quality care with her mother. She offered,

Make sure you have a real um, what you call it, people that are passionate—passionate about working with people that are going to have this sort of care—24/7 care. You got to be a passionate otherwise you shouldn't be in the job. If you can't get that passion,

and it doesn't matter what culture you're in; it doesn't matter; you need to people that are passionate about their job.

Similarly, Pare talked about the importance of relating when provided care regardless of cultural background: *'That's the only complaint that I have about palliative (care).... I've found the foreign nurses are better to work with. They can relate to us whereas our own tauwiwi [non-Māori, foreign peoples] they don't know how to relate to us.'* In contrast, Hone noted during the care for his late wife that culture did not matter because they had received such good care and that they knew what was going on during the care (she was a nurse). He stated, in response to a question about whether Māori health care kaimahi would have made a difference, *'Um no because really in, in our case we were in control. And that's a big thing so it didn't matter who was there. Co-operation was the main thing and that's all it was.'*

In sum, Māori cultural practices during the process of dying are important for the participants. Whānau need to be able to connect to each other in culturally appropriate ways. These practices can limit or encourage service utilisation depending on how the practices are implemented. In some cases, participants lacked functional health literacy about how palliative care services can be used with cultural practices at home to care for their love one. In other cases, health care kaimahi lacked cultural health literacy to know how to effectively provide services to Māori patients and their whānau.

Theme K2: Give and take with health care providers

Interview participants identified effective communication as a key component to satisfactory palliative care. The various aspects of effective communication were complex and involved both kaumātua/whānau and health care kaimahi. This section is divided into two subthemes of health care kaimahi responsibilities and kaumātua/whānau responsibilities.

Subtheme K2a: Health care kaimahi communication responsibilities

According to interview participants, health care kaimahi need to:

1. Respect culture and avoid prejudice.
2. Provide tangible resources in a caring manner.
3. Provide clear information that reduces uncertainty and leaves room for hope and respects rights.

We discuss each of these points and provide exemplar quotes.

The first responsibility is to respect Māori culture and avoid prejudice. The first primary theme focused on the importance of culture during the end-of-life journey and for palliative care services. This subtheme identifies examples of disrespect and prejudice that decrease the quality of care for kaumātua and whānau. Pare discussed her experience interacting with palliative nurses. She observed, *‘For me I think the palliative nurses need training on how to deal with our people because they are not user-friendly. I don’t care what anybody says; some are but there are a lot of those aren’t. And they need education with how to work with Māori people when they are sick.’* Hiria discussed three experiences she had with palliative care and how all of these were negative. A key aspect of this negative experience was her perception of stereotyping and prejudice: *‘I think, and call me prejudice, whatever. And I seen it with my whānau. You’re a Māori, you’re six over 60, you’re overweight, by a few kilos and they’re not interested.’* Overall, most kaumātua did not report prejudice during their end-of-life journeys; the majority reported either positive experiences or neutral ones (ie, where cultural sensitivity could be improved yet was not direct prejudice or disrespect).

The second responsibility of health care kaimahi is to provide tangible and informational resources in a caring manner. Kaumātua recognise that they and their whānau, in most cases, do not have the knowledge, capacity or training to provide quality palliative care. Thus, they need the assistance of the health care kaimahi. Kei noted the benefit of palliative care kaimahi in referencing to caring for her brother:

To be able to take him out where he wants to go. And if he does need extra medication, they can do that for him as well as get the doctor in too if he actually needs morphine. You know she's telling us all these things you know. And it's quite interesting too because we as a family can only do so much. The rest is up to the nurses and the doctors and it's good to know that they are there.

Ana noted the importance of restraining an ill patient who lost some mental capacities and getting training from health care kaimahi. She stated, *'Family needs to know how to restrain their whānau without hurting them. It's a frightening thing 'cause I got frightened the first time my mother got physical with me.... I think that's an important part of palliative care if the whānau going to be doing it at home.'* In addition to simply providing tangible and information resources, the manner of care was very important for participants. Hone discussed the process when his wife was dying. He said, *'They were really great and her friends were great everyone was. You know, it was a, a sad time but everything went smoothly which it does help.'* He went on to say, *'The whole thing was about the, I guess the care of people that were there. And there was just that feeling all the time from the staff especially that you know about their care and how they would love to, well, make you feel as though if they were wanting people to stay alive rather than die.'* Kohu, talked about the care her whānau received during palliative care and noted,

I felt they were highly skilled. They were older. The two main women were older women I use to think. But I didn't ask them. They must not have much responsibilities with younger children at home because Roger and Mari say to this day they actually received constant nourishment from palliative care.

These participants (and others who had similar experience) note the positive aspect of palliative care when health care kaimahi were compassionate and provided excellent service and quality care.

A third component to health care kaimahi communication is the importance of providing clear and free flowing information to reduce uncertainty. Ana noted the importance receiving good information (coupled with tangible resources):

I must emphasise it was only over two days 'cause that's how fast mum went. And they came in the short time as soon as the doctor rang they were straight up the hospital. They were there to explain what they 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 before we took our mum from the hospital to home....In that short time we just couldn't get over how much they had done and [provided] a lot of information.

The quote reflects the gratitude and relief that came with getting good clear information in order to properly take care of a love one that was dying.

A couple of participants emphasised the importance of simply getting honest information. Hiria noted, *'The doctors weren't interested and no one will tell you the truth. No one will say yup we know he's dying, you know. We can't give you how long. But we know he's on his on his way out.'* Further, Hiria stated, *'We knew he was dying and the doctor said oh he's very ill, and I said "Get off the grass, he's dying. You know we all know that."'* In general, participants wanted to have honest information or at least be given the choice to receive honest information. They did not want health care kaimahi to protect them.

Honest information, however, does not mean absolute certainty, particularly when it comes to hope. Miriama discussed the importance of good information and not closing down hope:

Well yeah they took us, the doctor came and said, 'We'd like to meet with your whānau, family.' So, she took us into one of the rooms there. And that's when they explained to us that, he, he only about had two weeks. Everything had deteriorated. His legs were skinny and, and, and all that sought of thing, yeah. So when he said that in my mind I said I was thinking, 'That's what you think' (and he died 3 months later).

Hemi echoed this sentiment when addressing the information he received when his wife was living and dying with cancer. She lived with cancer for almost 10 years and he received up and down diagnoses during the process. He noted, *'It was always a pressure when you're dealing with someone you love dearly. And the information lifts you up to because you're feeling hope in what they are saying. And with the doctors that we had I never blamed them because I knew they were doing their best.'* Finally, Keri discussed her own experience and one that many kaumātua could relate to—that there had been many people who were told a loved one was dying and the person lived many more years than expected:

They said [to my daughter] your mother is not going to make it. I didn't know my liver split in half; all my ribs were broken some in three places; except four, all the rest were broken. My lungs were badly punctured and had to go on life support. My sternum was crushed my bowels were torn and I had to have a bag. They told her [daughter] that we don't think we can save her.

Thus, participants generally want to know their loved one is likely to die and not to close down hope that they might live longer than expected.

The final communication responsibility is to respect the rights and choices of patients and whānau. Participants told stories about quality care with kaimahi respecting the communication preferences and choices/decisions of patients

and whānau. Kohu discussed a Māori care worker and her respect for her patients' communication preferences:

The kuia [older Māori woman] first had a karakia and said to them, 'Are you more Māori than Pākehā?' And my brother said, 'Yes I am.' And his wife said, 'Yes we are'. She said then, 'If I spoke to you in Māori would you understand?' and my brother said, 'Very little' and his wife said, 'Nil.' 'So would you prefer me to speak in English?' And they looked at each other and agreed with each other let it be English. So that I thought was excellent value that they would be asked by the whaea (the woman carer) because she said there is no use in babbling on in Māori when you can't understand.

Hemi also emphasised the importance of having choices from the doctors:

'They're [doctors] sorting out what to.... They would discuss it in front of us and they were giving us an option and we would say, 'Oh I don't know. Well it's either A or B.' And we would say, "Well we did that the last time and we'll go this way." And that's how it was.' These participants felt valued and supported by having the option to communicate in their preferred way and/or make decisions about their own health.

In contrast, a few participants told of stories about how basic rights were not always protected. Hiria discussed the care of her auntie and how bad it was. She offered,

She was early eighties, but she couldn't see and she couldn't hear. I go up there, yeah [they] were gonna operate on her arm. So they starved her all day left her in a corner... Three days in a row they starved her till eight o'clock at night.. . . So we had the big haka [confrontation] again through me. Man [they] love me up there. And um yeah no and they just, everyone ignored her again, the nursing staff ignored her.

In addition, Anna discussed her experience of not receiving basic information regarding the care for her dying mother. Specifically, she was having hallucinations in her last days and Anna and her siblings thought she was ‘faking it.’ She noted,

We used to think that she was playing up, all the time because we didn't have that information...It wasn't till after she was gone a few days that we realised, '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.

These stories were in the minority of those told and yet they do resonate with participants because similar stories have been shared in the community.

Subtheme K2b: kaumātua/whānau communication responsibilities

The communication responsibilities are not only for the health care kaimahi.

Participants noted that kaumātua and whānau need to:

1. Teach health care kaimahi about culture and personal wishes.
2. Assert their wishes.
3. Ask for help.

The first responsibility for kaumātua and whānau is to teach health care kaimahi about their culture and about how they would like to be cared for.

These approaches can be proactive and reactive. Mere noted, ‘Yeah, we can teach them. Teach them. And you know what they'll appreciate it.....It's just like us teaching them don't sit on the table that's where we have a kai.

We've, we've taught many people, ‘Don't sit on the table.’ Kohu discussed the importance of teaching about culture through a formal complaint:

She said to write the complaint, name your complaint and name the solution, what culturally, what how would it be culturally effective and what we do and what would make what would make a positive and lasting impression. So we did that we had all of this ngaungau



[point of discussion; getting at the nitty gritty]. And we had all of this what we knew would be appreciated by others.

From these kaumātua participants' perspectives, care kaimahi need training in tikanga: what is culturally appropriate and important. They know that everyone has to learn about culture and health care kaimahi would appreciate knowing how to be respectful.

A second responsibility is to assert rights and wishes when they are not being met. This perspective is similar to the reactive approach about teaching about culture, but occurs more in the moment rather than after the fact. Hiria discussed her experience about fighting for information and care:

When we had this big meeting and my niece who works for health insurance in Australia asked them what kind of cancer he had and they wouldn't [tell]. It was a big fight to get the name of it. Because we thought it was um, he worked at the wharf. What's that cancer they get um, you know it's some ceiling cement. We thought that had caused it and um they wouldn't tell us. We had a big stand up fight. Liz had a big stand up fight with them.

Similarly, Pare talked about the importance of standing up for a decision and taking responsibility for the choices rather than having the doctors take the responsibility for the decision. She noted,

The renal doctor took us to the office to talk to us and she was the one that told us there was no more that could be done for my dad. And she said if he was to have a heart attack and they say that to everybody did we want to revive him I said, 'Yes' because we wanted to keep him you know for as long as we could and she said, 'He could come back as a vegetable' and I said, 'Well that's our problem, it's not yours, it's ours.'

In both of these cases, whānau had to assert their wishes to ensure for the care they wanted.

The final communication responsibility is asking for help. A number of patients exclaimed that their whānau and Māori in general, need to take on less burden or responsibility and seek out help from health care kaimahi. For example, Ana offered the following advice for Māori going through the end-of-life process: *'Main thing is to get that help. People don't be afraid to ask for that help and get it and get it because you need it.'* Similarly, Mere stated, *'I'd like our people to maybe, be less critical of the others and try to open up the heart and say we need your help.'* Further, Kei noted her perspective about many Māori, *'I think that we as a whānau, you know, we, we think of ourselves first to do it instead of asking outside the family.'* Finally, Pare urged, *'Yes it is very important you know a lot of our Māori people are like if I ask this question it might be dumb. It doesn't matter if it's dumb at least they're asking and whānau should learn to support.'*

All of these quotes illustrate the importance of asking for help even though it is not how most Māori have done it traditionally (at least from their perspective). They would like to see kaumātua and whānau get the help that is available to them.

In sum, this theme examined the communication responsibilities during interactions between health care kaimahi and kaumātua/whānau. The participants recognised the give and take nature of effective communication for the benefit of kaumātua, whānau, and health care kaimahi. They do recognise that both parties need to build interactive health literacy skills. There is recognition that both parties will need some training on communication skills in order to be most effective. In addition, the importance of being assertive, asking for help, and teaching about culture, hints at political health literacy. That is, the participants understand the importance of changing the system to better meet kaumātua and whānau needs for effective palliative care.

Theme K3: Responsibilities during the end-of-life journey

The third theme emphasised the responsibilities of care during the end-of-life journey. These responsibilities come in different facets. For those who are ill, they tend to think in terms of how they are burdening their whānau and also the challenges they face in their last days. Whānau tended not to think of these as burdens; rather they were framed as responsibilities for caring for the ill person and also the larger whānau who are helping to care for the emotional, physical, and spiritual needs of the ill person. These responsibilities are stressors and place various strains on care givers. We present three subthemes to illustrate these responsibilities and challenges:

1. Tino rangatiratanga and tino whanaungatanga (autonomy and connection).
2. Balancing needs of self and other.
3. Maintaining relationships among the whānau.

We discuss each of these subthemes and provide exemplar quotes to illustrate.

Subtheme K3a: Tino rangatiratanga and tino whanaungatanga.

This subtheme represents a dialectical relationship between tino rangatiratanga (autonomy, self-determination) and tino whanaungatanga (connections). A dialectic is the tension that occurs between two opposites such that addressing one end means that you cannot address the other. Thus, having tino rangatiratanga may not allow you to be connected and tino whanaungatanga may not allow tino rangatiratanga. The tension happens as kaumātua want to have love, support, and connection with their whānau. They also want their mana (the supernatural force in a person), which is integral to tino rangatiratanga, to remain whole, as well as maintain their self-respect, dignity, freedom, and respect from others. Managing such tensions can be challenging.

In terms of tino rangatiratanga, kaumātua want to be accorded dignity and respect. During the debriefing process, Hare noted that his father had been the head of the family for a long time and always was respected and listened to. When he was dying, he lost some of his mana because he was being told

what to do and not being allowed to do things for himself. Thus, he lost his tino rangatiratanga, but equally as important, his mana was diminished. Mere noted this feeling more directly, *‘Don’t take away my rights. Yeah don’t take away my rights and as long as we still got it up here.’* Kei noted this concern when caring for her brother: *‘What he wants is more important than what we want, you know. Like he said I’ve got to have some dignity. Well whatever you want bro that’s all we in too.’* The quotes and stories support the importance of tino rangatiratanga or Māori values of self-determination and power.

The importance of connection was already noted in the Theme K1.

Whanaungatanga is also a key Māori value and thus balancing the values of tino rangatiratanga and tino whanaungatanga can be challenging and contradictory. Huia noted the challenge in discussing her desires at the end of life:

You wouldn’t want them [whānau] to come in run in every half an hour to see if you’re alright. Once you know, they put me in a home that is really nice and go on with their life....The good parts is to see the smile on the, on the on the whānau face to know that there is somebody around round them all the time you know.

The challenge of this dialectic can also be seen in caring for your loved one. Moana noted this dialectic in discussing not knowing the diagnosis of her loved one, *‘As a family member who’s looking after my, my ah 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.”’* Thus, the dialectic of rangatiratanga and tino whanaungatanga creates dilemmas and challenges for the ill person and the whānau.

Managing the dialectic becomes important to reduce burdens and clarify wishes. Participants noted that a key way to address this dialectic is to do some sort of advance planning. In some cases, this was simply to complete a

power of attorney. For example, Mere discussed her perspective about protecting her rights: *‘That’s important; see my sisters are saying to me you need a power of attorney. Ah I say, “What do I, what do I want one of those for?” Oh well maybe there comes a time where I might have an accident and I can’t think.’* In other cases, participants discussed the importance of having a conversation with whānau. Hine discussed her own experience with a health problem as an example of how to have the conversation around palliative care. She stated,

The idea would be to have the conversation openly with your children. Now have your conversation with your children now and include your mokopuna’s (grandchildren) in that and perhaps if I can use as an example. When I had the diagnosis for the breast cancer, my daughter in-law and my mokopuna came with me. We came here they sent me up to have the radiation thing done. My mokopuna was sitting right there lying on the bed beside me. She saw and she was lying there watching me yes through her eyes and through every aspect of that journey when I went through that she was right there with me she was with me climbed onto the bed when we went back to the ward. She’s eleven now it was only three years back since this happened here. She climbed on the bed with me and she waited. She stayed with me right through till I went down to the theatre. And when the doctor came into take me, she was sleeping in the bed beside me. So she saw all of that all of that journey right from the very beginning. When I told my family that I had this and then her mum suggested that we have a booby party, which is what we did. We had a booby party and my mokopuna had a couple of balloons stuck up here. It was just invite-only so she knows exactly what this entails exactly what I had to go through and when the doctor came in and told me what they were doing my moko (grandchild) was right there looking at the whole thing.

Overall, kaumātua desire to keep their mana and self-respect, to be accorded dignity and respect through tino rangatiratanga and at the same time maintain connection to whānau. Managing these dialectical tensions can be challenging in the best of situations. Advance planning and conversations helps to address these tensions so they are not as difficult to handle during the end-of-life journey.

Subtheme K3b: Balancing needs of self and other

There are stressors for those providing care for a dying loved one. One stressor that was noted was the burden that the ill person felt. For example, Roimata noted that her husband did not want to burden her. She noted,

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 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.

In addition, Pare noted,

Well my experience with palliative care was my first experience was when my mother in-law had cancer stomach cancer and I looked after her at home. And one of the things she didn't want to do was die in my home because she felt it might have frightened my children because they were only young when she got sick. And she was given six weeks so she had four weeks at home with me and spent the last two weeks at hospital.

The desire not to burden loved ones is also related to the desire to have tino rangatiratanga and support rather than diminish mana. The nature of the relationship meant that one wanted to help their loved one, while the other did

not want to burden their loved one. Thus, the concern is trying to balance needs of self and other.

One obvious stressor for whānau is the emotional demands of providing the care for the person who is dying. For example, Kei talked about her experience with her brother and following his desires of when to talk about his illness (and when not to talk). She offered, *‘[He said] “I’m very sick I’ve got leukaemia, and I’m not expected to live very long.” And I looked at him and I said to him, “No offense bro. I’m lost for words you know.” And he goes, “Oh go make us a cup tea please” and that was it and we never talked about it again.’* Thus, this participant did not talk with her brother again because he did not want to not because of her wishes. In another example, Roimata talked about caring for her husband whose emotional state changed during the end-of-life journey. She stated, *‘Because he couldn’t remember anything and that was it. I had to be careful sometimes, and he was loving and caring at other times, you know he was one fellow and then he was the other one.’* She had to be careful about what she said to him to not *‘make him angry’* and she was happy to do this because he was a good husband all of her life. Thus, the emotional challenges for both of these participants were difficult even though they were distinct. It meant emphasising the other’s needs over the self.

Other participants discussed the tangible responsibilities of caring for whānau during the journey. Often these responsibilities fell to women. For example, Hine talked about her responsibilities for taking care of the house when whānau came to visit. She noted, *‘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.’* Similarly, Moana discussed her responsibilities: *‘I was the one, you wash the sheets, you wash the blankets, you wash the dishes you well cook the kai.’* In both these cases, the women had significant responsibilities and put

others' needs above their own. However, they did not interpret this as a burden. Rather as Kei noted, *'Cause that's your, it's your whānau, you just do it aye.'*

Subtheme K3c: Maintaining relationships

The final subtheme is the challenge of maintaining relationships among the whānau. The end-of-life process brings out conflicts between whānau about the best way to handle the journey and also unearths unresolved conflicts among whānau. Some of the conflicts were the results of the stressors creating frustration and anger that encouraged lashing out of each other. For example, Mere noted, *'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.'* Similarly, Hine offered, *'Well we ended up in a big row like nearly a fist fight...I was storing that up and they were storing up and stirring that up some more....And it just literally blew.'* In both of these cases, the anger and frustration built up over time and led to direct and combative confrontations.

In other conflicts, there were feelings of being forgotten or excluded. For example, Hine noted that she was only 19 when her mother died. Since she was the youngest, she was excluded from decisions or participating in discussions. She offered,

The exclusion that I felt really affected me ah because I ended up having confrontations with my aunty. And mummy used to go in and out of consciousness and because of the conflict that was going on, I used to sit on the side of the bed and put my head on her and cry. Aunty said 'Don't say anything' and I'd cry and say [to myself] 'How could she do this to me?' And out of respect for my aunties you know you keep your mouth shut.

Finally, some conflicts occurred because of questioning of the decisions made earlier in the end-of-life journey. Hemi talked about how he and his wife received a wrong early diagnosis about her cancer. He explained,

And I've always looked at myself why didn't I do something when she was going through all of that. If I had of thought about it earlier on or a year before you know changing our doctor....I just don't want to think about it and I still don't want to think about it now the differences I would of thought about it earlier, but I'm only a human being. I'm not the one to blame and my kid's even said that 'It's your fault. You should have done this and you should have done that and said how could I how could I do that.' And even now they still say that.

In sum, the third theme illustrates the various responsibilities that ill people and their whānau face during the end-of-life journey. These responsibilities involve tensions between tino rangatiratanga and tino whanaungatanga, and honouring mana as well as self or other's needs. These tensions are charged with strong emotions and also result in conflict among whānau. Managing these dialectics, tensions, and challenges requires good communication skills and also is difficult during a very stressful time. Thus, these are illustrating the need for interactive health literacy within the whānau.

Theme K4: Balancing the tensions of receiving and providing support during the end-of-life journey

Although the third theme identified the tensions and challenges, the fourth theme focused on the ways to balance some of the challenges in receiving and providing support during the end-of-life journey. Essentially, the participants identified the need to receive and provide emotional support to address the responsibilities and stressors. The support can come within the whānau, from health care kaimahi, and from outside rōpū whakahaere. However, the need for support is more important for kaumātua and whānau who are isolated from their communication and/or have low health literacy. This section describes four subthemes, offering illustrative quotes for each.

1. Challenges for those who are isolated or have low health literacy.
2. Receiving/providing support from whānau.
3. Receiving/providing support from health care kaimahi.

4. Receiving/providing support from outside rōpū whakahaere.

Subtheme K4a: Challenges for those who are isolated or have low health literacy

According to participants, the challenges for people who are isolated or have low health literacy are greater than those who are well connected or have high health literacy. Health literacy in these examples tended to focus on the functional health literacy or knowledge about palliative care and what services are available.

Isolation was a challenge because it meant that whānau care givers had to shoulder the responsibilities by themselves. Some participants discussed the responsibilities when they were almost solely responsible for the physical and emotional care for their whānau. For example, Hemi talked about his responsibilities of caring for his family when his wife was dying:

And you know feeding family it was a real hard thing to do. So you know during 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. And the kids would sometimes do the same thing; they'd go home after work because all our kids were grown up and had their own families. So it was tough going those years.

In some cases, isolation meant being away from their cultural community. For example, Rongomai noted about her husband: *'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.'* In these examples, the participants were isolated from their whānau and cultural environment and the stress of caring for an ill loved one fell completely on them.

Isolation does not necessarily mean an extra burden so long as there is high health literacy. Raina was a skilled nurse and discussed caring for her husband. She offered,

I did it all myself I was independent. I was really active then and my first husband I did take him to hospital but I slept there on the chair. They had these chairs there and now they don't. And you would go to sleep there but they had the chairs there for us to make sure that I was comfortable and I kept my eye on him all the time.

This participant had tangible resources to aid her and the isolation in providing emotional and physical support from not a burden because she has skills that most people do not have.

People who have low health literacy end of shouldering extra responsibilities and financial burdens during the end-of-life journey. For example, Hemi talked about having to pay costs because she did not know what palliative care would provide: *'If I only knew 2 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."'* Moana related a similar story: *'And we didn't realise there was stuff that we could get her to awhi (care for) her. So if we had been educated on, on what facilities could've been used to awhi her ah. It would've made it so much easier for us.'*

Subtheme K4b: Receiving/providing support from whānau

This subtheme emphasised the receiving and providing of emotional and tangible support for loved ones and each other. At an emotional level, participants discussed the importance of providing emotional support for the ill person. Miriama offered, *'Sometimes you know it's not just about medicine. You know, it's about the wairua.'* Roimata offered advice to others when she stated, *'I would say have patience be loving and caring.'*

Participants recognised the importance of providing good emotional support for people who are dying. This part is consistent with the Theme 1 and the subtheme (1c) of cultural practices of connection.

Often forgotten in the end-of-life process are the emotional support needs of the whānau. That is, whānau need to support each other. As discussed earlier, there are challenges to the interpersonal relationships during this journey and effort is needed to maintain these relationships. Rongomai discussed the needs of a loved one who was providing care: *'Need for emotional support. Wairua. Aroha (love). Being a carer takes a lot of energy.'* Hine talked about how the whānau needs extend to after the person dies: *'It's wrong to assume that when the eyes are closed that it's finished. And I would love to see from this research that it ends somewhere; and 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 alright to feel like that.'* These examples illustrate how important it is for whānau to address their own emotional needs, especially given the tendency to focus on others during the end-of-life journey.

Subtheme K4c: Receiving/providing support from health care kaimahi

Although health care kaimahi are usually seen in terms of providing tangible support, they also have a role of supporting ill people and whānau emotionally. Participants reported that the best health care kaimahi are the ones who cared for their emotional and physical needs. They are not substitute whānau and yet they can deliver care in a way that is emotionally supportive. Hemi discussed the importance of his doctor for him as he negotiated blame from his children. He noted,

The kid's 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.' That's what happened that night. He came he told them off. 'Cause he heard it himself see he was a really good doctor. 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.

Miriam told a similar story about the doctor caring for her husband. She stated,

We got him the last few weeks, you know to look after him. And he came and of course he said, 'Look if you need me you know.' He gave his home number, cell phone number, his work phone number. You know then he come there. And he'll kneel beside him and say 'Uncle, how are you?' you know, so it was personal.

In both of these examples, the health care worker helped to support the emotional needs of the whānau.

Subtheme K4d: Receiving/providing emotional and tangible support from other rōpū whakahaere

Affiliated rōpū whakahaere play an important role in the end-of-life journey. They offer emotional and tangible support for all kaumātua. Rōpū whakahaere provide support by training ill/whānau how to interact with the system and more importantly provide a social network, especially for those who are isolated or have low health literacy. Two types of rōpū whakahaere can be considered: Work and community.

Work rōpū whakahaere can be useful resources for people. One participant worked for a health-related rōpū whakahaere that served as key source of information. Rongomai explained, *'I work for the Cancer Society in um, Auckland and I got a lot of information through them and they were the ones that supported me.'* For other participants, work rōpū whakahaere gave them the resources to be able to care for their loved ones. For example, Hemi noted that he was able to care for his wife and deal with his isolation because his work gave him time off with pay: *'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.’ Similarly, Hone noted that his family members were able to support him and his wife: *‘My girls were very lucky. They were given ...as much time as you need so the girls were there the whole time.’* In all of these examples, work rōpū whakahaere provided tangible support to enable the whānau to care for their loved ones.

Community rōpū whakahaere also provide emotional and tangible support for kaumātua and whānau. Miriama noted that a community rōpū whakahaere would *‘every Tuesdays, from 9 ‘til 10, they would come in. A whole group of them would come in and Waiata to him.’* For other participants, a community rōpū whakahaere is a sanctuary for them. Roimata offered, *‘[a community rōpū whakahaere] is my sanctuary. I told [named person] that. And she says, “Don’t you ever be afraid. You come here you sit there and you come see me. And don’t ever be afraid if anyone pushes you around she said you tell me.”’* Hine explained,

[a community rōpū whakahaere] is where I can come and tangi [mourn, weep] and share my journey and know that I’m safe. That’s the role that I see with the [a community rōpū whakahaere] so not just anybody to have that mantle. We need special people to have that empathy to share that kind of feeling with.

Thus, a community rōpū whakahaere provides safety and emotional support for its members. This support can be in addition to, or instead of, support from the whānau.

In sum, participants identified the importance of emotional support from whānau, health care kaimahi, and work/community rōpū whakahaere. Health care kaimahi and other rōpū whakahaere become particularly significant for people who are isolated from whānau or community and/or have low functional health literacy. The findings point to the need to strong interactive health literacy for kaumātua and whānau and also health care kaimahi.



Summary

The kaumātua interviews identified four core themes about the end-of-life journey and using palliative care services during this journey.

1. Cultural practices, values, and beliefs illustrating traditional Māori values
2. Give and take with health care providers
3. Responsibilities during the end-of-life journey
4. Balancing the tensions of receiving and providing support during the end-of-life journey.

These themes emphasised the importance of interactive health literacy for kaumātua and whānau and interactive and cultural health literacy of health care kaimahi. Essentially, these areas are ones where health literacy can be improved to enhance the quality of palliative care services and the end-of-life journey. Table 4.1 below provides a summary of these core themes and subthemes as they relate to health literacy.

Table 4.1: Summary of kaumātua themes and subthemes as they relate to health literacy

Theme	Subtheme	Area of Health Literacy	Description
Cultural practices illustrating traditional Māori values	Cultural practices around death and dying	High cultural health literacy of kaumātua and whānau	Practices that serve as markers of identity, connection with whānau, and spiritually. These practices help to provide a context for understanding kaumātua and whānau perspectives about what is important at the end of life.
	Cultural practices limiting service utilisation	Kaimahi awareness of cultural literacy along with kaumātua interactive literacy	Desire to be close to home, close to marae and spiritual foundations sometime limits use of services. Additionally, tapu related to opposite sex touching limits seeking of services.
	Cultural practices supporting service utilisation	Kaimahi displaying cultural literacy	For many kaumātua, having Māori kaimahi who respect and support cultural practices would encourage more to use services.
	Situations where culture is not a primary factor	Kaimahi displaying high (or low) levels of health literacy in general	A few participants noted that culture was not a primary issue because the care was either so good or so bad.
Give and take with providers	Kaimahi responsibilities	Kaimahi demonstrating technical, interactive, and cultural literacy	Kaimahi have responsibilities to 1) respect culture and avoid prejudice; 2) provide tangible resources in a caring manner; 3) provide clear information that reduces uncertainty.

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Author: Rauawaawa Kaumātua Charitable Trust Research Project Team

Theme	Subtheme	Area of Health Literacy	Description
	Kaumātua responsibilities	Kaumātua demonstrating interactive literacy	Kaumātua have responsibilities to 1) teach kaimahi about culture and personal wishes, 2) assert their wishes, and 3) ask for help.
	Tino rangatiratanga and tino whanaungatanga,	Kaumātua and whānau having interactive literacy	This subtheme includes the negotiation of Kaumātua mana, and self-determination, as well as respect and dignity while also having connection with whānau.
Responsibilities during the end-of-life journey	Balancing needs of self and other	Whānau having interactive literacy	Whānau need to balance caring for ill person and also making sure they get their own needs met.
	Maintaining relationships among the whānau	Whānau having interactive literacy	Whānau need to negotiate the tensions that occur among whānau members during the end-of-life process (eg, managing conflicts).
Balancing tensions of receiving and providing support	Challenges for those isolated or with low health literacy	Kaumātua and whānau having functional and interactive literacy	Kaumātua and whānau who are isolated or have low health literacy perceived (and have) burdens and challenges that are difficult to overcome.
	Receiving/ providing support from whānau	Kaumātua and whānau having interactive literacy	Kaumātua and whānau need to effectively provide emotional and tangible support for each other.

Theme	Subtheme	Area of Health Literacy	Description
	Receiving/ providing support from kaimahi	Kaimahi having interactive literacy	Kaimahi need to provide effective emotional support to kaumātua and whānau (ie, deliver care in emotionally supportive manner).
	Receiving/ providing support from outside rūpū whakahaere	Rūpū whakahaere having interactive and cultural literacy	Outside rūpū whakahaere are a critical source of tangible and emotional support for kaumātua and whānau.

Chapter 5: Whai Whakaaro o Ngā Whānau—Hopes and Thoughts of Whānau

Whānau hui or whānau (kin) focus groups were central to the research. Our goal was to understand the facilitators and barriers to whānau using palliative care from a health literacy perspective. This chapter first describes the participants and the methods for conducting and analysing the whānau hui. Then second, it discusses the themes identified from the analysis.

Participants

Thirty-nine whānau members, representing 14 whānau groups, participated in five focus groups. Participants' ages ranged from 32 to 85 years (eight did not declare age) and included 30 wāhine and 9 tāne, and 35 Māori and 4 non-Māori. Information about hapū and marae affiliations was not collected from individual kaumātua (Māori elders, men and women) and whānau members participating in whānau hui (whānau focus groups). All of the participants had experienced end-of-life care with a parent or parents, and/or other whānau members.

Methods

The whānau focus group process was designed to be culturally appropriate for eliciting whānau stories. As with the kaumātua interviews, we heeded the guidance of the advisory group to ensure that the processes were culturally appropriate and facilitated whānau participation.

As a result, we developed four provocative statements (see Appendix 5.1) designed to enable whānau to their stories about direct and indirect experiences with palliative care, as well as promote discussion within the hui. We also developed probing questions around the topics identified during the literature review such as communication with providers, communication with whānau, and facilitators and barriers to seeking service. The provocative

statements and question prompts were meant to be applied with flexibility and focused on getting whānau to tell their stories.

Analysis Procedures

The nature of focus groups is such that individual groups may end up focusing on the topic in slightly different ways because the process ‘is bound up with people’s lives—their projects, their developing identities, their evaluations’ (Puchta and Potter 2004 p 2). Therefore, we accepted that each whānau focus group’s discussion may develop its own focus and that each group may offer unique contributions that would inform experiences of palliative care. The five whānau hui were analysed using thematic analysis (see Chapter 3 for details).

Themes

The four primary themes centred on whānau cultural dimensions of care and communication, whānau roles and responsibilities with palliative care, whānau roles in communication and mahitahi (coordination) with clinical kaimahi (worker), and whānau learning from and passing on knowledge from palliative care experience. Each of these themes has parts or subthemes that reveal their complexity. We describe each theme and its subthemes and illustrate with quotes from participants (using pseudonyms for people they refer to). We also identify links to the most relevant dimension or dimensions of health literacy. So that we can easily identify the themes related to each participant group, the themes emerging from whānau hui are coded ‘W’ (for whānau).

Theme W1: Cultural dimensions of care

The first theme identified the role of Māori cultural beliefs, principles and practices that play a part in palliative care. Cultural practices are incorporated in all themes, but two particular dimensions of Te Ao Māori (Māori worldview) are mentioned here: wairua (spiritual) and the in-between worlds, and the significance of tikanga (customs, practices, beliefs) and meanings of

whānau in palliative care. While the issues of the meaning of whānau and tikanga were discussed in only one focus group, we took the view that the level of engagement between those present was such that we should include them (ie, forcefulness, Owen 1984). Another reason for including this topic was that it aligns with the cultural practices theme (Theme K1) identified in the kaumātua interviews.

Subtheme W1a: Karakia and waiata support wairua

Whānau talked freely about the last days and hours spent with a dying whānau member or friend as a spiritual experience. Whānau specifically mentioned the role of waiata (songs and singing, chants) and karakia (prayer) in facilitating the dying person's spiritual journey, and each of these is discussed below.

Whānau highlighted the role of waiata in managing pain and helping the dying person with their journey. Some whānau also talked of the dying person preferring to rely on waiata for pain management rather than morphine; they wanted to be present and lucid with their whānau during their last hours and days, and not 'out of it.' For example, one participant noted in her story about caring for her brother, *'What they used to relieve that pain was to sing. And I would have to sing my brother's song to him. Even though you could see the pain on his face, but you know when his song was sung to him, it soothed him a lot and I couldn't understand that'* (WG4-ono, wahine). In addition, another woman caring for her sister offered,

It wasn't about going into a home and putting her into a bed and having people walk in and out administering medication. . . . It wasn't going to be dictated to by a system that gives you something that puts you to sleep. That's what she said to the doctor when he asked her if she was in pain and if she would like some pain relief. She said 'When I close my eyes finally, I will sleep forever. I don't want to be asleep when people are visiting me.' (WG4-rua, wahine)

Waiata served a spiritual purpose for whānau as well as the person who was dying. Each of the following quotes from the whānau hui illustrates the effects of waiata on the dying person and whānau as well as others.

When Hone was sick in hospital I went there one time and Mavis his wife said that he would be going in a few minutes. So I went there and Hone was laying back, eyes shut. I tapped his arm and I said, 'Hone, you okay?' He opened up his eyes and said, 'Oh yeah' and we started singing. He lasted for another two weeks. He was okay. He was singing all the songs and hymns. (WG3-rua, tane speaking about his friend)

One of Mum's cousins had arrived and on her own and she said, 'I'd like to go in and see mum on my own I would like to sing to her' . . . and it wasn't long after the cousin had come out from singing to her that two of the sisters went up . . . and they came out and said, 'She is gone.' So for us it was a very spiritual um being spiritually involved with her journey. (WG2-wha, wahine)

The minister up [at the hospital] asked me if we were able to take [our] group up there to sing to these kaumātua. And you know to go up there and do waiata for them in the chapel up there, it's amazing, you know all these old people in the wheelchairs, in bed, it just, well they probably never seen it ever. And then next thing you'll find 'cause [the minister] tells us that so-and-so is gone, so you know and I think it's through that it's been wonderful like, especially for [us] you know to go up there and then tautoko (support) our group, not just for Māori but those up there, all of them up in the hospital so. Yeah it's wonderful. (WG5-whitu, wahine)

In each of these examples, waiata supports the dying person, the whānau, and others as they experience care in dying. Waiata are uplifting, spiritually enriching, and emotional supportive.

Karakia was used in whānau care for the dying person and it assisted with the transition from this life to the next. This was particularly important when someone was close to death, as karakia was part of protecting the person on his or her way to the next world. For example, one participant stated, ‘*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*’ (WG4-warū, wahine). This quote also illustrates the relationship between this world and the next, and the role of karakia in connecting with tūpuna. The reality of this connection was particularly evident when whānau talked about witnessing the dying person talking to people who had passed on:

Mum would be talking and smiling and doing hand gestures her body language you can just fill in the gaps . . . like a mokopuna (grandchild) you know [would] come and she would say oh who is holding her hand and she referred to the next one down and then the boy; we knew that she was talking to family members [who had died] and that was a indication as—well she’s never had this experience before; that indicated to us that her time—and they were coming to get her but um then she would focus refocus on going from the children in front of her to oh oh and you know just pointing everywhere at these people and she would be having this conversation and you would just wish you were in the conversation with her then she would start laughing and you know wow! She’s having a grand old time—having a reunion. (WG2-rima, wahine)

These quotes illustrate the ease with which whānau were able to talk about such experiences as normal within Te Ao Māori. Of central importance for Māori are the connections between the spiritual and material worlds. Wairua

travel the path from Te Kore (primal energy of potential) to Te Po (the realm of becoming), to Te Whai Ao (the emerging world), to Te Ao Mārama (the realm of being), and on physical death, return to Te Po (Marsden 1975, p 134). In short, there is ‘two-way traffic’ linking these three worlds: the departed spirits leaving, and those on their way to, the world of being (Marsden 1975, p 134). Whānau stories highlight the connection between the spirits about to leave and those about to receive them

While not exclusive to palliative care, this dimension of Te Ao Māori is important for palliative care kaimahi to recognise and work with. Recognising spiritual perspectives and experiences of Māori are critical elements of cultural health literacy of palliative care services and their kaimahi.

Subtheme W1b: Understandings of tikanga and whānau

In one focus group, the principle of tikanga (cultural protocols) and meanings of whānau were discussed. While raised by only one focus group, the issues may have implications for a range of parties associated with palliative care. We first discuss tikanga and then whānau.

Tikanga was discussed in relation to first, what it means in different situations, and second how different tikanga relate to each other. The group talked of the ways in which iwi, church, and rūpū whakahaere (organisations) influenced expectations and practices, and also how individuals had some say in what happened to them as they were dying and after they had died. Each of these had impacts on whānau role and responsibilities as well as implications for palliative care services.

The next quote illustrates how whānau accommodate the differences between systems, by accepting (rightly or wrongly) that the system can’t necessarily change.

My auntie's husband who was very ill and she would always say to him, 'Robert, can you hear the harps?' And he would say, 'Not yet Alma.' 'Tell me when you can hear the harps Robert.' Before he died he said, 'Alma, I can hear the harps.' And off he went and I think that it can be as beautiful as that. I think that some systems fail to provide that. I think the Hospital has tried its best to change that but you can't change that tikanga up there 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.
(WG4-rua, wahine)

One significant part of this quote is the phrase 'but you are explaining it from the offset that this is what we want to do.' This suggests that the system is not asking or initiating, but rather that action depends on the whānau, even if 'they will adhere to your wishes.'

In other examples whānau talked about respecting the wishes of the dying person, even though they may not strictly fit with tikanga of their iwi or marae. For example, one participant remembered a kaumātua from her church having his wishes carried out:

One time we had one of our kaumātua die in church, the Mormon Church and that night they left his body in the chapel and that is the first time I had seen a body lie in the chapel on his own all night, nobody was with him. Now his wife told us that his understanding of Psalms was that he was to lie quietly on his own. . . . That was his wish. You have had everything going on around you all of those days and then they took him into the chapel, put the korowai on his casket and he lay there. In the morning the whānau knew what time to be there to be with him right up until the time of the funeral service. (WG3-tahi, wahine)

The concept of whānau was discussed explicitly within the focus groups. In some groups, whānau was taken to mean those close and immediate, but in others whānau included supporters by association, such as church groups or Rauawaawa. There were differences when talking about whānau as a support network and whānau as those who need to know what is going on with care. For instance one man said. *‘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’* (WG3-rua, tane). However, when support was discussed, who counted as whānau was extended to include non-kin, and especially those connected by church or service relationship. One woman described whānau this way:

Whānau is a big, huge world. It’s not just our immediate whānau. Um today it’s [community rōpū whakahaere]—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.
(WG1-wha, wahine)

While the first emphasises the rights of close kin, the second emphasises the supports offered by a wider group that includes non-kin (eg, community rōpū whakahaere, hospital and hospice) as well as extended whānau. Kin connections were especially significant, but other relationships were also important in providing support during palliative care.

Theme One highlights the significance of waiata, karakia and tikanga in the care of kaumātua and whānau using palliative care services. For clinical kaimahi, knowing that this is case should be enough to prompt asking questions about what can be done in the clinical setting in particular, to enable kaumātua and their whānau to do what they need to do. Thus, palliative kaimahi 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. These dimensions of understanding are central to palliative care providers and kaimahi cultural health literacy.

***Theme W2: Tuitui ngā Tangata Kotahi—People working together:
Whānau roles and responsibilities in palliative care***

This theme links to the theme of ‘give and take’ identified in the kaumātua interviews (Theme K2), and concerned the rights of whānau to be involved in the ways that whānau members wanted, and had the capacity, to be involved. This included enabling younger whānau (eg, rangatahi/teenagers and mokopuna) to play a role in care, as well adults and kaumātua choosing the ways in which they will be cared for. The preference was for whānau to handle most of the care by themselves with some help (when requested) from palliative care kaimahi. While home care was preferred, when care at home was not possible, whānau wanted to be involved when care was in hospice or hospital. This did not mean providers would *expect* that whānau would do it, but rather that they consulted and involved whānau.

Whānau involvement in palliative care included personal, cultural and spiritual care, at home and in clinical settings, and relied on good working relationships with palliative care providers and kaimahi. This theme is therefore divided into two subthemes; enablers and barriers to whānau involvement in palliative care.

Subtheme W2a: Enablers to whānau involvement in care

Enablers to whānau involvement in palliative care centred on two areas: Support within the whānau and support from palliative care and other services. Success in each of these areas included whānau and palliative care provider strategies.

Whānau hui participants described strategies for being involved in palliative care that we grouped broadly as *mahitahi* (coordination) and *tautoko* (advocacy). *Mahitahi* occurred both within whānau and between whānau and

formal palliative care services. *Tautoko* also involved whānau, but also may have included other individuals and organisation. Mahitahi whānau included communication strategies, task coordination systems, and allocating roles for different whānau members. Each of these is discussed below.

Mahitahi (Coordination): The first aspect of whānau mahitahi were strategies the facilitated communication with the whānau. Whānau held regular meetings and set up communication books—notebooks that ensured everyone kept up to date. The following excerpts from whānau participants illustrate this strategy and the reasons behind it:

Well people started coming arriving at the hospital and I wanted to . . . be able to tell her in a later time. . . I wanted to record those things and be able to tell [Mum] later who it was and what [their] name was, the days that . . . her people who came to support and people who came and visited and dropped off things yeah. (WG2-rua, wahine)

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. (WG5-ono, tane)

And the mokos [grandchildren] love reading it, knowing what their Dad was going through for the day and they really enjoy that book. (WG1-toru, wahine)

Each of the excerpts demonstrates the significance of keeping a record of care to share within the whānau. There were practical reasons such as being able to tell the sick person later or, because whānau were ‘*sick of telling each other*’ (WG1-toru, wahine), as well as the desire to share with each other—

'knowing what their Dad was going through for the day' and beyond experience—'we still have those books today.'

Mahitahi whānau care also meant setting up systems to enable care tasks to be shared among whānau. The following excerpts show the ways in which whānau organised themselves to provide palliative care at home:

We had a roster that had about ooh, twelve of us, twelve, fifteen of us that included the brothers and sisters, our children and some of our in-laws. So we had a roster and every time a new person came on, that book was there for that person to read up on. (WG1-wha, wahine)

The doctor saw the dilemma, my daughter was hapu (pregnant), I was hapu, we were all living in the same home and we got my Dad to look after. So he says to us, 'Have you got anyone in the whānau that could actually take over his care?' So my son, my second youngest son, who was 16 at the time, wasn't going to school but he was—I said to him, 'What are you going to do? It's your choice, go to school, wag school, or look after your grandfather.' So he looked after my Dad. (WG5-rima, wahine)

Each of the above highlights the practical solutions whānau developed to meet the care needs of the person, as well as whānau needs. The first was developing rosters and the second, meant digging deep to involve a younger whānau member. Both strategies exemplify a strengths-based approach within the whānau: identifying the strengths within the whānau and how can they be best deployed to meet needs. Organising rosters, whānau, and keeping communication books required identifying tasks, negotiating who could do what, and monitoring the situation, all of which suggest an ongoing network of mahitahi. These examples demonstrate how effective self-directed mahitahi enables whānau to participate in care.

The second part of mahitahi involved support from palliative care and other services that enabled whānau to be involved in care. Close working relationships between providers and whānau enabled whānau to access services and resources. The following quotes from whānau participants highlight the positive outcomes for whānau and the person being cared for when care between palliative care services and whānau tuitui (coordinate):

The staff at Ward X were just tremendous and nothing was too much trouble . . . and it was that staff that really made my wife's passing quite, not bearable, but took a lot of the stress and strain out of it. And I just wanted to pass that on I suppose they still do a tremendous job 'cause they're under huge pressure really. (WG5-tahi, tane)

The transition from hospital to home [pause] well there were really good things put in place before she came out so she got to choose what caregiver group that she wanted to go with and we had lots of options of—because we took her home to our home so we had to adjust some things and we had to get things that she could hold on to you know we had to move things down our hallway that she could use a walker, the toilet seat holders; just all things she could pull herself with up with, so all of that were really good yeah there is a whole list of things that I wouldn't of even known. (WG2-rua, wahine)

Two phrases in particular within these quotes suggest that the whānau and the person needing care, were able to exercise choice, ask for help, and access resources: '*nothing was too much trouble*' and '*she got to choose what caregiver group that she wanted to go with and we had lots of options*'. These phrases also suggest that whānau and palliative care staff worked in together.

Tautoko (Advocacy): Tautoko included support for whānau to access services and resources, as well providing emotional, spiritual, and cultural support. Tautoko and support from agencies other than, as well as from individuals within, palliative agencies was stressed as important as support for whānau. Several quotes from participants illustrate this perspective:

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. (WG3-tahi, 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 and wonderful. (WG2-wha, 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. (WG4-warū, wahine)

Each of the above quotes highlights a different aspect of tautoko, and highlights issues related to health literacy. The first, in stressing the problem of not being up to 'Pākehā language' and need to 'carry the weight of the kōrero,' suggests issues with medical or technical language—that is, technical health literacy. The second illustrates problems with accessing services, and the need for 'direct links' and someone with the skills to cut through the otherwise indirect routes to access entitlements. These factors suggest issues associated with interactive health literacy. The third quote identifies a person 'to help the whānau to look after your loved one,' which suggests a 'walk-

alongside role' for an individual with the necessary cultural and technical health literacy skills to assist the whānau.

One noticeable aspect, was that those whānau who had existing knowledge (eg, of equipment, palliative care, care techniques) and networks (eg, other agencies, advocacy services, whānau connections), were better able to navigate the system and access palliative care resources and services. Therefore, it is clear that learning about palliative care before it is needed would benefit whānau and kaumātua.

In summary, this subtheme incorporates two dimensions: *Mahitahi* within whānau, as well as between whānau and formal palliative care services; and *tautoko* from individuals and rōpū whakahaere. Mahitahi within whānau included strategies for in-whānau communication, organising whānau care tasks, and using whānau strengths to give care. The second mahitahi dimension suggests that whānau with interactive health literacy skills are able to work in with culturally health literate palliative care kaimahi. The tautoko dimension suggests that when good levels of interactive and cultural health literacy skills are not present with whānau and kaimahi respectively, that individuals or rōpū whakahaere with existing relationships with whānau and kaumātua are in the best position to offer support. Having the support of a kaitautoko (advocate), helped whānau to navigate the technical (eg, resources/services that meet needs) and cultural (eg, how the system runs) paths to get, or do what they needed. This brings us to the specific barriers that whānau experienced which are discussed in the next subtheme.

Subtheme W2b: Barriers to whānau involvement in care

Barriers to whānau involvement in palliative care centred on the same two areas: Within the whānau and within the palliative care service. It seems that both involved expectations; the whānau and palliative care kaimahi expectations of each other's roles.

First was the capacity of whānau to ask. Within whānau, the most common barrier to being involved seemed to be not knowing who or how or what to ask for, or being reluctant to ask for help—which can result in stress. One participant said,

So, sometimes it's our fault for not asking for help because we're too proud like the immediate whānau. 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 can't go out we can't do this because we've taken on that whole work load ourselves. . . . we need to tap into and say to ourselves, 'Yes, we can't do it ourselves. We need to get that help.' (WG1-wha, wahine)

This participant highlights the needs of whānau to attend to other members as well as to the person needing palliative care and needing to look after themselves.

The flip side of whānau not being able to ask was *having* to ask for information or services because they were not offered. Whānau examples illustrate how they needed to be direct and assertive when seeking information or accessing services. The following whānau participants illustrate this perspective:

This nurse we always um pushed her for answers and she was free to give them and everything she told us happened in the timeframe she said would happen but she was very sensitive to our needs.
(WG2-rima, 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. (WG1-tahi, wahine)

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.' You had to ask them. (WG4-warū, wahine)

The first quote highlights the importance of there being a sensitive palliative care kaimahi available to answer whānau questions, but the phrase '*pushed her for answers*' suggests that whānau were unable to get answers from the expected sources. The second quote highlights two things: the ability of the whānau to ask and a view of the kaimahi as not deliberately obstructive, but rather unaware. It highlights the taken-for-granted culture of rōpū whakahaere; that staff members are not intentionally creating barriers to care, but working within a mainstream culture that takes certain things for granted. The third quote illustrates the frustration at having to initiate information seeking, rather than being offered service information.

While asking for help was one barrier, a second, more commonly identified problem, was the inability of clinical kaimahi to listen to whānau. This was a significant barrier, not only to their being involved in palliative care, but also to their kaumātua receiving proper care. For instance:

The brothers wanted their sisters, us, to do the personal care for Mum 'cause that's what we did for Dad. So it wasn't a problem for us we wanted to do that wait on her 24 hours but they 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. (WG2-rima, wahine)

Somebody does that kanohi ki te kanohi (face to face) that's what we do. These people [providers] need to come out and talk; we shouldn't have to—that is, what they said to us, we shouldn't have to 'Oh you will have to bring her in for the next appointment tomorrow—she may be well enough to go to a appointment or she might not. 'I think our services our mainstream services don't accommodate to our whānau needs around palliative care—they don't get it they don't get the picture. (WG2-wha, wahine)

Each of these quotes highlights two sides of the same issue: cultural expectations, but in this case expectations related to rōpū whakahaere culture and whānau culture. Whānau and palliative care kaimahi, in these instances, seem to both expect to do the care themselves. Whānau expectations of themselves prevent them from being able to ask for support; and palliative care kaimahi expectations (of themselves and/or whānau) prevent them from being able to accommodate whānau roles in the care process. This subtheme highlights the systems or rōpū whakahaere levels of technical and cultural health literacy. In order for kaimahi and whānau to develop appropriate levels of health literacy, systems need to change.

In summary, this theme highlights the capacity of whānau to tuitui communication, care, and whānau members to give palliative care. It also illustrates the role of different levels of tautoko needed for whānau, as well as the importance of previous relationships with non-palliative care service organisation in facilitating access to and use of palliative care services. In addition, while good relationships between whānau and palliative care kaimahi result in positive outcomes for whānau and the person being cared for (Subtheme W2a), whānau expectations of themselves and palliative care kaimahi expectations of themselves and/or whānau have the capacity to prevent such outcomes (Subtheme W2b).

This theme illustrates health literacy at work in several ways. First, whānau with interactive and/or technical health literacy are able to work in with palliative care services (Subtheme W2a). Second, whānau need tautoko support when palliative care kaimahi lack cultural literacy, or when they themselves lack the confidence, or, the interactive or technical health literacy skills to navigate the palliative care pathway with kaimahi (Subtheme W2b).

Theme W3: Whanaungatanga: Tētahi ki Tētahi —Whānau communication as creating and maintaining relationships

Whānau expressed the desire to be the communication go-between for kaumātua or the person who is unwell and clinical kaimahi—that is, to be the communication bridge between the individual receiving care and whānau, and clinical staff. Whānau also expressed the desire for clinical kaimahi to listen, give them information, involve them in care, and support them with the care including whānau role in cultural and spiritual care. Such desires suggest communication responsibilities and skills to make the whole performance work well. The analysis revealed some strategies that are already in place that may be used to build whānau capacity to take on the role of a communication bridge and to enhance worker capability to support this role. The two subthemes that contribute to this overall theme are: Whānau role in bridging clinical-kaumātua communication, and kaumātua and whānau building relationships with palliative care and other service organisations prior to the need for palliative care.

Subtheme W3a: Whānau bridging clinical-kaumātua communication

Whānau made it very clear that they were there to support their whānau member receiving palliative care. They understood they needed to know what was going on so that they could explain it to kaumātua and other whānau members. This subtheme focused on the tautoko (support) role that whānau play in relation to kaumātua receiving palliative care. This was lead primarily by an expectation and desire to ‘be connected’ to what was going on. This role involved maintaining dignity and mana (self respect, status) of the

kaumātua, in part through understanding and interpreting technical and medical information. This role manifested in several ways. The first was in the way that whānau saw dignity, or their own mana (self-respect) as coming from understanding for themselves as well as the relative in care. This is illustrated in a quote from one participant:

And yet sometimes you don't want to appear ignorant and lose that dignity of comprehension. That you know, you think 'Nah, yeah, yeah' and that's awesome. Do act it out [so] that they [kaumātua] understand and it's that keeping that dignity of comprehension within the patient is very important to them. (WG1-rima, wahine)

The second way in which 'being connected' linked to kaumātua dignity and mana, was where whānau saw themselves as needing to hear information—often alongside the unwell relative. This was particularly important when clinical kaimahi used complex language. The following quotes illustrate this perspective:

We whānau had to understand it first. We can even talk to them you know. We had to get a gist of what they were saying. Well we can relate that back to Mum and Dad. (WG1-toru, wahine)

But when they talk to the Pākehā (English) it's like very, you know, the wording and everything is yeah, quite difficult for them [kaumātua]. So if they didn't understand, we were there to get them through that. (WG1-wha, wahine)

In the above quotes, whānau are stressing their role in translating for the kaumātua—'we can relate that back to Mum and Dad' and 'if they didn't understand, we . . . get them through that.' While this appears to focus on assisting kaumātua with understanding technical or medical information, it also supports kaumātua mana and dignity at a time when they are vulnerable.

A third way in which ‘being connected’ linked to kaumātua mana and dignity was that whānau efforts to maintain tino rangatiratanga o te kaumātua — kaumātua right of choice. This was most illustrative in situations where the whānau stressed inclusion of the kaumātua in everything. Critically, when whānau interacted with clinical kaimahi they simultaneously supported the kaumātua. This called for careful balancing of kaumātua and whānau needs and respect for kaumātua during any communication. For example, one participant offered,

We had to be involved in the whole initial process from day dot. 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. So we kept ourselves quite informed and we made it a point as family to do so. . . . And we wouldn't leave until they [parents] knew exactly what was happening. So it was important that we got involved from day one.
(WG1-wha, wahine)

The above quote stresses the involvement of whānau in asking the questions that the parents may not know to ask, or know *how* to ask. Whānau support of kaumātua was also evident in their efforts to include them. This sentiment is expressed in the following conversation between the same participant and her sister:

A: We had to involve [Dad] with everything. You know he couldn't be left on side and we're just focusing on Mum. Everything we did for Mum, we explained to Dad what we're doing, [and] why.

E: He was always in the room.

A: He was there.

E: Always there. Every time everyone was there, my Father was there, my Mother was there, we were there. Never left out.

A: So we did very little without our Father knowing and that was just to keep him involved and him aware of what was happening to his partner, our Mum. (WG1-toru and WG1-wha, wāhine)

This conversation illustrates the commitment of whānau to including their father in decisions about care for their mother. The dignity afforded their father by his involvement was of central concern to the daughters.

In summary, the connectedness for whānau meant keeping informed about what was going on for the person in care, as well as supporting the koroua (older man) or kuia (older woman) by ‘translating’ information and providing care. Such responsibilities put whānau under enormous pressure, which may go some way to explain whānau calls to connect with support agencies before they needed them—discussed in Subtheme 3b.

Subtheme W3b: Whakawhanaungatanga—Building relationships prior to the need for palliative care

This subtheme relates to the Theme W2 and specifically tautoko (Subtheme W2a) and concerned relationships with agencies other than palliative care services. Several participants mentioned other rōpū whakahaere, and that having a relationship with such rōpū whakahaere helped them and their kaumātua in their moment of need. Trust within existing relationships aided understanding and stress.

My dad being at [community rōpū whakahaere] he’s built and is building, a relationship with a lot of people here. That’s like the nurses, that’s whoever he gets involved with here, he’s building a whānau relationship. So my question is, ‘Why do we have to go to another service provider to get this palliative care?’ . . . Why can’t we build on having this provider, provide that for our kaumātua?

'Cause like, they don't like being changed around—gotta go here for this, gotta go here for that. You know, they like everything nice and simple. So they're already getting that support here 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] because you've already got that relationship.

(WG1-wha, wahine)

Cause you know they [community rōpū whakahaere] could step back a little and I couldn't so yeah they 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. (WG2-rua, wahine)

These two quotes show how trust within an existing relationship was important when faced with a crisis or uncertain situation. Such trust is developed over time when service organisations meet social, health, and other needs of kaumātua. In the case of community rōpū whakahaere, staff and volunteers within the organisation get to know the kaumātua (and sometimes whānau), and the kaumātua gets to know them. These relationships provide a trustworthy basis to support a kaumātua and whānau when palliative care becomes needed. Whānau highlighted the need for the flexibility to use community rōpū whakahaere services with whom kaumātua already had a relationship.

Whānau also suggested kaumātua building relationships with palliative care services before they needed them. For example, *'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]'* (WG1-wha, wahine).

Theme Three centred on the relationship role that whānau bring to the palliative care situation. Whānau generally desire to help their kaumātua navigate care systems, through translating and supporting. However, they also need support, and therefore knowledge of, and relationships with support agencies, which can assist with accessing palliative care services and resources, before the need arises.

In terms of health literacy, this theme demonstrates the whānau capacity in interactive health literacy: the ability to engage in conversation, ask questions, and relate to palliative care kaimahi and services. Problems emerge when whānau or kaumātua do not have existing relationships to work within, and when whānau and kaumātua or palliative care workers are unable to meet the interactive or cultural health literacy skills of the other.

***Theme W4: Me Waihotanga ki ngā Whānau ngā Tupuranga ngā o Mua
—Whānau passing on their learning to the next event and next generation***

This theme cut across many levels and included sharing information at the time to enabling immediate whānau to learn from the experience, to building knowledge capacity for kaumātua, and other whānau groups. The focus was on learning from a specific event and sharing that experience with the extended whānau, so the next time may be a better experience.

The first level of whānau learning concerned sharing the tasks and experience of care with each other during the care via whānau meetings and communication books. This is discussed under mahitahi strategies in Subtheme W2A.

The second level of whānau learning concerned that which occurred as a result of the experience and is actively passed on to the extended whānau. The following quotes illustrate this situation; one of active knowledge sharing

within the whānau, and another where having learnt from experience, the speaker aims to do something different next time:

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.
(WG5-rima, wahine)

So as a whānau that's gone through it, you need to. . . . 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.
(WG1-wha, wahine)

The first participant emphasises that the whole whānau can learn from the experience through talking: 'everybody's learning together'. The second participant identifies a specific learning: to next time take 'care of ourselves' as well as the person who is unwell. This is also the case with the next quote, where the participant has learnt to take care of herself and in so doing is teaching her children:

I've got things in place because when my husband died, everything was left on me and my two children. Which was jolly hard you know. . . . So this has really bought things home, planning, which I have started with my children. I told them 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. And that's what I have done because my husband had none.
(WG5-wha, wahine)

The following quote explicitly states how whānau learning can support other whānau. The journey with palliative care has enabled her whānau to help others who are now on the same journey.

Because we've been through that journey we're also helping our own whānau. Last year . . . a nephew got sick. He was palliative care, his wife looked after him, [and] we were there to support them. We travelled from Waikato here to [a town] just to see how they were doing and it's very important. (WG5-rima, wahine)

The next participant speaks from an experience where she didn't know what was available at the time. Although she does not explicitly mention passing on learning to others, she implies this, and that learning must be active, when she says *'Instead of just . . . picking them up'*.

I think it's important that family . . . must know that there are resources out there to help palliative care more comfortable especially for the patient and then it becomes easier for the caregivers. Instead of just you know, picking them up. (WG1-rima, wahine)

The final quote captures the essence of whānau learning and passing on the knowledge that is integral to kaumātua and whānau relationships.

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.

(WG4 waru, wahine)

In summary, Theme W4 demonstrates the opportunities that whānau take in order to learn from a given situation and pass it on to others either actively or indirectly through experience. In terms of health literacy whānau show here had they are able to develop a range of skills in various dimensions of health literacy and passing them on. Learning about resources, rōpū whakahaere in palliative care, as well as practical tools to support them, fit within interactive and technical health literacy, broadly speaking, as well as cultural health literacy when dealing with mainstream rōpū whakahaere.

Summary

The whānau focus group themes revealed that some whānau have the skills and knowledge to access to navigate the palliative care pathway. They also demonstrated that palliative care providers and kaimahi understanding of cultural health literacy need to be developed. In addition, knowing how and when to be proactive with regard to meeting the needs of kaumātua and whānau in palliative care, is a cultural health literacy issue for kaimahi and mainstream rōpū whakahaere.

Knowing the system, whānau members were able to identify and ask, and work well with palliative services. Having the support of a kaitautoko (advocate), whether an individual or agency, helped whānau to navigate the technical (eg, resources/services that meet needs) and cultural (eg, how the system runs) paths to get, or do what they needed. It was evident that learning about palliative care before it is needed would benefit whānau and kaumātua, as would building relationships with providers.

The analysis showed that problems emerge when either party—whānau and kaumātua or palliative care worker and service—were unable to meet the interactive or cultural health literacy skills of the other. Yet, the *system* and

rōpū whakahaere culture impacts levels of technical and cultural health literacy. Systems need to change to be able to better meet and develop kaimahi and whānau levels of interactive, cultural, and technical (systems) health literacy.

These themes highlight the role of whānau interactive and technical health literacy, the need for systems-driven kaimahi cultural and interactive health literacy. Theme 4 also suggests the potential for enhance political health literacy for whānau with its emphasis on critically reflecting on the role of non-palliative care social organisations in accessing services and resources that benefit, personal, whānau, and community wellbeing. The four themes suggest areas where health literacy can be improved to enhance the quality of palliative care services and experience of whānau in supporting their kaumātua and looking after themselves in the process. Table 5.1 below provides a summary of the themes and sub-themes as they relate to health literacy.



Table 5.1: Summary of whānau themes and subthemes as they relate to health literacy

Theme	Sub-theme	Area of Health Literacy	Description of practices
Cultural dimensions of care	Role of karakia and waiata support wairua	Recognising spiritual perspectives of kaumātua and whānau are critical to cultural health literacy of palliative care services and their kaimahi.	Kaumātua and whānau practices that serve as markers of identity, connection with whānau, and wairua. Kaimahi 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 within palliative care provision.
	Understandings of tikanga and whānau		
Whānau want their own roles and responsibilities in palliative care	Enablers to whānau involvement: Mahitahi and Tautoko (Coordination and Advocacy)	Whānau with interactive health literacy skills are able to work in with culturally health literate kaimahi.	Whānau have responsibilities to 1) inform kaimahi about culture and personal wishes, 2) assert their wishes, and 3) ask for help. Kaimahi offer to assist whānau to (1) tuitui (coordinate) in-whānau communication; (2) organise whānau care tasks; and (3) use whānau strengths to give care. Whānau use advocates to, help navigate technical and organisational-cultural service and resource pathways.
	Barriers to whānau involvement in care	Whānau with interactive and/or technical health literacy work in with palliative care services.	Tautoko support for kaumātua and whānau is offered when palliative care kaimahi lack cultural literacy, or when kaumātua and whānau lack the confidence, or, the interactive or technical health literacy skills to navigate the palliative care pathway with kaimahi
Whānau communication as creating and maintaining relationships	Whānau bridging clinical-kaumātua communication	Whānau demonstrate interactive and technical health literacy. Kaimahi demonstrate interactive and cultural health literacy.	Whānau practices include (1) keeping informed about what was going on (2) supporting kaumātua by 'translating' information and providing care. Kaimahi offer to help whānau to work through specific technical terms, processes, and practices of palliative care; and help whānau to assess cultural implications and personal and whānau impacts of these.

Title: Māori health literacy and communication in palliative care: Kaumātua-led models

Author: Rauawaawa Kaumātua Charitable Trust Research Project Team

Chapter 5: Whai Whakaaro o Ngā Whānau

Theme	Sub-theme	Area of Health Literacy	Description of practices
	Building relationships prior to the need for palliative care	Whānau build interactive and political health literacy.	Whānau need support, and therefore knowledge of, and relationships with support agencies that can assist with accessing palliative care resources and services, before the need arises.
Whānau want to pass on learning from their experience to the event and next generation		Whānau demonstrate interactive, technical and organisational-cultural health literacy.	Whānau learn from given situations and pass it on to other whānau either actively or indirectly through experience. Rōpū whakahaere that support kaumatua and whānau, learn from them about how to improve their own roles in palliative care.

Chapter 6: Whai Whakaaro o Ngā Kaimahi—Hopes and Thoughts of Palliative Care Workers

Focus groups with palliative care kaimahi (workers) were another core element of the research. Our goal was to understand the interactive and cultural health literacy factors associated with delivering high quality care to kaumātua and whānau from palliative care kaimahi perspective. We did not attempt to assess how well palliative care was delivered nor assess the quality of those services. Participants did express what they thought they should do, what they thought they did well, and what they would like to improve. This chapter first describes the participants and the methods for conducting and analysing the interviews. It then discusses the themes identified from the analysis.

Participants

We conducted three focus groups with a total of 21 palliative care kaimahi. The first focus group was with six hospital palliative care kaimahi and included one doctor, one counsellor on practicum, three nurses with various specialisations, and one director of the unit. All of these kaimahi were Pākehā. The hospital palliative care focuses on providing direct medical care in hospital as well as coordinating medical care in hospice and in the community. Thus, they work closely with district nurses and general practitioners (GPs) to provide palliative care.

The second focus group was with eight hospice palliative care kaimahi and included the director of the unit, one counsellor, and six nurses, four of which oversaw specific programmes. Seven of the participants were Pākehā and one was a different ethnicity (not identified here due to anonymity concerns). The hospice provides four types of services.

1. Inpatient care: medical services provided by GPs backed up by specialists.

2. At-home care for people living in the nearby communities: direct care in specific areas such as nursing, counselling, children, social work.
3. Collaborative care: working in partnership with district nurses throughout the region and outside of the nearby communities; hospice does psychosocial and district nurses do day-to-day nursing.
4. Children's services: working with the children/grandchildren of patients who are dying and also provide care to sick children.

The third focus group included community-based palliative care kaimahi who were all Māori. There were a total of seven community kaimahi who provide 'wrap around' services supporting kaumātua. Their roles included clinical nurses (two), community health workers (three), manager, and transport kaimahi. All have experience working with palliative care services and yet none specifically specialise with palliative care. They work directly with palliative care specialists to provide services. In addition, these kaimahi serve as cultural and information advocates for kaumātua.

Methods

The focus group process was designed to be a focused and pointed discussion about key interactive and cultural health literacy issues that arose in the literature review, interviews with kaumātua, and focus groups with whānau. The research team members worked collaboratively to design the questions. In particular, the palliative care doctor was critical in focusing the guide. Appendix 6.1 displays the specific focus group questions and probes. Overall, our goal was to get palliative care kaimahi to talk about their experiences in providing care to kaumātua and whānau focusing on communication and health literacy issues.

Analysis Procedures

Themes

The three focus groups were analysed using thematic analysis (see Chapter 3 for details). We identified four primary themes during the analysis process. In brief, the themes centred on engaging culture, engaging whānau, communicating with kaumātua /whānau, and coordinating with other care kaimahi and providers. Most of these primary themes have parts or subthemes that illustrate the complexity of the themes. We describe each of the themes and subthemes and provide quotes to illustrate the themes. So that we can easily identify the themes related to each participant group, the themes emerging from kaimahi focus groups are coded 'M' (for mahi/work).

Theme M1: Engaging culture

The first theme related to the manner in which palliative care kaimahi understood and engaged with culture. The kaimahi clearly identified that culture is a factor in providing services to kaumātua and whānau. As one hospice nurse noted when asked about the difference between kaumātua and other older people: 'Well I think there's always cultural differences so that's a big one.' The range of engagement varied. Some participants had lower levels of cultural literacy and yet a desire to learn more. In contrast, other participants expressed ways to express cultural competence through their own actions and by working with cultural liaisons. Finally, many participants cautioned about over-generalising about culture. In all, four subthemes were identified:

1. Lower cultural literacy and open to learning more.
2. Expressing cultural sensitivity.
3. Using cultural liaisons.
4. Avoiding over-generalising.

Subtheme M1a: Lower Cultural Literacy and Open to Learning More

For the first subtheme, a few participants (from hospice and hospital only) noted that they wanted to know more about what they could do to better meet

needs of Māori. They express a sense of low cultural literacy but shared a desire to know more. For example, one of the hospital participants stated:

I think one of the other things is, you know, that, well that I know I've struggled with in the past is what do Māori want from us? (Some of group agrees) And I know I have approached the Māori management teamand all that was forthcoming was the Tikanga booklet which, you know, 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.

Similarly, another person expressed an openness to learning more about culture although she felt that the current service is good. She stated, 'I think we provide a very good service to Māori but I do think that there is room for improvement. I think people need to be comfortable with us and I'm not sure that always happens and I'm open to, I think we're all open to that.' Overall, these quotes illustrate a desire from Pākehā providers to learn more about Māori culture and be more culturally literate.

In addition, community kaimahi also noted some instances where cultural literacy could be improved. Specifically, these kaimahi noted that sometimes tikanga and cultural sensitivity was not always followed in medical environments. One participant noted,

I see the other thing, that really grates me even in the hospitals and rest homes, is seeing kaumātua with bottles on their eating tables. And that still happens today (other participants agree with obvious disgust), for goodness sakes, even in the hospital. You know like I've

gone in to see them and there's a urinal sitting on their tray where their food is.

Another offered, *'You know? Why is this still happening? And they've got feet on their pillows to elevate their feet.'* Thus, the improvement of cultural literacy is endorsed by all palliative care kaimahi, particularly for community kaimahi who noticed practices that are tapu, or violations of cultural norms, and see ways to improve the cultural climate in medical settings.

Subtheme M1b: Expressing Cultural Sensitivity

The second subtheme demonstrates the palliative care kaimahi focus on the importance of expressing cultural sensitivity and to be culturally literate. One participant from hospital summarised the position of cultural sensitivity: *'So if we approach kaumātua it's a question of respect for age and position.'* In response to a question asking what people should do to train new kaimahi on in working with Māori, one nurse offered, *'Respect (group in agreement), partnership and communication.'* Another added to this by saying, *'And basic protocol (group agrees), like for me as a foreigner, taking off our shoes is something we don't do at home. So it was learning that. For me, that was a huge learning.'* A third person stated that respect for names is important: *'Am I pronouncing your name properly? [group agrees] It's important that I do that, you know.'* They also mentioned not touching children's head or being careful about sitting on beds and tables. Similarly, one participant offered that the palliative care approach at hospital respects culturally specific practices. Specifically, he noted,

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. We don't have any prejudice against that.'

Essentially, these participants recognised some cultural protocols and tapu for Māori and felt that it was important to be aware of these cultural practices.

Another aspect of expressing cultural sensitivity was the perceived fit between what the services do and Māori culture. For example, one of the hospital kaimahi offered a situation that showed a respect for a patient's desire to be close to home and near her whānau:

Like yesterday. The lady wanted to go home but she was too unwell to go home so we talked to the whānau and they said _____ hospital was the next option and they would be far more comfortable for her to be there. So she went yesterday after. We managed to get a bed. That's where she's gone to be close to her whānau.

Similarly, a nurse at hospice offered, 'Well, I think just having...being able to keep people at home is the biggest thing for me, because when I was a young nurse, we used to have them in hospital where they'd shut the doors and people use to die alone often, and in pain.' Finally, one hospice participant explained another aspect of cultural fit:

The Hospice philosophy for holistic care fits very well with the Māori philosophy of holistic care. And I think that's strength and I think that is recognised by Māori that do come in to the service; that we're not afraid to talk things through—emotional and social.

In sum, these participants perceive that the fit between their philosophy and practice fit well with Māori cultural values.

The degree of fit between culture and palliative care was also noted by community kaimahi. The nature of the fit was different in that the culture comes first and figuring out how palliative medicine fits was the new addition. One community worker noted that Māori have always practised

palliative care with their whānau and now integrating the Western medicine into the palliative care journey is the challenge. She expressed,

It's more common now for Māori to enter into rest homes because whānau actually identify that 'we can't cope' and they are not ashamed now, you know, they're not as now to say that 'we can't cope' or 'we can met mum or dad's—or whoever it is—we can't meet their needs now'. . . There was a stage where we would, as a culture, we wouldn't put our whānau in hospice or palliative but because, I don't know, it's more known now.

Thus, the participants are seeing palliative care as an option for kaumātua when it is delivered with cultural competence. They cautioned that the training in cultural competence must lead to action and practice as one participant expressed, *'But as soon as the training [about cultural competence] is finished, it's never really actioned. It's become more of a conduit between filling my work obligations but the actual "putting it into practice" is where it really falls down.'* So, these kaimahi see that palliative care is a good option and fit for some Māori if the services are delivered in a culturally literate manner.

Community kaimahi also expressed other examples of cultural practice to fit kaumātua needs and display cultural sensitivity. These practices help to display deeper-level emotions such as aroha and wairua. For example, one community worker stated,

For me, it's going up as a group to the hospital to waiata to our kaumātua. And just knowing you go to waiata to one but really you're waiata-ing, you're singing waiata, to the whole ward because they come out of their rooms to see where the music's coming from. They come and they stand and they watch and they listen and they feel. You know, so you can't tell me that's not expressing love, you

know. You have that love aura around you and that's encompassing for all, not just for the person you've gone to see. We've witnessed that many times.

Similarly, another community worker expressed the importance of tikanga to support other cultural values: 'That's what makes a big difference in the health and wellness of our kaumātua. (Group agrees.) If we can provide that, it not only comes with kaupapa Māori, but it comes with tikanga and that manaakitanga and kotahitanga and that all comes into it as well.' Thus, community kaimahi cultural expertise helps to connect with kaumātua in a spiritually uplifting and healing manner.

Subtheme M1c: Using Cultural Liaisons

Participants at both the hospice and hospital stated the importance of working with Māori health care kaimahi or community members who can help them meet the cultural needs of kaumātua and whānau. The level of involvement with liaisons is different in these two rōpū whakahaere. At the hospital, care kaimahi noted that they can offer an advocate to work on their behalf: '*And then we introduce our services if we find that there is some difficulty we do offer Māori advocate services to them if they so required.*'

The hospice has a stronger relationship with a cultural liaison in that they have a kaumātua who works directly with them. As one participant noted, '*I think we are extremely lucky because we have got our own kaumātua who we can call on day and night and he will visit with any of the staff that are having problems. He will go to the unit; he talks to all our volunteers, and he is just a very special person.*' Another participant described a story with one of her first referrals where the kaumātua provided advice to help her work effectively with a patient and the whānau:

I went to visit a family with the Hospice nurses and it was an elderly gentleman who was very near the end of his life. And I didn't understand that grandparents adopted grandchildren. Lots of

learning went on. And they had one of the grandchildren was living with them and the grandmother was really worried about the little girl, and so was the grandfather. So we talked about coming and finding out what support there was. And I said 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.

Thus, the hospice feels they can enhance their cultural sensitivity and competence by working with a cultural liaison who can help them follow tikanga, avoid tapu, and also to teach them about cultural literacy.

Subtheme M1d: Avoiding the Tendency to Over-generalise.

The final subtheme was a caution offered by most of the participants that it is important to not generalise to all Māori. Rather, it is important to recognise individual differences as well. One hospital participant offered,

See you have to be careful there though that we don't look for one answer. I think there's a tendency to say 'What do Māori want?' as though it's going to be 'Well, this is what they want.' Whereas, I think with Māoridom, everybody's an individual with different requirements at different times, aren't they?

In the same conversation, another participant noted:

I can remember some time ago when we did have a Māori social worker. Having a discussion with her one day about how we might better meet the needs of Māori. And she said 'You meet them the same as everybody else because we want the best of care too' and I think that's something to remember.

The hospice participants recognised some individual differences as well. For example, one participant noted some of the variation in their clientele that impact on their perspectives and needs:

It's difficult to be very specific though because we work with kaumātua who are very sophisticated and they have a place in their community, respect. They are very well cared for. They are quite well off. Through to those that are economically disadvantaged. Those who have no whānau around them, or those who have twenty or thirty in close constant contact. I haven't seen anyone that I have seen that I would call, this is a typical kaumātua. But I remember sitting with kaumātuas [sic], sitting on the floor with them talking at a health day and they were very aware about what palliative care meant and what Hospice did. And some of the things they talked about was for them, not bringing the young people home to look after them. Not bringing their very successful young people, often in Australia or in other parts of the world. Not wanting them to feel obligated to come home and look after them.

Māori community kaimahi also noted the importance of not over-generalising, particularly as it relates to support for kaumātua. One participant noted, '[Health care kaimahi] just take for granted [that] "You're a Māori. You're going to take care of your own people" and that's that.' Thus, this worker recognised that not all kaumātua have strong whānau support close by and may have some specific needs that should be addressed. In sum, the participants suggest respecting and supporting cultural practices and also not

assuming that everyone wants that same thing as summarised by one of the hospice participants: *‘Everybody practises that, you know, their own cultural things too. You can go into some family and we have got to be careful not to just presume.’*

Theme M2: Engaging whānau

Related to engaging culture, participants also emphasised the importance of engaging whānau in the palliative care process. One hospital participant noted, *‘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 and there’s quite a lot of questions.’* The community health kaimahi stated that whānau is the most important element for kaumātua, in general and during palliative care. For example, one participant offered,

I think really it’s about also bringing the family in and having the family participate in that journey with you because at the end of the day it’s the family that are going to be the ones that will, you know [take care of the patient]. Keeping that strength within the whānau is really important to us as well because we’re not going to be there 24/7 for them. So it’s about engaging them.

Overall, the participants stated they have a desire to work with whānau and help the patients and whānau reach the best decision about care for their needs. The community health kaimahi noted the importance of being aware of needs of kaumātua and working with them to best meet these needs. One hospice participant explained,

I think it’s about meeting families where they are (group in agreement). We are going into their lives. It’s their life...you know 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.

Similarly, a hospital participant explained,

We had a patient just quite recently who wanted to go and I think the whānau were saying that he was too ill and they couldn't look after him but he wanted to go home. And he didn't want to stay in hospital and the compromise was eventually [name of facility], I think it was. So that was the compromise. And he said 'Oh, I'm happy with that. At least I'm in the area.'

In addition, the participants try to meet the needs of the whānau. This sentiment was especially true in the hospice where there are resources to meet whānau needs. For example, one participant offered, *'I suppose it's a big plus when they've got the whānau room over there as well (group in agreement), so they are not coming in by themselves.'* Another participant in the same conversation noted, *'Particularly for end of life care, is having extra space for the family to stay. We find for Māori, it is particularly important.'* For the hospice, participants stated:

[Another nurse] and I went into a family and it was a father who is our patient and his daughter looks after him in her brother's house. So we discussed the patient, but then we talked about her brother, didn't we? And his health problems. So it's about acknowledging everything that is going on in the house.

The engagement of whānau is not without its limits. Participants in both hospital and hospice exclaimed that working with a spokesperson is important in working with large whānau. One hospital participant noted, *'I think with some of the larger whānau [sic], it's trying to discover who the decision maker is within the group because you're going to often have a lot of disparate opinions about what should happen. Not everybody's on the same page at the same time. And sometimes it takes a little bit of negotiation, doesn't it?'* Similarly, a community worker stated:

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.' They needed to elect someone that was going to speak on their behalf because I only wanted to hear one person, I didn't want to hear the entire whānau and there was about fourteen of them in this one room. So that was really important ay? So it was really about putting those strategies into place for the family.

The hospice has additional limits with its impatient facility as a nurse stated: *'It's really hard to accommodate because they think that 50 people can come. But we can't have 50 people staying and that is where we could...although we try and explain, because we have very strict rules. Not rules. . . but we try to discuss with them what the things are.'* Thus, setting limits works for the care kaimahi to have effective communication and engagement with whānau.

Theme M3: Communication with kaumātua and whānau

The third theme explored the nature of communication in the engagement of culture and whānau. Good communication was the key to effectively navigating the palliative care decision-making process and service delivery.

Good communication consists of three core points:

1. Building relationships.
2. Listening and collaborating with the patient and whānau to meet their needs.
3. Addressing functional health literacy.

Subtheme M3a: Whakawhanaungatanga—Building relationships

The first subtheme emphasised the importance of whakawhanaungatanga (building relationships) with kaumātua and whānau. During initial consultations, participants expressed how important it was to take time and to build relationships. One participant stated, *'Spending time and not rushing people (group in agreement) and relationship building and it needs to happen.'* Another participant offered, *'It's about building relationships, and*

what I've always found one of the best ways to build a relationship is to show an interest in the family in the background and you know, who's important to them and where they fit in the family tree sort of thing.' Some even noted that respecting space and culture helps to build relationships: *'I always ask permission. I don't just assume that I can sit on the bed. I will say, "Do you mind if I sit here?"'* Thus, these participants suggest that using respectful communication and spending time interacting helps to build relationships and thus trust with the care kaimahi and services.

The building of relationships extends beyond the individual patient and whānau to community rōpū whakahaere (organisations). For example, one participant noted, *'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.'* Similarly, another participant explained,

But also frontline staff being aware of the importance of building relationships outside the rōpū whakahaere and the communities that they work in. And I think that is one of the reasons that we have primary nurses in primary areas is because that way they are able to build that relationship.

These quotes illustrate the awareness of building relationships with groups that can refer people to services and that ultimately helps to meet kaumātua and whānau needs.

The community kaimahi also took building relationships a step further. In some cases, the community kaimahi become part of the support network, particularly when kaumātua do not have whānau nearby. For example, one participant noted,

We had a kaumātua who we knew he had whānau in Waiheke Island...You know, so we kicked in. It was the kaimahi here that

done the kai hākari (feast), done the paepae (speakers' seat or bench), done the everything and then trying to get hold of the whānau was a mission and then they turned up five minutes before the service and then after the service they were gone. So, for him, we were his whānau. And we done what we saw needed to be done.

For the community kaimahi, the boundaries between patient and care kaimahi is blurred because of the relationships built up over time with patients and the cultural connection.

Subtheme M3b: Listening and collaborating with the patient and whānau to meet their needs

The second subtheme was similar to building relationships, but more specifically focuses on listening to understand needs and collaborating with patient and whānau to meet their needs. The focus of this subtheme is to listen carefully to patients and whānau to understand their needs and then working with them to determine the best course of action; the participants clearly noted that palliative care kaimahi are there to help, but the patients and whānau have the ultimate decision-making rights.

The participants explained that they have to work hard to make sure they understand patients' true desires. One hospice participant noted, *'It's about listening and I think, you know, we talk about listening but do we actually hear what their saying. You know, take it in at a deeper level as to what their needs are. I think don't think we necessarily know that we are doing that, but we are. We're picking up all sorts of things.'* Others expressed that listening sometimes means exploring the issues further to make sure the needs are being addressed. One hospital participant noted, *'Well sometimes it a good time to explore why they've said no. Whether it was discomfort or whether it's actually a genuine feeling that the family will provide for their needs.'* Thus, listening involved carefully paying attention to what is said and to make sure that the palliative care worker is not overlooking needs.

The listening includes being aware of how ‘things are’ as there are clues in the situation and the relationships and patients and whānau do not always directly express. This type of ‘listening’ involves paying attention to what is being said and what is happening. It reflects a deeper level of understanding. For example, one hospice participant offered,

It's always being aware of who's in the room and you can be talking to people and you can see they are all listening, but there may be one person away in the corner. You know, it's being aware of everybody outside the patient and the immediate family. It's about who else is in there as well because you can actually identify that there is actually a problem with that person; you know, the aunty in the corner.

Some care kaimahi emphasised that patients and whānau have to make the decision and yet are not always aware of how to lead that decision. Thus, palliative care kaimahi have to help them by asking questions and steering the conversation in the right direction. For example, one hospice nurse noted,

It's also about letting them take the lead and quite often, they don't know how to take the lead. As far as they know, they have been given a diagnosis and quite often they are not really at that point that they want to accept the fact that they are dying. So it's important for us to actually establish first where they are and by, you know, if they are asking questions like, 'Am I going to die?' then you don't just say, 'Yeah', you say, 'Well, what did the doctor tell you?' You put it back to them and they actually end up answering their own [question]. And that's establishing a....they like you to be professional, but also down to earth and not going in there and just taking the lead and telling them how it is and what we are about. Just letting them remain in charge, that's important.

Part of taking the lead is for patients and whānau to be respected to make a decision for what is best for them. Sometimes, this means that palliative care services are not desired. One hospital participant expressed, *'The outcome may not be an ideal outcome from our perspective but from the patients' perspective it's ideal and that's what is important at the end of the day. It's not our need it's what the patient and whānau need is.'* Another hospital worker added,

The patient has said, 'No, I don't want palliative care. I'll just have my whānau.' And so we need to respect that side of it as well. But still give them information and allow them to change their mind if they think about it and feel they're not getting the support at home then it's there available for them.'

Thus, the focus is on listening to patients and respecting their decisions.

Subtheme M3c: Addressing Functional Health Literacy Concerns

The final subtheme of communication was addressing health literacy concerns. Community health kaimahi explained that functional health literacy is key to providing quality services: *'There is a problem with kaumātua who have a problem with the terminology that is out there that they don't understand. And, if they don't understand, they shut down.'* Other palliative care kaimahi noted that there is a lack of awareness for some whānau as one hospice nurse noted, *'Yeah, 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.'* The hospital participants expanded on the issues of functional health literacy around palliative care as they noticed that some Māori patients and whānau were not aware of the specific services they offer. For example, one hospital participant stated,

I think sometimes that is the difficulty for patients to understand the difference, particularly if they have come in from oncology where they have been closely monitored by the specialists there. I think

often there is an expectation that we will closely monitor them in the same way, whereas, we are trying to steer them back to their community providers.

Thus, clarifying what palliative care services specifically do is important for patients and whānau to make sure they have the right type of services.

Additional, functional health literacy was also about having an (in)accurate perception of what medical services are included. One hospital nurse noted,

There's also a fear of the drugs that we use, like morphine. There's a stigma attached to morphine and some of the other mind-altering drugs that we use like the anti-psychotics and the benzodiazepines and a lot of people are really fearful, especially the older people. You mention morphine and they think either that 'you're going to kill me quicker' or 'I'm going to become addicted.' So I think there is a fear, sometimes, in accessing services because of that and also because of hearsay; what we used to talk of as the sort of informal grapevine.

Thus, palliative care kaimahi in the hospital see the need to 'correct' the image of medical care in the palliative care journey.

The participants offered some illustration about the best ways to meet these functional health literacy needs. Specifically, they suggested that they need to use clear language, have clear information on who to contact, and resources for whānau. For example, one hospital participant offered,

Well I think it's explaining to them. We really try to simplify it down into in saying 'If you have more pain, or you have more tumour, you have more area for the pain receptors and for the molecules to bind onto; whereas, if you don't have pain it would go straight through.'

You sort of break it down into simple language, generally, people are more accepting.

One community participant stated, *'Well I had an experience recently with one of our kaumātua and the scary thing there is that we didn't have any after-hours information: Who was out there? Who was available to provide the palliative care should that need arise.'* Another community participant explained,

I think what needs to happen is that they need to be given the information that's appropriate. They need to be given the right contact details for people. Because sometimes what happens is when someone is told oh, you know, 'Dear, you've got cancer' or 'you've got this condition and it's irreversible.' I tell you, you know, there's a sudden flood of 'Oh my God.' They don't care about the outside world all they care about is what's going on in their face and in their mind. To be given information verbally is not going to help that person ay? So they need to have the resources available to be able to give to the whānau or to be able to give to the people to take away with them. So that's just my thought ay? Just making sure the resources are available for them.

The community health kaimahi also noted that they can serve as advocates for kaumātua to help improve health literacy. For example, one participant explained, *'As kaimahi, we've had the opportunity to go to meetings, to hui, at palliative and hospice and to be more educated ourselves in what they provide and what they're all about –that the service is there for all people.'* Similarly, another participant noted why tautoko (support, advocacy) is so important for kaumātua:

The kaumātua concept also, or mind set of kaumātua is, don't make waves. They don't like to intrude; they don't like to upset the apple

cart. They just like things to flow along and they don't like to inconvenience anybody. But, if you have a Māori provider that steps in, they will open up and they will tell you all their concerns or their needs and then they don't expect you to sort it all for them, but being a Māori provider you just do. Do everything you can to try and have all their needs met. I mean, anyone of us can tell stories of us stepping in to advocate for kaumātua.Unless it's recommended to them, they don't because they don't want to make those waves.

Thus, the community kaimahi see tautoko as an important role to improve functional health literacy about palliative care.

Participants also offered insights about what they think kaumātua and whānau can do to enhance their health literacy. One hospice participant offered advice before kaumātua need services: *'Ask us to come and talk to them. Go to the huis [sic] that we provide. And bring in other kaumātua, because that's the easiest way. Because they ask so many questions and they are so grateful, aren't they?'* Others offered insight about their preferred approach from whānau. For example, one hospital participant noted:

I think the focus is on the patient and the family or whānau, are wanting the right things and they are wanting to know what steps need to happen to access the right services. So there's a lot of information giving that is not always going to go into such a lot of detail which is good, I think, that people feel comfortable enough to ask all those questions.

Similarly another participant indirectly noted his desire to have more information and questions from whānau: *'Sometimes we don't know these things, you know. Sometimes we're going in blind and you've got to fudge your way through.'* Thus, asking questions and offering information is seen as a way for palliative care kaimahi to help kaumātua and whānau to increase

functional health literacy. Ultimately, this health literacy would help the kaimahi to better meet the needs of patients and whānau.

Theme M4: Mahitahi—Care Coordination

The final theme related specifically to the mahitahi between various health care providers. All participants expressed that they work with other palliative care kaimahi (such as district nurses and general practitioners) as well as other rōpū whakahaere to provide the palliative services. As one hospital participant noted, *‘The way we work is that we work with other agencies, like the Hospice and the district nurses and the general practitioners and anybody else that might well be involved. It’s a team effort really.’* The team effort of coordinating care is due in part to the fact that palliative care services are at the end-of-life and patients and whānau already are working with other providers. One hospice participant explained,

Because of lot of the time the families that have been with these particular providers have got to know those nurses really well. And so it’s actually working alongside those nurses as well. We are a specialised field where we can work beside those nurses, you know, and they can provide what they need.

Community health kaimahi also stated that they must tuitui (coordinate) with hospice and hospital to provide the full spectrum of palliative care services. The community kaimahi can only provide psychosocial care without medical supervision. However, these services fill an important void as one participant noted:

We had about three kaumātua... We identified a gap in the cancer service then. They didn’t fit hospice, they didn’t fit palliative and so we, as kaimahi, were stepping outside of our roles and going to help them with home help, you know, with their basic needs – shopping and vacuuming –because they could not do it for themselves and yet

there was no service out there that they could fit into that could cater to their needs.

Some frustration was expressed by community kaimahi in this coordinating process as they felt they were not on the same level as other rōpū whakahaere. They felt their services were under resourced and that they were not always treated as equal partners in the provision of care. For example, several community kaimahi discussed experiences where they felt diminished either because of cultural background or because of not having a clinical background. We offer two quotes to illustrate these feelings:

One for me that sticks out is being taken seriously; being perceived as a professional. And I've worked amongst, 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 staffing 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'. That's the feeling that I got. And I experienced that for two years so I don't believe that was perceived, that was quite real.

So I guess that's one perspective but I also know that 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 or your skin and your eyes.

Thus, these participants see their contributions were perceived as not as important as the medical kaimahi and thus they did not feel there was good mahitahi in patient care.

Part of the coordinating care involves working together to meet others' needs and also to stay current with what others are doing. As one hospital participant illustrated their various connections:

Yeah well the [name supplied] palliative care network. There are strong [name supplied] links. So we actually support Lakes, we do a clinical a month down there. [Two localities] yeah both of them for one day a month which is a beginning space really. . . . And then [a worker from another rōpū whakahaere] works here one day a week . . . So we sort of are all quite interconnected. The palliative care community in New Zealand is quite small so we really know the national scene quite well over the years.

Coordinating care also involves challenging other agencies and the status quo. Sometimes palliative care kaimahi need to challenge the approach of other departments. For example, one hospital participant stated,

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 and answer questions in saying. 'Look, you know, in the home situation this is what's needed' or what can be provided and ultimately it becomes a choice [for patients and whānau].

In addition to challenging other departments, one hospice participant suggested a way to improve mahitahi of palliative care: *'Better communication and collaboration between services. That's something we have to, as the health sector; continue to strive to do better. There will always be a shortage of resources, but we've got to work better with the resources that we've got.'* Thus, the mahitahi of care means that palliative

care kaimahi strive to improve the system of care to better meet the needs of kaumātua and whānau and all palliative care patients/families.

Summary

In summary, palliative care workers had four themes around addressing interactive and cultural health literacy components in the palliative care journey. Table 7.1 displays the summary in tabular format and includes the dimension of health literacy addressed. The first theme directly addressed cultural health literacy of palliative care workers. Some mainstream workers noted that they themselves, or other mainstream care workers, needed to learn more about culture to better provide services. Māori community workers particularly emphasised the need for enhanced cultural literacy by palliative care workers. Other workers described ways to offer cultural sensitive/competent care and include the use of cultural liaisons. In addition, community workers noted the importance of integrating tikanga in the palliative care process. Finally, all of the participants cautioned about over-generalising about Māori culture and to recognise individual differences within the culture; for community kaimahi, this included not assuming that kaumātua would be cared for because they have whānau.

The second theme further explored cultural health literacy and specifically focused on engaging whānau. All participants noted that working with whānau is a key part of working with kaumātua and offered suggestions about how to engage whānau; they also acknowledge there will be limits, given their constraints. These limits included using a spokesperson for a large whānau and also limits to the number of whānau accommodated for specific services.

The third theme offers insights about interactive health literacy. Specifically, the participants noted the importance of building relationships through communication and also listening carefully to the spoken and unspoken needs of kaumātua and whānau. Further, respect for those needs, and decisions

about those needs, is critical, whether the kaimahi agree or not with the decisions. Finally, the participants offered suggestions for improving the functional health literacy about kaumātua and whānau about palliative care services. In addition, Māori community kaimahi recognised that they themselves become a part of the support network for kaumātua and even serve as advocates on their behalf.

The final theme addresses another interactive health literacy concern related to the importance of coordinating care with other care workers and rōpū whakahaere. Māori community kaimahi agreed that they have to coordinate with other agencies to meet the needs of kaumātua and yet at times feel like they do not get the respect from mainstream palliative care workers and also do not receive the financial resources to provide care. Taken together, the themes offer key suggestions for enhancing interactive and cultural health literacy in palliative care for kaumātua and whānau.

Table 6.1: Summary of palliative care kaimahi themes and subthemes as they relate to health literacy

Theme	Subtheme	Area of Health Literacy	Description
Engaging culture	Lower cultural literacy and open to learning more	Developing cultural literacy of kaimahi	Some hospice and hospital participants expressed an interest to learn more about Māori culture to better meet the needs of kaumātua and whānau.
	Expressing cultural sensitivity	Kaimahi displaying cultural literacy	Kaimahi asserted that expressing cultural literacy through respect of tikanga and effective communication is a key aspect of providing effective service.
	Using cultural liaisons	Kaimahi working to enhance cultural literacy	Hospice and hospital participants noted the importance of using for kaumātua or other liaisons to help improve service delivery (usually by training kaimahi how to do it). Community kaimahi noted that the training has to lead to actual practice and improvement.
	Avoiding over-generalising	Kaimahi displaying interactive literacy	Kaimahi making sure to communicate with kaumātua and whānau to identify their specific needs rather than stereotyping or assuming cultural practices.
Engaging whānau		Kaimahi displaying interactive and cultural literacy	Kaimahi communicating and engaging with whānau to best care for the ill person.
Communication with kaumātua and whānau	Building relationships	Kaimahi displaying interactive literacy	Kaimahi taking the time to build rapport and trust with kaumātua and whānau. Building relationships also includes community rōpū whakahaere. Community kaimahi see their role also as being part of the emotional support network.
	Listening and collaborating	Kaimahi displaying interactive literacy	Kaimahi using effective communication skills of listening and collaboration to meet the needs of kaumātua and whānau. This approach includes respect the decision not to accept services.

Title: Māori health literacy and communication in palliative care: Kaumātua-led models**Author:** Rauawaawa Kaumātua Charitable Trust Research Project Team

Theme	Subtheme	Area of Health Literacy	Description
	Addressing functional literacy	Kaimahi displaying technical literacy (and political literacy for community kaimahi)	Kaimahi need to help establish an accurate awareness of the available services and to also communicate in a clear and non-technical manner. Community kaimahi also note the importance of being advocates for kaumātua and whānau. Finally, hospice and hospital participants would like kaumātua and whānau to ask for information and have more questions.
Coordinating Care		Kaimahi displaying interactive literacy with each other and political literacy	Kaimahi need to work together—tuitui (coordinate) manner in order to meet the needs of kaumātua and whānau. Kaimahi also challenge other agencies, departments, and the status quo to meet these needs. Community kaimahi want to have a strong role.

Chapter 7: Kei Whea Ngā Mōhiotanga? A Cultural-Discursive and Health Literacy Analysis of Palliative Care Brochures

This study examined brochures from hospice and other palliative care services in New Zealand to understand the capacity of palliative care agencies to convey culturally resonant messages. We took the view that several fundamental assumptions guide the production of palliative care service brochures. Brochures are intended to be read, by people who need to know about palliative care services and aim to effectively communicate information about their services, so that the right people get to use these services.

Integral to these assumptions is the expectation that the intended messages of the brochures will be understood as intended by the target audiences. The target audiences in this case were those needing, or potentially needing, palliative care services and their whānau. Brochures in this research therefore, included documents designed to inform and advise people about a given hospice, hospice care, and its specific services. Consequently, brochures about funding, bequests, volunteers, community newsletters, and internal documents for use within the service were excluded from the research.

We wanted to assess how the brochures may relate to kaumātua and their whānau accessing palliative care. Therefore, our conceptual approach comprised the two dimensions of health literacy and Te Ao Māori, the worldviews, beliefs, values and practices including whānaungatanga, manaakitanga, and wairuatanga (see Durie 2001; Mead, 2003). We aimed to identify the ways in which the brochures communicated their services to readers and, in particular, kaumātua needing palliative care and their whānau (extended family network) including mokopuna (grandchildren).

Methods

We determined that the most effective option given the time available was to first, to focus on brochures only and exclude web-based information, and second to email hospice organisations. This approach depended on contact addresses being current and in use, as well as hospice staff being available and having time to respond to our request. We also know that at least one hospice did not receive the original email, so the information may not have been current for all on the list.

We identified palliative care and hospice services via the New Zealand Hospice webpage and in September 2011, emailed 33 (27 North Island and 6 South Island) hospices. We included a FREEPOST self-addressed label (see Appendix 7.1) and stated that the hospice was entitled to a summary of the findings from this part of the study.

Twelve North Island and five South Island hospices responded; of these, two replied but one did not have documents, and the other was unable to send material within the timeframe. The response from just over half of the hospices contacted, is more than what can usually be expected of a ‘cold-call’ email strategy. In addition to hospice material, we included documents from Palliative Care services at three District Health Boards (Auckland, Taranaki, and Waikato).

The original data-set was 135 brochures from 19 palliative care service rōpū whakahaere. We excluded booklets with 10 pages or more and material aimed at audiences other than palliative care service users and their families or whānau, as well as anything from other non-palliative care agencies. The final data-set was 99 documents (Table 7.1).

Table 7.1: Brochures included and excluded from the analysis

Brochures included: By final category and separate type	Total
General information (location, range of services, who for, contact information)*	26
Technical Information (medical interventions, legal issues about wills etc, after death)	19
Bereavement, grief, and loss (individual processes, family needs, services)*	17
What to expect when someone is dying (incl. 5 with Liverpool Care Pathway brand)*	14
<i>Specific patient and family services:</i>	
Day stay, counselling, family support, education, personal therapies	9
Planning a funeral	6
Biography service	5
Spiritual care	2
Services specifically for Māori*	1
Total included in analysis	99
Brochures excluded: By type	Total
Internal documents (policies, models of care, forms)	10
Booklets (Inpatient communication books, information books, general)	7
Volunteering information	7
Newsletters	6
External documents (information about other agencies)	6
Total excluded from analysis	36
*Includes brochures that used Te reo Māori phrases, waiata, whakatauki	

Analysis Procedures

We examined the full data-set in four ways. First, the brochures were analysed using a ‘cultural-discursive’ approach incorporating Te Ao Māori (worldview; Māori beliefs, values, and practices) and rhetorical analysis perspectives. The *cultural* part of our cultural-discursive approach acknowledges that there are differences between cultures that prevent them from being able to take fully each other’s perspective (eg, Liu, 2005). Even so, we have worked from both domains because of the nature of palliative care services organisations, and the need of Māori for culturally aligned services. These largely mainstream organisations write brochures for people needing palliative care, and their families, and they aim to include Māori and their whānau, *even though the texts are nearly all in English*. This called for a bi-cultural approach to communication. Using Te Ao Māori perspectives, we were able to focus on the ways in which the brochures used Māori language and images; expressed or aligned with Māori values; and exhibited patterns of Māori forms of communication.

The *discursive* part of our cultural-discursive approach acknowledges that because the majority of brochures are written in English, Western methods are also necessary. We therefore used rhetorical criticism which focuses on the forms of expressions and communicative intentions of the organisation as author of a given text (eg, Gill and Whedbee 1997). In our approach the constructions of text, and choices of phrases, words, and images, as well as the substantive topic, help to influence the extent to, and ways in, which intended audience are able to identify with the palliative care service and organisation.

Second the researchers (one Māori and one Pākehā) sought input from members of the Advisory Group with de-limiting the original data-set to achieve a smaller data-set (a) for review by two focus groups, and (b) for close textual analysis. Two kuia from the Advisory Group, and one wahine associated with the research, who was experienced in creating documents, were involved. Each of these women had been involved with palliative care,

either as representing organisations providing such care, or as formal care workers, and as whānau members and informal carers. Being formally associated with the research meant that in making their assessments of the brochures, they were able to draw on the kaupapa of the research as well as Te Ao Māori and their own experience with palliative care. On this basis, the kuia and wahine selected brochures that appealed or not to them. They assessed the brochures on the basis of imagery (ie, Māori images, people included), colour, quality of printing (ie, photocopied, glossy print), font-size and density of text, the diagrams used, the language used, and the way the text ‘spoke to’ them overall. The result was a small data-set of 25 brochures.

Third, this smaller set of 25 brochures was examined by participants of two focus groups; one with kaumātua (4 tāne and 4 wāhine), and one with whānau (2 tāne and 5 wāhine; aged 32 to 65). We developed question guides that focused on getting kaumātua to tell their own views and to tell how they responded to the selection of brochures. We asked for comments on how the selected brochures felt to kaumātua, as well as the information, format (eg, layout, font style and size, colour, and number of pages), writing style, Māori language and images used. The kaumātua and whānau focus group were invited to comment on presentation of the brochures, writing style, and use of Māori language and images used.

Finally, this smaller set of 25 brochures was further reduced to 22 when it became clear that three were almost identical in text to two others. This set was then analysed for readability, writing style and vocabulary by the researchers. Specifically, the process began with reading of brochures and identifying key words, phrasing, vocabulary and images, as well as notes on layout, font size, style and colour. We then examined the features of the brochures in terms of three dimensions of health literacy:

1. Functional health literacy, focusing on readability and writing styles.
2. Technical health literacy, focusing on use of medical vocabulary.

3. Cultural health literacy, focusing on how the brochures text and images connected with Māori readers.

Procedure 1: Readability of the brochures

For the purpose of this study, we used the term ‘readability’ as referring to *text complexity* and applied a combination of readability scores (Scott n d) to brochures excerpts. Readability in this context means the length of words and sentences. As such, readability scores do not measure those aspects of a given written artefact that *influence* the readability of a document; they gauge only text complexity as a likely predictor of reading difficulty (Courtis 1987; Collins et al 2007).

Readability scores do not account for factors that contribute to the ‘understand-ability’ of a written artefact; that is, factors such as active and passive sentences, stylistic features of the text, the use of diagrams, or readers’ prior knowledge, motivation, or comprehension (Bailin and Grafstei 2001; Manning and Dickens 2006; Todhunter et al 2010). Even so a readability score (eg Fry’s Graph in Courtis 1987 and Fry 1968; Flesch-Reading Ease in Collins et al 2007) is a useful ‘yardstick’ (Courtis 1987) for predicting reading difficulty, and readability scores are used with written health care information (Collins et al 2007).

From a communication perspective, writers of health information need to be able to match the readability levels of the documents they create, with the functional literacy levels of their target audiences (Friedman and Hoffman-Goetz 2006 p 353). With these aspects in mind, therefore, we examined grammar and passive and active construction, as well as formatting including heading hierarchy, font (style and size), and density of text, in addition to readability scores.

Specifically we took three 100-word excerpts from each brochure within the small set of 22 brochures (see above) and applied a combination of readability scores (Scott n d). As readability tools are English-based, we removed all

Māori terms, including place and hospice names. The three excerpts were taken from the beginning, the middle (as measured by number of total words in the brochure excluding contact and address information) and the end of the brochure. These excerpts were entered into a spread sheet and subjected to a combined readability analysis (Scott n d).

Procedure 2: Vocabulary used in the brochures

To assess vocabulary we examined *language* (as opposed to text complexity), including the use of medical terms and metaphors. In addition we looked for notable absences, uses of personal pronouns (eg, we, our, you, your), and words and images that resonated with kaupapa Māori—values, principles, tikanga and language. We noted where Māori words were used with English words in what contexts and we considered how words, images, and layout called to Te Ao Māori, values and principles.

Procedure 3: Images used in the brochures.

To assess imagery we identified Māori and other images used in the brochures. The Advisory Board kuia and focus group participants were instrumental to this process. We also looked at the connection and disconnections between images and the written text, and how images were positioned in relation to each other.

Findings

Finding 1: Functional and technical health literacy: Accessibility and relevance

Finding 1a: Readability levels: From easy to read to difficult to read

As pointed out above text complexity is only one part of reading and understanding written language; hence our emphasis on functional literacy (which includes comprehension) rather than readability scores alone. We took that view that readability scores were a useful first step. Readability scores for each of the 22 brochures are summarised in Table 7.2.

Table 7.2: Summary of readability scores for selected brochures

Brochure Type	Readability Age and Level*
General Information (5)	
These focused on the organisation, location, range of services, who for, contact information, and overall philosophy.	Reading Age: University graduate
	Reading Level: difficult to read
	Reading age: 18-19 years (New Zealand University) Reading Level: difficult to read.
	Reading age: 15-17 yr (Y10-12)
	Reading Level: fairly difficult to read.
	Reading age: 13-15 years (Y9-11)
	Reading Level: fairly difficult to read
	Reading age: 12-14 years (Y8-10)
	Reading Level: standard/average.
Technical or Medical Information (5)	
These focused on technical information about medical interventions, specific issues in managing care, pain management, and legal issues related to wills and formal steps for the family after death.	Reading age: 15-17 yr (Y11-12)
	Reading Level: difficult to read.
	Reading age: 12-14 years (Y8-10)
	Reading Level: standard/average.
	Reading age: 11-13 years (Y7-9)
	Reading Level: standard/average
	Reading age: 11-13 years (Y7-9)
	Reading Level: fairly easy to read.
	Reading age: 8-9 years (Y4-5)
	Reading Level: easy to read.
Dying- what to expect (2)**	
These focused on preparation for dying, including understanding dying process.	Reading age: 11-13 years (Y7-9)
	Reading Level: fairly easy to read.
	Reading age: 11-14 years (Y7-10)
	Reading Level: fairly easy to read.

Brochure Type	Readability Age and Level*
Family Support Services (5)	
These focused on specific support services for the carer/s, and/or family or whānau of the patient, including accommodation, respite care, counselling, and education.	Reading age: 15-17 yr (Y10-12)
	Reading Level: difficult to read.
	Reading age: 17-18 years (Y13)
	Reading Level: difficult to read.
	Reading age: 14-15 years (Y10)
	Reading Level: standard/average
	Reading age: 14-15 years (Y10)
Patient Services (5)	Reading Level: standard/average
	Reading age: 12-14 years (Y8-10)
	Reading Level: standard/average.
These focused on specific personal services for the person receiving palliative care, including biographic service, counselling, and natural therapies.	Reading age: 18-19 years (University)
	Reading Level: difficult to read.
	Reading age: 11-13 years (Y7-9)
	Reading Level: standard/average
	Reading age: 11-13 years (Y7-9)
	Reading Level: standard/average
	Reading age: 14-15 years (Y10)
	Reading Level: standard/average
	Reading age: 10-11 years (Y5-7)
	Reading Level: fairly easy to read.

*The scores originally used U.S. school grades, for which we approximated to New Zealand 'Year' and age-equivalents (eg, Grade 5 in the US is approximately Year 6, or 10-11-years old; Scott, n.d.).

**Three other brochures very similar in content to these two were not included in the readability assessment

Five of the brochures were found to be easy or fairly easy to read (ie, of low text complexity) for someone with late primary to early secondary education in New Zealand. Eight were difficult or fairly difficult to read (ie, of high text complexity), with readers needing senior-secondary school (Year 11 to 13) or

university education to be able to read them comfortably. The remaining nine were standard/average level with a reader needing two years secondary education.

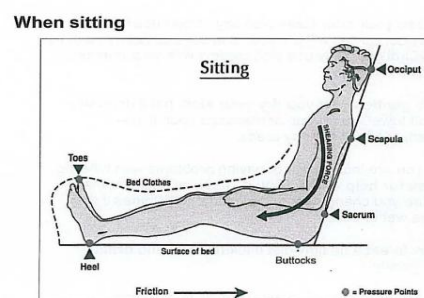
The limitation of using readability scores is that they only refer to text complexity. Moreover, this sample of 22 is only a portion of the total data-set of 99 brochures. However, if we accept that premise that text complexity is an indicator of reading difficulty, it would seem that only those with senior-secondary school (Year 11 to 13) or university education would be able to read all 22, while those with primary education would likely be able to read less than a quarter of them. Many older people have had fewer years in secondary education than later generations (Robson and Reid 2007), and some argue that the education system has failed 'to perform equitably for Māori' over many decades (Robson et al 2007 p 22). Such factors would suggest that this set of brochures would have difficulty communicating effectively with kaumātua and whānau, as well as other New Zealanders (see Ministry of Health, 2010).

Finding 1b: Mixed writing styles: Short and active to structurally complex

Writing style, including grammar, sentence and paragraph structures, and use of diagrams contribute to audience ability to comprehend key messages (eg, Manning & Dickens, 2006). The writing styles ranged significantly from some using short active sentences to others using complex, wordy sentences and paragraphs. 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 most extreme poor example was a 72-word sentence that referred to five topics, four rūpū whakahaere, as well as contractual relationships. While the information was likely to be relevant to readers wanting to know about the agency, 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.

Diagrams related to aspects of palliative care were seen in two brochures: one about pain management and another on managing pressure areas. Kaumātua found the pressure-area brochure easy to read and the diagrams helpful (Figure 7.1). While they liked the information in the brochure about pain management, and particularly the question and answer format, kaumātua and whānau found layout hard to read (eg, font size, style and colour) and they could not ‘relate to’ the smiley faces (see Figure 7.2).

Figure 7.1: Example of Diagram—Managing Pressure Areas

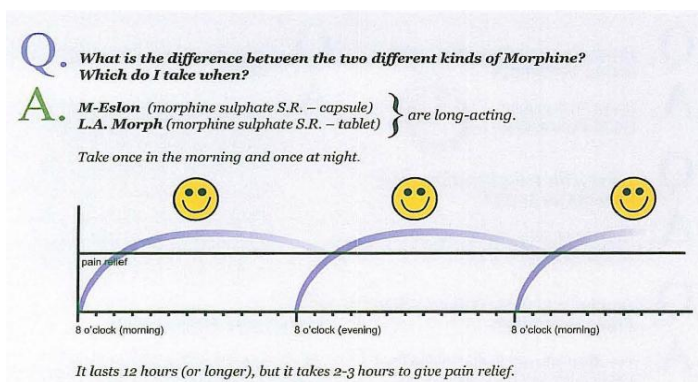


Advice:

- 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.

From *Prevention of Pressure Areas*,
Hospice Taranaki

Figure 7.2: Example of Diagram—Managing Pain with Morphine



From *About Morphine*, Arohanui
Hospice

Finding 1c: Medical terms that assumed reader knowledge

We noted ‘everyday’ medical terms used in the brochures that indicated a medical, nursing, or palliative care orientation (Table 7.3).

Table 7.3: Health care and palliative-care vocabulary used in brochures

<i>Terms and Phrases</i>	
Allergy	Oxygen therapy
Allied health professional	Paediatric
Cannula	Podiatry
Cardiac	Palliative care
Cardiopulmonary resuscitation	Pharmacist
Clinical services	Physical potential
Cultural	Psychosocial
Day Care	Public health
Diagnosis	Service coordination
Dietician	Subcutaneous
Disease progression	Registered nurse
Dying process	Renal
End of life presence	Respiratory
General practitioner	Respite care
Health professional	Social
Hospice	Subcutaneous
Hospice philosophy	Subcut prn
Drip infusion	Syringe
Inpatient	Symptom
Intravenous	Terminal patient
Life-limiting illness	Terminal phase
Medication	Therapist
Needs Assessment	Vocational

While medical terms were sometimes explained, some brochures used terms that assumed a certain level of knowledge was possessed by the reader. For

example, most of the general information brochures explain ‘palliative care’ as caring for terminally ill people, and supporting families or whānau as part of that care: For example ‘We provide support and care for people in the last stages of an incurable disease’. Also, term such as ‘subcutaneous’, ‘cardiopulmonary resuscitation’, and ‘intravenous’ were explained in some brochures that used these terms, but not others. In addition, terms such as ‘terminal’, ‘terminal patients’, ‘medical diagnosis’, ‘psychosocial’, and ‘respiratory’ among others, were not explained and often left to speak for themselves.

The use of medical and technical terms assumed readers would have knowledge of palliative care and related services (see Zarcoodallas, Pleasant & Greer, 2006). This suggests that brochures were created from the service providers’ knowledge base, rather than being oriented towards readers’ worldview, experience and knowledge.

Finding 1d: Relational devices: Personal pronouns as tools of inclusion and exclusion

We noticed that when brochures focused on special patient and carer needs or services (eg, bereavement, medication, planning a funeral) they often used personal pronouns such as ‘we’, ‘our’, ‘you’ and ‘your’. Brochures used the pronouns ‘you’ and ‘your’ when the provider was speaking directly to the reader. For example, brochures about grief and bereavement used ‘we’ is to include the speaker (of within the brochure) and the reader as having something in common: ‘Some of what we may experience’ (Taranaki). They also used ‘you’ and ‘your’ when recognising the potential for uniqueness as in ‘Whatever you experience it is normal for you’ (Taranaki) and ‘Emotions and feelings you may experience’ (South Canterbury). The pronouns were also used when speaking directly to the particular audiences such as carers, as in when discussing what to expect when someone is dying (various brochures); for example, ‘How will you know when death comes?’ This also applied when talking to the person with a life-limiting illness in ‘Planning your

funeral’ and using medication to manage pain; ‘Remember it may make you feel a little drowsy’ (Arohanui, original emphasis) .

We also noticed two key uses of ‘we’ in the brochures. The first was ‘we’ with the provider speaking: For example, ‘We provide support and care’ (Tokoroa); ‘We realise that making decisions about treatment can be very difficult’ (Nurse Maude); and ‘We are affiliated to Hospice New Zealand’ (Wairarapa). Such use of ‘we’, particularly alongside ‘you’, creates a sense the ‘who’ behind the text that is separate from, but aware of, the ‘you’ who is the reader with particular needs. For instance ‘We will visit you in your home’ (Taranaki).

Depending on how the reader responds to the tone, or message itself, the use of ‘we’ also invites identification with the palliative care service provider. That is, the brochure communicates a sense of the provider, what it does, and who they are, and so invites readers to identify with its representations of itself (Cheney, et al 2004). In selecting certain phrases, words, and images, the provider may invite identification but equally, also create barriers. For instance a technically complex, but informative text could communicate that the provider is skilled, informed, and successful. Such a text may also indicate that it can only communicate with select groups of people.

Second, the brochures used ‘we’ in a broader way to talk about ‘we’ as in greater humanity and the human experience. For instance ‘What happens as we are dying?’ (Totara Hospice). This assumes some universal worldview on what happens when people are dying. While there may be common processes and events, there will also be differences that are not able to be recognised or given appropriate priority within a brochure. For instance these brochures tended to focus on the physical and practical dimensions of dying, when some readers may benefit from the inclusion of spiritual dimensions.

Figure 7.3: Symbols used in the brochures

**Finding 2: Cultural health literacy: Māori images and te reo in brochures**

We counted the Māori terms and images within the 99-brochure data-set.

Table 7.4 summarises the uses of Māori from the total data-set of 99 documents, and Figure 7.3 shows a selection of the small number of explicitly Māori symbols that appeared in the brochures. In short, while ‘family/whānau’ occurred in 30 percent of brochures, less than 10 percent of brochures used Te reo Māori beyond single words or phrases, or images that kaumātua and whānau might relate to culturally.

Table 7.4: Use of Te reo Māori across the brochures

<i>A. Use of single Māori terms/phrases</i>	<i>Total Occurrences</i>	<i>No. Brochures (out of 99)</i>	<i>No. Rōpū whakahaere (out of 19)</i>
Whānau as in 'family/whānau' or similar	90	29	12
Karakia as in 'prayers or karakia'	4	4	4
Haere mai in a list of greetings in other languages	2	2	1
Koha as in 'donation or koha'	2	2	1
Kia Ora as in 'Kia Ora—Welcome'	1	1	1
Total	99	38	N/A
<i>B. Other uses of Te Reo Māori</i>		<i>No. Brochures</i>	<i>No. Rōpū whakahaere</i>
Brochures fully in Te reo Māori		2	1
Integrated with English		2	2
Included waiata and/or whakatauki		3	2
Contents page headings; single sentence translations		2	2
Total		9	7

Finding 2a: Mixed messages, contradictions, and notable absences

On the whole most of the images were mainstream-oriented with a few Māori images or symbols. For instance, palliative care and dying seem to be associated with autumn, sunsets, and journeys. Butterflies also featured, along with pleasure-boats on the water, but these images were not understood by the kaumātua and whānau hui. The kaumātua questioned the use of butterflies; one group of four asked 'How long does a butterfly live?' Another asked 'Why couldn't it be a Monarch butterfly?' This suggested that if the butterfly had been a photographic image as instead of 'clip art', it may have

been more acceptable—even they did not necessarily accept the intended meaning of the butterfly within palliative care.

Notably absent were images and symbols that communicate directly with kaumātua and their whānau. See Figure 7.3 for a sample of the few that appeared. The koru (curled new fern shoot; symbol) was used most, appearing in brochures from five of the 19 rōpū whakahaere; one of these included a stylised koru pattern. Given the nature of the New Zealand Hospice—the kowhai—it seemed important to note that eight of the 15 hospices. The kowhai also appeared in one hospice brochure. Other symbols included the single use of carved pounamu (Otago Community Hospice), a wood carving (Arohanui Hospice), and two panels (North Shore Community Hospice and Otago Community Hospice; see Figure 7.3). The koru and pounamu (New Zealand greenstone) resonated deeply with kaumātua.

Kaumātua expressed concern when words and images did not support each other's message and meaning. The first 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 7.3). 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 for the kaupapa (topic) of the brochure: A comic aeroplane appeared on the front cover with the words 'Taking Control'. For kaumātua, this image did not exhibit the due respect for the topic.

Finding 2b: The use of unnamed landscape and stock images

Images of landscapes appeared in nearly 25 per cent of the data-set and generally included mountains, surf beaches, gardens, and parks. These were used in information about what to expect when someone is dying,

bereavement, and planning a funeral. Bodies of water (eg, lake, sea), were used in mostly in brochures about what to expect when someone is dying, grief, and bereavement.

Some images were clearly photos of local places (eg, Whakatane and Whaingaroa), 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 whānaungatanga (eg, Mead, 2003; Tate, 2010). Therefore, naming pictures of localities in the brochures is important. Images of identifiable local landscapes and features communicate more than the service or information; they help to connect people of the local area and help to ‘ground’ the service for the reader.

Finding 2c: Appropriate placement of Māori images

The kaumātua focus group selected one koru (see Figure 7.3) from the ones used because it was complete, and the correct way. They stressed that the correct way could be different for other Māori iwi. In addition they commented that the panel (see Figure 7.2) was 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 cut off eternity. However, it was the position of a ‘clip-art’ butterfly next to a pounamu taonga (greenstone) that kaumātua and whānau members were most uncomfortable with (see Figure 7.3). The ‘cheap butterfly’ did not match the symbolic, spiritual significance of the pounamu.

Finding 2d: Unintentional denial of alternative worldviews

All but two of the brochures were in English, with fewer than 10 including more than single or two-word Māori phrases. While clearly committed to supporting individuals and families who need support with seeking, using, and making the most of palliative care services, the service providers could not avoid infusing their brochures with mainstream voices and values. One specific instance of unintentional 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 live and may visit the living. Kaumātua and whānau spoke of dying relatives seeing people who had passed. There were certainly examples of sincere efforts to connect with Māori, but the nature of the brochures themselves prevented this: Kaumātua and whānau expressed the preference for kanohi ki te kanohi (face-to-face) communication as well as brochures that were ‘direct’, ‘easy to read’ and ‘not too much information’.

Summary

The first group of findings centred on functional and technical health literacy in terms of the accessibility and relevance of the brochures to kaumātua and their whānau. Readability levels, mixed writing styles, unexplained medical terms that assumed reader knowledge, and the mixed use of relational devices such as personal pronouns, combined to make the communication process between palliative care provider and audience a mixed experience.

The second group of findings centred on cultural health literacy in terms of the used of Māori images and te reo in brochures. 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 kaumātua and their whānau would be unlikely to relate culturally to the services offered.

In short, we found that while some brochures used Māori words, phrases, and symbols, overall Māori worldviews were absent from most of the brochures. On a positive note, many brochures aimed to connect sensitively with the intended reader and make them feel welcome. In summary, however, the providers would be unlikely to connect with kaumātua, or their whānau using brochures alone.

Given cultural preferences for face-to-face communication, questions remain about the role brochures play in informing kaumātua and their whānau about palliative care services, and influencing them in their decision to use them. Brochures are often used to support other forms of communication (Manning and Dickens 2006). Reading information however, cannot be expected to replace sense-making that takes place in face-to-face communication, ongoing conversations, and retrospective reflection. 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). Thus, if brochures (or other media for that matter) are used to inform kaumātua or their whānau receive 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.

These outcomes emphasised the importance of context-relevant functional, cultural, and by association, political health literacy for not only kaumātua and whānau, but also for the palliative care organisations themselves. Essentially, these findings suggest areas where health literacy can be improved to enhance the quality of palliative care services and the end-of-life journey. Table 7.5 below provides a summary of these finding as they relate to health literacy.

Table 7.5: Summary of findings as they relate to health literacy

Finding	Subtheme	Area of Health Literacy	Description of practices
Accessibility and relevance of brochure material	Readability levels: From easy to read to difficult	Brochures attend to functional health literacy of target audiences that may be different from the writers.	Writing that actively attends to word use and sentence length; and that applies the principles of Plain English. This means using a plain word rather than a complex one, and applying a one-idea-one-sentence rule.
	Mixed writing styles: Short and active to structurally complex	Brochures attend to functional health literacy of target audiences that may be different from the writers.	Writing that uses active language, short, active sentences and applies a one-topic-one-paragraph rule.
	Medical terms that assumed reader knowledge	Brochures attend to technical health literacy of target audiences that may be different from the writers.	Writing that takes account of audience knowledge of a given topic. This means explaining medical and other complex terms the first time they appear in a brochure.
	Relational devices: Personal pronouns as tools of inclusion and exclusion	Brochures attend to relational domains of writing, and therefore interactive health literacy.	Writing that takes demonstrates intentional use of 'no-subject' sentences (ie, no person is identifiable) and personal pronouns. That is, writing that takes into account the likely impact on reader engagement with the writer of the brochure.
Use of Māori images and te reo in brochures	Mixed messages, contradictions, and notable absences	Brochures demonstrate cultural health literacy, and meaning congruence in their use of images and text.	Palliative care organisations consulting with local kaumātua in the design of material aimed at kaumātua and their whānau. This would include evaluating images in view of the nature

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Author: Rauawaawa Kaumātua Charitable Trust Research Project Team

Chapter 7: Kei Whea Ngā Mōhiotanga?

Finding	Subtheme	Area of Health Literacy	Description of practices of the topic.
	The use of unnamed landscape and stock images	Brochures demonstrate cultural health literacy, by including local landscapes.	Palliative care organisations consulting with local kaumātua about the inclusion of local images.
	Appropriate placement of Māori images	Brochures demonstrate cultural health literacy, by attending to placement of images.	Palliative care organisations consulting with local kaumātua about the inclusion of Māori images and their placement in informational material.
	Unintentional denial of alternative worldviews	Brochures demonstrate cultural health literacy, with different worldviews.	Palliative care organisations consulting with local kaumātua.
For palliative care organisations to consult with local kaumātua in the design of informational material		Brochures demonstrate political health literacy by being co-produced	Co-creating material that enables palliative care providers to communicate in ways that enable kaumātua and whānau to respond positively. Working together to critically analyse the presentation of information that impacts on decisions in the wider community.

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Chapter 8: The Use of Emergency Departments by Palliative Care Patients: A Document Audit

It is recognised that a busy, noisy and often overcrowded Emergency Department (ED) may not be the optimal treatment environment for patients with terminal illness (Lawson et al 2008; Smith et al 2010). Consequently a palliative care patient who needs to visit the ED is seen by some as a failure of the health care system and some have suggested reduced use of the ED to be a quality measure (Lawson et al 2009). Research has shown that a common cause for visits to the ED is the need for symptom control, for example, increasing dyspnoea or failure of pain relief (Grudzen 2012).

Waikato District Health Board covers a population of 369,000 of which 20% are Māori (although only 8% of those aged over 60 years are Māori) and 129,000 (35%) live in Hamilton. It operates five EDs; one in a major tertiary hospital; one that covers the Thames/Coromandel region and three smaller centres south of Hamilton in Te Kuiti, Taumarunui and Tokoroa—known as the Southern ‘T’ hospitals. The palliative care service at Waikato District Health Board supports patients through a multidisciplinary team of health professionals, including nurses, doctors and social workers. In conjunction with other services and agencies, such as Hospice Waikato, district nurses and community general practitioners (GPs), they provide comprehensive support for palliative care patients both within the hospital and in the community. Palliative care patients are referred to the specialist service and details are entered onto a comprehensive database. Patients are advised of the services available to them in the community and how to contact the palliative care service. It is believed that there should ideally be few circumstances that require palliative care patients to present to ED where they will be seen by a generalist who is new to their situation.

The aim of this part of the study was to examine attendances by palliative care patients at Waikato EDs. We aimed to identify the number, illness and palliative care needs of people presenting at ED in relation to patient age, gender, ethnicity and domicile. We also wanted to examine the outcome of their visits.

Methods

This was an observational study using record linkage. The study population was palliative care patients aged over 20 years of age who were on the Waikato DHB palliative care register between 1 November 2010 and 31 October 2011 and were living in the Waikato DHB catchment zone. We used hospital attendance records to identify all visits to any one of the five EDs by patients who were on the palliative care register in the defined time period. Patients were identified through their unique national Health Index (NHI) number. We used a Microsoft Excel spreadsheet to enter data from the two patient data systems. For each patient their age, gender, ethnicity, domicile (Hamilton or other), hospital visited and number of visits to ED were captured from hospital records. Diagnosis and date registered with the Waikato DHB palliative care service were identified from the palliative care register. Ethical approval was granted by the local Health and Disability Ethics Committee (Northern Y Ethics NTY 11/11/111).

Analysis procedures

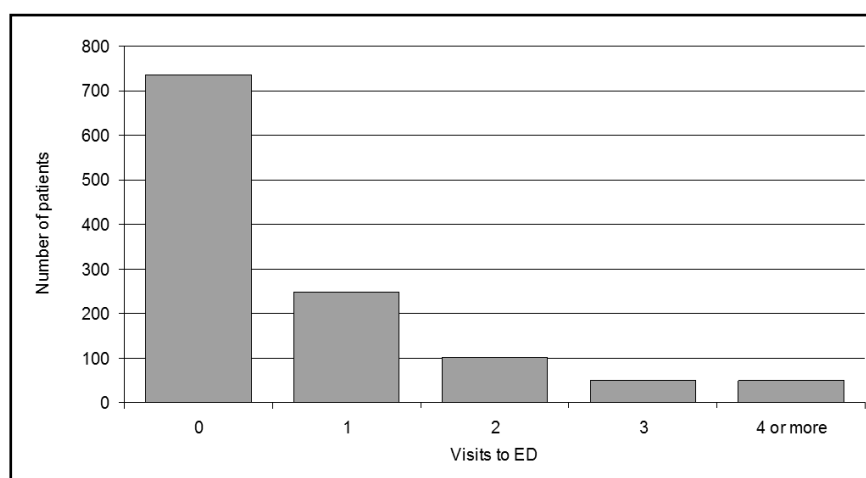
The key outcome of interest was a visit to the ED. The attendance rate was analysed by age in the groups; 20-49 years, 50-59, 60-69, 70-79 and 80-plus, gender and ethnicity (categorised as Māori, Pacific or other). We also looked at attendance rate by diagnosis – this was categorised into 8 groups – Breast cancer, colo-rectal cancer, gynaecological cancer (cervical, uterine, ovarian etc), lung cancer, upper gastro-intestinal cancers, uro-genital cancers (prostate, bladder, renal etc) and other cancers (eg lymphoma, sarcoma etc). A single category of non-cancer was included for diseases such as chronic obstructive pulmonary disease, congestive heart failure and neurological

disorders. We also looked at reasons for attendance at ED and the outcome of the visit; for example, admission to hospital or discharge to the community. These outcomes were looked at by age and ethnicity. Data were analysed using Microsoft Excel (Microsoft Corp, 2007) and STATA 11.2 (StataCorp. 2011. Stata Statistical Software: Release 12. College Station, TX: StataCorpLP).

Results

We identified 1185 palliative care patients residing in the Waikato DHB catchment area from the palliative care register from 1 November 2010 to 31 October 2011. There were 645 men (54.4%) and 540 women. 197 Māori (16.6%), 18 Pacific (1.5%) and 973 (81.9%) 'other'/non-Māori were identified. The age ranged from 20 – 101 years of age (IQR 23-97). The mean age overall was 70.8 years: non-Māori 72.5 years, Māori 63.3 years and Pacific 64.1 years. The mean length of time on the register during the year of interest was 120.7 (median 66) days: women 129 days (67.5), men 113 days (66), Māori 123 days (62), Pacific Peoples 68 days (31) and for non-Māori 121 days (69). Of the study population 449 (37.9%) visited Waikato DHB EDs at least once during the study period. The distribution of visits to ED is presented in Figure 8.1.

Figure 8.1: Distribution of visits to the ED visits by palliative care patients



The percentage of Māori who visited ED at least once was similar to non-Māori (62.4% vs 61.3%) and was not statistically different ($X^2=0.048$, $p=0.827$). The maximum number of presentations by any one patient was 12. Of the 449 patients who visited the ED at least once, 202 patients (45%) went on to have more than one visit. This was similar for Māori and non-Māori (15.2% vs 17.4%) and was not statistically different ($X^2=1.19$, $p<0.552$). 38 percent of visits to ED were within a month of a previous visit to ED. This was also similar between Māori and non-Māori.

When looking at the diagnoses responsible for patients' referral to palliative care categorised into 9 major groups, it was established that there was an excess of lung cancer cases for Māori compared with non-Māori (27.9% c.f. 17.3%) whilst uro-genital cancers (principally prostate cancer) were more common in non-Māori (8.4% c.f. 4.6% non-Māori). All skin cancer cases on the register were for non-Māori. These are in keeping with national incidences (Robson et al 2010). Otherwise the diagnosis between Māori and non Māori were similar (see Table 8.1). Apart from gender-specific cancers, colorectal, lung, skin, upper GI and other cancers were more prevalence in men than women (60-70% vs 30-40%). The percentage of the study population with non-cancers was also higher in men than women.

Women with gynaecological cancer were most likely to visit ED. Of the 449 patients who visited an ED, 78.4 percent attended Waikato Hospital, 169/1185, 8.69 percent visited Thames Hospital and 12.9 percent visited one of the Southern 'T' Hospitals. When looking at patient domicile, 36.9% of patients were from Hamilton – which is similar to the expected 35 percent based on population – suggesting that rural patients with palliative care needs had similar access to the ED.

Table 8.1: Illness of palliative care patients presenting at ED

Illness category	Māori		Non-Māori		Percentage of who was seen in ED (N=449)
Cancers					
Lung	55	(27.9%)	171	(17.3%)	39.8
Upper GI	28	(14.2%)	135	(13.7%)	35.0
Colorectal	21	(10.7%)	106	(10.8%)	37.8
Breast cancer	12	(6.1%)	60	(6.1%)	38.9
Uro-genital	9	(4.6%)	83	(8.4%)	37.0
Gynaecological	7	(3.6%)	34	(3.4%)	56.1
Skin	0	(0%)	47	(4.8%)	40.4
Other cancers	30	(15.2%)	170	(17.2%)	36.0
Non-cancer	35	(17.8%)	182	(18.4%)	35.9

The main reason for attending the ED department was due to pain (24%), followed by shortness of breath/respiratory problems (16%), nausea and vomiting (6%) and infection (6%). Reasons for presenting to ED were similar for Māori and non-Māori.

A multivariate analysis of likelihood of a palliative care patient visiting ED and examining key variables including age (in 10-year age bands), gender, ethnicity (Māori, Pacific and Other) and cause of illness revealed that being male increased the likelihood of attending ED by 60 percent ($p=0.001$). Having a gynaecological cancer increased the odds of attending ED by 180 percent ($p=0.004$).

Discussion

There were proportionately more Māori (17%) on the register than expected (8%). A possible reason could be due to the greater incidence of advanced cancer that is seen in Māori compared to non-Māori (Robson and Harris

2007). While there have been concerns that ethnic minorities groups (Ahmed et al 2004) and in New Zealand, Māori (Lawrenson et al 2010; Minister of Health 2001) may not access palliative care in the same way as the predominant culture, this study does suggest that Māori have reasonable access to the hospital palliative care service. Māori were found to be more prone to lung cancer and less prone to uro-genital cancer (mainly prostate) than non-Māori but otherwise the proportion of cancers was similar.

The length of time Māori patients were on the palliative care register was similar to non-Māori suggesting that, although the natural history of cancers varies, the stage that patients come on to the register is similar. The difference in the length of time Pacific patients were on the register was much shorter. This involved only 18 patients and may be an artefact of small numbers. The possibility of late presentation due to a lack of coverage for health care was not examined in this study.

There was little difference in the proportion of Māori and non-Māori who had non-cancer palliative care diagnoses. As expected, Māori were generally younger. The overall age of patients on the palliative care register was 72 years while the average life expectancy for the general population is 80.6 years. This suggests that very old patients may be less likely to be referred to palliative care and is consistent with findings from Canada (Burge et al 2008). It was shown that over a third of palliative care patients will visit the emergency department for help at some stage of their final illness. This is a similar proportion to that recorded in a Canadian study where nearly three-quarters of patients on their register did not attend the ED department during follow up (Lawson et al 2008). In this study attendance at ED was similar for Māori and non-Māori after adjustment for age and the cause of the palliative care.

Continuity of care from a family physician can have a profound impact on the need for hospital-based palliative care services (Burge et al 2003). We did not

examine when patients presented at ED (for example do more patients attend at weekends and holidays).

The Midland Health Network which provides the majority of primary care to the DHB region have a subsidy available for up to 12 visits from a GP for patients with palliative care needs therefore cost should not be considered a barrier. There are no data to indicate whether Māori access this service equitably although there is some evidence from the literature that patient income can influence access (Burge et al 2005). It could be that there are barriers to other services such as the Community Hospice or district nursing. Integrated community based services have also been shown to reduce visits to the emergency department (Brumley et al 2003; Lawson et al 2009:) but again we do not have data on usage by ethnicity. There are other potential barriers that need to be explored further. One which we are interested in is the idea of health literacy as a barrier to accessing appropriate services. A qualitative study is being planned to explore the understanding of palliative care patients – particularly Māori patients to determine if improvements can be made to the information provided for patients.

The study shows that reasons for attendance at ED seem similar to the reasons found in other examples (Grudzen 2012); that is, urgent need for relief for pain, dyspnoea and other symptoms. Once patients had presented to ED there appeared to be no disparity with regards to management of Māori and non-Māori with similar rates of admission and discharges home. It would appear that older patients are more likely to be admitted which may be a reflection of the type and capacity of the care givers. The relationship of the caregiver to the patient has been shown to influence the likelihood of attendance of palliative care patients at ED (Lawson et al 2008). We do not know if this is also a factor for Māori where the extended family structure is an integral part of the care provided.

The whole aim of the palliative care service is to reduce the need for urgent symptomatic treatment. However it may be that for some patients that ED is the most cost effective way of providing specific services out of hours. Some patients with complex needs will require expert diagnostic facilities or intravenous medication which may best be provided in a hospital.

The study highlights that ED does provide care for palliative care patients and consideration need to be given to how they are best integrated into the service. Integrated care requires the sharing of records and an understanding of the link between the primary care services in the community (general practice, district nursing and Māori providers) with the specialist palliative care services in the hospital. Generally in Australasia ED is not viewed as part of this integrated approach to palliative care (Lukin et al 2012). However in North America hospice and palliative medicine has now been recognised by the American Board of Medical Subspecialties as a field with a unique body of knowledge and practice (Quest et al 2009). In Australasia palliative care is currently not seen as part of the scope of an emergency medicine specialist and there are no palliative care training rotations available for emergency medicine registrars in training in Australasia (Lukin et al 2012). Any review of our palliative care system should consider the role of the emergency department in providing an integrated approach to care, and should consider the training required for staff in ED to take on this role.

This study has helped quantify the characteristics of palliative care patients utilising the emergency departments in a relatively rural population with a high proportion of Māori. It has shown, however, that Māori and non-Māori patients have similar likelihood of using the emergency department. Further research into the factors which influence this, such as service user costs and whether community palliative care resources meet the needs of Māori is needed. We do believe that New Zealand hospitals should consider the role of their emergency departments in the management of palliative care patients

and ensure that their staff members are offered any relevant training to help them meet the needs of this important group of patients.

Summary and Conclusion

The key findings from this study are that there were no statistically significant differences between attendances at ED by ethnicity. The odds of attending were greatest if the patient was a male, or a woman with gynaecological cancer. Significantly, the study highlights the role ED provides in caring for palliative care patients and thus signals that research needs to be undertaken to assess how EDs may be integrated into the service.

Unfortunately there is little from this record-linkage audit that directly informs health literacy issues for kaumātua and their whānau. Three points noted in above discussion, however, signal the possibility of important issues for health literacy, not only for kaumātua and their whānau, but other palliative care services users. The first is that people over 80years may be less likely to be referred to palliative care, which suggests potential issues for communicating with very old people, and the possible roles of family or whānau of the very old. This audit suggests that if ED is to play a role in palliative, that role needs to be investigated. Second, palliative care kaimahi (workers) need to provide better information and networks for kaumātua to get care outside of the ED, and to better understand the reasons for patients using EDs. Finally, palliative care Rōpū whakahaere need to critically analyse service use and gaps to better serve patients and their whānau using palliative care service. Table 8.2 below provides a summary of these points as they relate to health literacy.



Table 8.2: Summary of ED audit findings as they relate to health literacy

Points of Note	Implication	Area of Health Literacy	Description of practices
Patients over 80years may be less likely to be referred to palliative care	Issues in communicating with very old people	Kaimahi interactive health literacy	
	The impact of roles of family or whānau of the very old.		
Patients using ED instead of GP or palliative care services	Available information and access to care networks	Technical health literacy of patients and family or whānau.	palliative care kaimahi need to provide clear information and networks for kaumātua to get care outside ED.
The relationship between ED and palliative care services	Whose role is to do what?	Political health literacy: The impact of organising has an impact on care delivery.	Rōpū whakahaere need to critically analyse service use and gaps to better serve patients and their whānau using palliative care service.

Chapter 9: Ngā Tuhituhinga me Ngā Kōrero—Making connections: Models of Communication and Health Literacy in Palliative Care of Kaumātua and their Whānau

The aim of this project was to identify key communication practices that contribute to Māori health literacy and kaumātua (Māori elders) and whānau (kin) experiences of end-of-life planning and care, as well as to clinicians' and community kaimahi (worker/s) delivery of these services. Each part of the study has contributed to identifying such communication practices and the salient dimensions of health literacy. We begin this chapter with summarising the key aspects of communication and health literacy emerging from across the parts of this study. We then identify three communication models that summarise the challenges and ideal connections to enhance health literacy in the palliative care pathway. We finish with identifying a set of recommendations for enhancing health literacy in the palliative care pathway for each of the major parties in these models: a) kaumātua, b) whānau, c) kaimahi, d) rōpū whakahaere (provider organisation/s), and e) the health sector.

Communication and Health Literacy

The analyses of kaumātua interviews, whānau hui, kaimahi focus groups, and palliative care brochures, and the outcomes of the ED audit revealed several central communication and health literacy foci. These include the desire for meaningful communication between kaumātua, whānau, and kaimahi during palliative care, and for information and services that are accessible, relevant, culturally appropriate, and easily understood. We take the view that these five domains often overlap in the lived experience of using or providing palliative care. We now explain how the five dimensions of health literacy related to communication in the research.

Cultural health literacy concerned the ability to provide palliative care services in a manner that matched the cultural needs of kaumātua and whānau. Cultural health literacy was a core responsibility of palliative care kaimahi although some kaumātua and whānau, and Māori community kaimahi, saw the importance of being kaiako (teachers) of culture. Additionally, cultural health literacy concerned whānau in their learning to navigate the ‘service culture’ of rōpū whakahaere.

Interactive health literacy emphasised the communication skills to be able to talk about palliative care services and address the needs of kaumātua and whānau, and therefore was relevant to kaumātua, whānau, and palliative care kaimahi. Interactive health literacy supported the give-and-take between kaumātua and whānau, and health care kaimahi in the delivery of palliative care services. It also enabled identification and sharing of the responsibilities of each party during the end-of-life journey, as well as the balancing of tensions for the parties in receiving and providing support.

Functional and technical health literacy are closely connected in palliative care. Functional health literacy focused on kaumātua and whānau awareness or lack of awareness, about palliative care services. Technical health literacy concerned kaumātua and whānau capacity for understanding palliative care itself, as well as the associated procedures and medical terms. In addition, both health literacy dimensions also related to mainstream kaimahi being aware of the need to explain such things in the everyday language of kaumātua and whānau—in written and spoken forms. In this instance, technical health literacy overlaps with those interactive moments between kaumātua and whānau and palliative care kaimahi.

Political health literacy concerned the engagement necessary to change societal and organisation policies and practices. This dimension of health literacy was seen primarily in calls for tautoko (advocacy) of kaumātua and

whānau in interacting with palliative care rōpū whakahaere, as well as tautoko for Māori community kaimahi roles within mainstream providers. Whānau members who knew the system were able to work well with palliative services. However, those whānau who did not benefitted from an advocate helping them to navigate the technical and cultural pathways of rōpū whakahaere in accessing services and resources. Similarly, Māori community kaimahi argued for greater recognition and utilisation of their cultural capital by mainstream palliative care kaimahi and rōpū whakahaere.

Communication Models

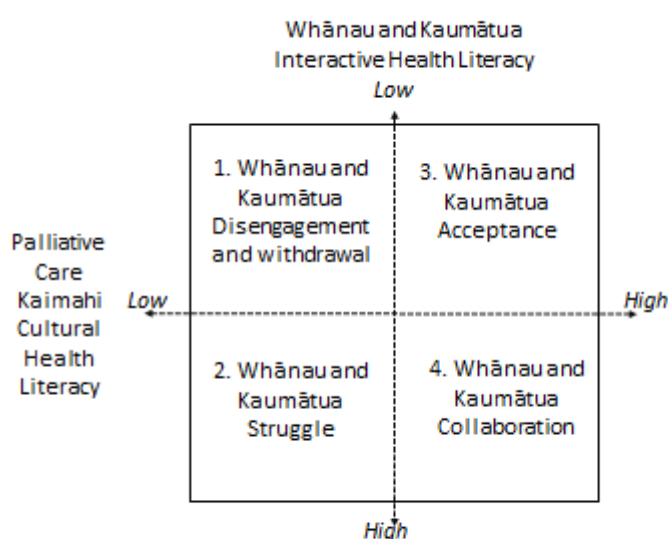
Communication underlies all of the elements of health literacy. That is, enhancing all of the dimensions of health literacy involves effective communication with others. We developed three communication models that illustrate these dimensions in the palliative care pathway. The first model centres on the intersection of interactive and cultural health literacy between health providers and kaumātua/whānau and illustrates why some challenges arise. The second model provides a summary of all of the communication elements discovered through the research and the intersection of the parties. The third model was adapted from the summary model to be more culturally relevant to kaumātua and whānau. We now present these three models and describe each.

Communication Model One: Challenges and connections in health literacy centred communication

The first model (Figure 9.1) takes a health literacy development approach to communication between kaumātua and whānau, and palliative care kaimahi. This model demonstrates the communication outcomes associated with the intersection of different levels of interactive and cultural health literacy, which were the most prominent dimensions in this study. We explain each of the intersections in relation to high and low levels of cultural and interactive literacy, and likely outcomes.

The first intersection of interactive and cultural health literacy concerns those ‘talking-past-each-other’ (Metge 1976; Metge and Kinloch 1978/2001) communication moments in palliative care. This is when kaumātua and whānau interactive health literacy is low and palliative care kaimahi cultural health literacy is low. When kaumātua and whānau feel excluded from being involved, or feel unheard by palliative care kaimahi, they are likely to withdraw from the situation and possibly, even the service. This results in resentment and the likelihood that kaumātua and whānau will avoid using this, or similar services again in a future.

Figure 9.1: Model One: Cultural and Interactive Health Literacy Communication



The second intersection of interactive and cultural health literacy captures those moments of communication struggle between kaumātua and whānau and palliative care kaimahi. These situations involve conflict between high and low levels of health literacy. Kaumātua or whānau have high interactive health literacy and often previous experience with palliative care, and/or the

health system more generally, and they know their rights and are aware of available resources. Palliative care kaimahi, on the other hand, are low in cultural health literacy, and in this situation take a strictly medical or institutional line, unaware of the cultural needs of kaumātua and whānau.

The third intersection of interactive and cultural health literacy captures those communication moments in palliative care when kaumātua and whānau interactive health literacy is low and palliative care kaimahi cultural health literacy is high. In these situations, kaumātua and whānau are likely to identify with the palliative care service and/or the individual kaimahi, and accept what is offered. Because cultural literacy is high with the palliative care kaimahi, there may be little need for additional or new kinds ‘interactive health literacy’ on behalf of kaumātua and whānau: they trust the provider and the kaimahi by nature of the culturally acceptable relationship.

The fourth intersection of interactive and cultural health literacy captures those communication moments in palliative care when kaumātua and whānau interactive health literacy is high and palliative care kaimahi cultural health literacy is high. In these situations, the parties are able to give and take, collaborate according to the skills and knowledge that each brings to the situation, and tuitui care and support of each other effectively. In contrast to the third intersection, kaumātua and whānau are active collaborators in this quadrant.

In summary, Communication Model One indicates those situations influenced by the interaction of high and low health literacy of kaumātua and whānau and palliative kaimahi. This characteristic can therefore help parties to ‘diagnose’ communication moments where kaumātua, whānau, and kaimahi are working to meet the needs of those affected and involved in palliative care and also those moments where needs are not being met. In this respect, Model One can be used to generate recommendations for actions that will

develop health literacy of not only of kaimahi, whānau and kaumātua, but also at the rōpū whakahaere organisational-cultural level, with changes in policies, procedures, and practices.

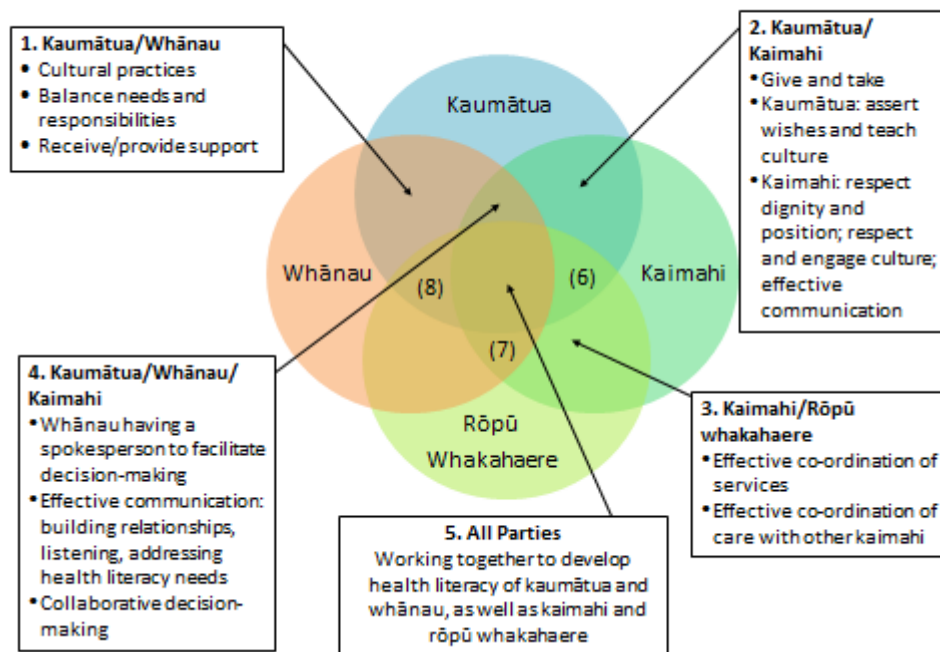
Communication Model Two: Relationships for effective communication and health literacy

In the literature review, we identified a strong need to examine what we called the ‘palliative care space’: the interactions among and between whānau, patients, health care kaimahi, rōpū whakahaere, and the health care system. We therefore developed an initial organising model to include all of the elements in the palliative care pathway. During our research meetings, we discussed this original organising model and its elements. The model was useful for helping us to keep in mind all of the relevant factors that might shape health literacy during palliative care. We also realised that the positions of the parties involved in the process—kaumātua, whānau, palliative care kaimahi, and rōpū whakahaere was also symbolic. That is, we positioned the kaumātua and whānau as overlapping and the palliative care kaimahi and rōpū whakahaere as overlapping; however, the kaumātua/whānau and worker/rōpū whakahaere did not overlap with each other. Research team members felt this was an accurate picture of how things are at the moment (based on the literature review and personal experiences) and yet not how they should be. The summary model we developed addresses the symbolic gap and illustrates the elements for enhancing communication and health literacy.

The summarising model, Communication Model Two, is called ‘Relationships for Effective Communication and Health Literacy’ (see Figure 9.2). It is presented as four overlapping circles each representing kaumātua, whānau, palliative care kaimahi, and rōpū whakahaere. The overlaps in circles represent the specific aspects of communication and health literacy that are important in a particular relationship. We describe these relationships starting in the upper left corner and working clockwise.

The first relationship is between kaumātua and whānau (see 1, Figure 9.2). Kaumātua and whānau emphasised the close connection, especially during the end-of-life journey. Participants discussed cultural practices and also the importance of effective communication to balance needs and responsibilities and to receive and provide support. Participants also identified some of the tensions that happen during the end-of-life journey and how effective communication can negotiate these tensions. Thus the need to for interactive health literacy was emphasised in this intersection.

Figure 9.2: Model Two: Relationships for Effective Communication and Health Literacy in Palliative Care



The second relationship is between kaumātua and kaimahi (see 2, Figure 9.2). Kaumātua and palliative care kaimahi both emphasised the importance of communicating effectively and displaying respect for cultural practices. For the kaimahi, this especially includes providing clear information, following cultural protocols, respecting the mana, dignity and position of the kaumātua, and offer caring service. For kaumātua, asserting their needs and teaching

about culture were two elements expressed to enhance the palliative care service. Thus, this relationship centres on interactive and cultural health literacy which we elaborated on in Model One (see Figure 9.1).

The third relationship is between health care kaimahi and rōpū whakahaere (see 3, Figure 9.2). The palliative care kaimahi offered that coordination or mahitahi is a key element in the delivery of care. The coordination is necessary as many district nurses and general practitioners provide palliative care services under the auspice of the hospital and hospice. In addition, with shrinking resources, effective coordination can deliver more efficient services. Further, there needs to be respect and coordination of mainstream kaimahi with Māori community health kaimahi. The mainstream kaimahi provide core medical support, while the community health kaimahi serve as core cultural liaisons. Thus, interactive health literacy is important within the rōpū whakahaere, and teamwork and coordination are skills that are not always emphasised because they are not directly involved in the patient care.

The fourth relationship is among kaumātua, whānau, and kaimahi (see 4, Figure 9.2). All participants recognised the importance of whānau for kaumātua during the palliative care journey. As a result, decision-making and communication about palliative care often involved whānau. The engagement of whānau and kaumātua involved kaimahi utilising effective communication to listen carefully to needs, build relationships and provide clear information to enhance awareness of palliative care services and support cultural practices. More importantly, this interaction involves collaboration during decision-making with kaimahi acting as supporter of whānau and kaumātua during decision-making. Thus, interactive and cultural health literacy were prominently displayed in this relationship, and this we elaborated on in Model One (see Figure 9.1).

The final relationship is between all of the parties (see 5, Figure 9.2). All of the phases of the research brought out that it is a team effort in the palliative care journey. The other intersections provide more concrete themes and dimensions of health literacy. However, this larger intersection is reminder that all of the parties need to be working together for effective communication and enhancing health literacy.

We noted three other relationships (see 6, 7, and 8, Figure 9.2) that highlight the role of the rōpū whakahaere in relationships with kaumātua and kaimahi (6), kaimahi and whānau (7), and kaumātua and whānau (8). These domains did not explicitly emerge in the findings, but their absence may be a function of research design—that is, we did not include rōpū whakahaere or spokespeople of them. However, these domains encouraged us to explore the dimension of political health literacy in that this literacy focuses on changes in policy and practices within palliative care systems. These areas and the role rōpū whakahaere in political health literacy are addressed in the recommendations presented later in this chapter.

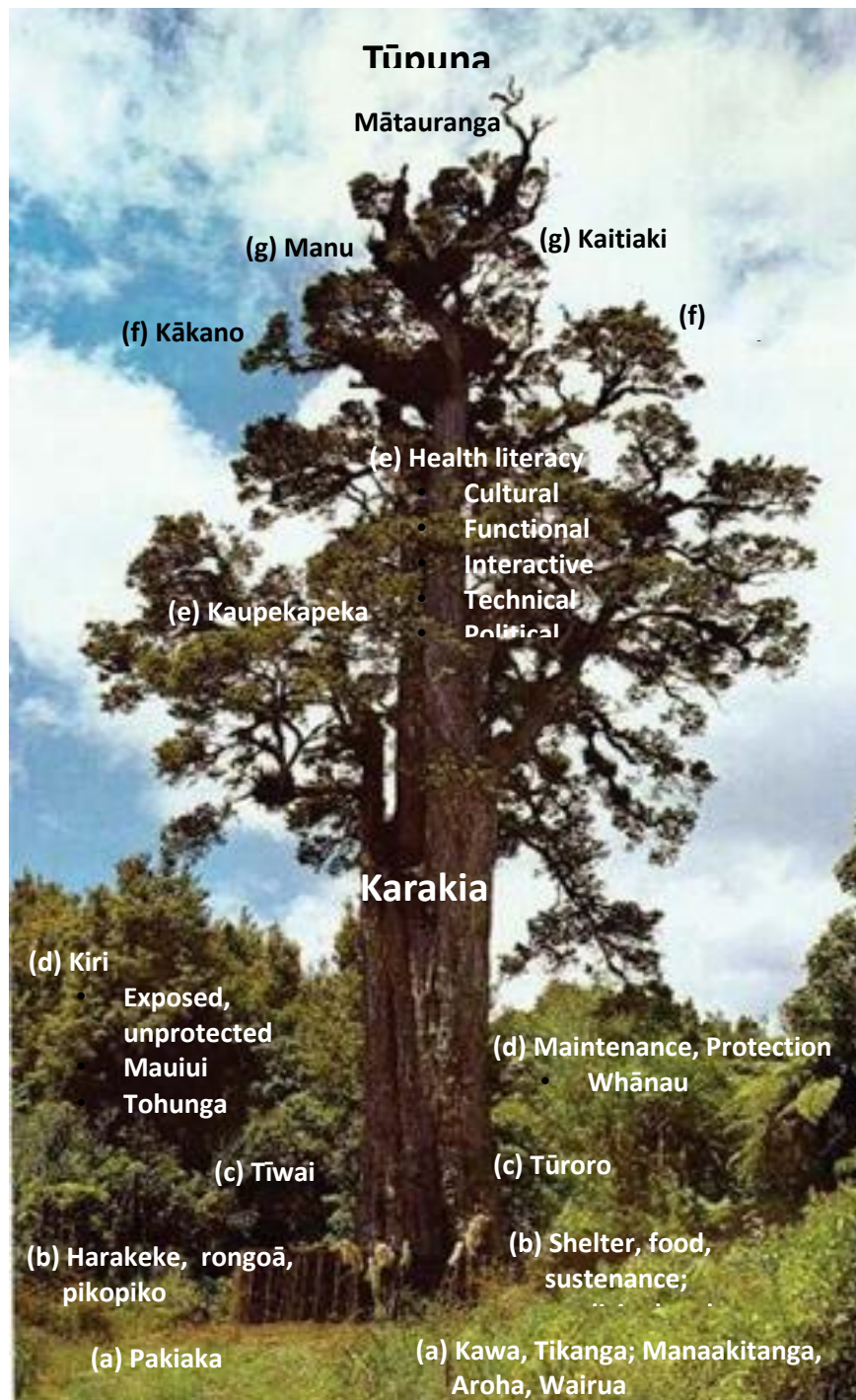
Communication Model Three: Te Tōtara

The research team acknowledged the need for a culturally relevant model of communication for kaumātua and whānau, and therefore, the third model (see Figure 9.3) adapted Model Two. We developed this model in consultation with kaumātua and kuia from Rauawaawa Kaumātua Charitable Trust, and the Advisory Board. The model aligns with the whakatauki, *Kua hinga te tōtara i te wao nui a Tane: A tōtara has fallen in the mighty forest of Tane*. This whakatauki is spoken when someone of great importance passes away, and it is particularly significant in relation to kaumātua and palliative care, and the matauranga kaumātua hold in relation to their whānau.

Te Tōtara uses the metaphor of the Tōtara to represent the inter-relationships and interdependence between the parties involved in palliative care, including

kaumātua, whānau, and palliative care service. We describe each aspect of Te Tōtara as it relates to communication in palliative care.

Figure 9.3: Model Three: Te Tōtara



Te Tōtara in this model is te tangata (person), whānaunga (relatives), and kaiawhina (supporters) involved in the palliative care process. Te Tōtara begins with its roots within the earth, Papatūānuku (Earth mother), and ends with its leaves reaching into the sky, Ranginui (Sky father). Surrounding and always with the Tōtara are tūpuna, the ancestors. Karakia (prayer) protect Te Tōtara through ever-connecting the spiritual and material worlds (see Marsden, 1975; Mead 2003).

The pakiaka (roots) are the values and principles that give the strength and purpose to the Tōtara. The key principles begin with kawa (governing protocol) and tikanga (practices), and include manaakitanga (care, nurturing and hospitality), aroha (love and support), and wairua (spiritual wellbeing). Without these Te Tōtara will die. At the base of the Tōtara, in the nearby surrounds are harakeke (flax), rongoā (medicine) and pikopiko (fern fronds). These represent the food, cultural and spiritual care, needed to sustain Te Tōtara. Only those with the right cultural knowledge and skills are able to provide this care. Without such care, Te Tōtara will be incomplete.

The tiwai (trunk) of Te Tōtara represents the person in strength and tūroro being the person in palliative care. Illness is only part of Te Tōtara and therefore, this model acknowledges that there are many dimensions of the person that need care and attention during palliative care. This brings us to kiri (tree bark). All sides of Te Tōtara are interconnected; the weathered or exposed side that is strong, and the side that is unprotected and soft. The tough bark on the weathered side is the whānau who protect and care for the Tōtara. With no sun nurturing it, the soft side is susceptible to becoming mauīui (ill). It is the tohunga (skilled agent of an atua [god, deity]) who discerns the health of Te Tōtara and directs treatment. When the soft-side needs attention, the palliative care kaimahi treat the matemate (illness) with guidance from the whānau. The palliative care kaimahi also provide resources and support the whānau in their role. Together whānau and kaimahi

work together in give and take of each other's skills and knowledge, looking to balance the needs of Te Tōtara and care of whānau with coordinated efforts.

Kaupekapeka (branches) represent the dimensions of health literacy that need to be accounted for in the care of Te Tōtara: Cultural, interactive and functional and technical, and political. Each of these branches needs to be strong for Te Tōtara, whānau and palliative care kaimahi to work-in together and to generate new knowledge for the next generation. Strength comes from knowing who has what skills and knowledge. Kaumātua, whānau and kaimahi need interactive health literacy to be able to avoid 'talking past each other' (Metge 1976; Metge and Kinloch 1978/2001). Mainstream kaimahi need to develop cultural health literacy by taking the lead from kaumātua and whānau; that is with kaumātua and whānau in the tuakana (older sibling) role, and mainstream kaimahi being the teina (younger sibling) in the relationship (eg, Glynn 2008; Tate 2010).

Kākano (seeds) of Te Tōtara represent the passing down of the learning and knowledge from Te Tōtara, whānau, and palliative care kaimahi, to mokopuna (grand children) who are the next generation of whānau and kaimahi. Kākano are the new growth and next generation; the tōtara rakau (tōtara trees), mokopuna.

Manu (birds) are the kaitiaki (protectors and guardians) feeding the mokopuna and supporting Te Tōtara and the whānau. These may be people and agencies outside of the whānau, who care in different ways for kaumātua and whānau of the person receiving palliative care, or the person themselves.

The mātauranga (knowledge) of palliative care develops from and contributes to the care of Te Tōtara. Only when all of the aspects of Te Tōtara and the associated whānau and kaimahi are functioning well in a coordinated way,

will each appreciate the gifts each brings to the journey. We are then able to develop the necessary knowledge for kaumātua-led models of palliative care.

Recommendations

The purpose of this project was to investigate the palliative care pathway for kaumātua and whānau from a health literacy perspective. During the previous section, we presented three communication models to summarise the research findings in this project and also provide suggestions for enhancing health literacy in the future. This section develops those models by presenting concrete recommendations for all parties in the palliative care pathway: a) kaumātua, b) whānau, c) kaimahi, d) rōpū whakahaere, and e) the health sector. Table 9.1 summarises these recommendations organised by types of health literacy and the parts of this study. A discussion of each recommendation now follows.

Table 9.1: Summary of recommendations organised by type of health literacy and participant/setting

Health literacy → Data-source	Functional Health Literacy	Technical Health Literacy	Interactive Health Literacy	Cultural Health Literacy	Political Health Literacy
Kaumātua Interviews	Kaumātua need to ask for help	Kaimahi should present clear information that reduces uncertainty.	Kaimahi need to provide tangible resources in a caring manner.	Kaimahi should respect culture and avoid prejudice.	Kaumātua and whānau need to stand up for their rights
			Kaumātua should assert wishes	Kaumātua should teach kaimahi about their culture	
			Kaumātua need emotional support from whānau, kaimahi, and rōpū whakahaere	Kaimahi should respect culture and avoid prejudice	
			Whānau and kaimahi need to show respect and maintain mana and dignity of kaumātua	Kaimahi who can speak te Reo Māori and use cultural practices will enhance service use (ie, more Māori kaimahi)	

Title: Māori health literacy and communication in palliative care: Kaumātua-led models

Author: Rauawaawa Kaumātua Charitable Trust Research Project Team



Health literacy → Data-source	Functional Health Literacy	Technical Health Literacy	Interactive Health Literacy	Cultural Health Literacy	Political Health Literacy
Kaumātua Interviews (cont.)			Whānau (ie, carers) need to make sure their own needs are met		
			Whānau need to manage tensions and conflict effectively		
			Kaumātua need emotional support from whānau, kaimahi, and rōpū whakahaere		
			Whānau and kaimahi need to show respect and maintain mana and dignity of kaumātua		



Health literacy → Data-source	Functional Health Literacy	Technical Health Literacy	Interactive Health Literacy	Cultural Health Literacy	Political Health Literacy
			Kaumātua should teach kaimahi about their personal wishes		
Whānau Hui		Whānau use advocates to, help navigate technical and organisational-cultural service and resource pathways.	Whānau have responsibilities to 1) inform kaimahi about culture and personal wishes, 2) assert their wishes, and 3) ask for help.	Whānau use advocates to, help navigate technical and organisational-cultural service and resource pathways.	Rōpū whakahaere that support kaumātua and whānau, learn from them about how to improve their own roles in palliative care.
		Kaimahi offer to help whānau to understand specific technical terms, processes, and practices of palliative care.	Whānau ask for and use advocates to, help navigate technical and organisational-cultural service and resource pathways. Whānau keep informed about what is going on and supporting kaumātua by 'translating'	Kaimahi need to be able to accept Māori worldviews and also to also make 'cultural space' for kaumātua and their whānau to fulfil their cultural obligations within palliative care	

Title: Māori health literacy and communication in palliative care: Kaumātua-led models

Author: Rauawaawa Kaumātua Charitable Trust Research Project Team



Health literacy → Data-source	Functional Health Literacy	Technical Health Literacy	Interactive Health Literacy	Cultural Health Literacy	Political Health Literacy
Whānau Hui (cont.)			medical information and providing care.	Kaimahi offer to assist whānau to (1) coordinate in-whānau communication; (2) organise whānau care tasks; (3) use whānau strengths to give care.	
				Kaimahi offer to help whānau to work through how palliative care processes and practices may have cultural implications and personal and whānau impacts	
	Kaumātua should seek out information and ask a lot of questions.	Kaimahi need to communicate with clarity and without technical terms.	Kaumātua should seek out information and ask a lot of questions.	Kaimahi should use cultural liaisons to enhance cultural literacy if they don't have it.	Kaimahi need to develop better mahitahi (coordination) with GPs, district nurses, and other agencies.

Title: Māori health literacy and communication in palliative care: Kaumātua-led models

Author: Rauawaawa Kaumātua Charitable Trust Research Project Team



Health literacy → Data-source	Functional Health Literacy	Technical Health Literacy	Interactive Health Literacy	Cultural Health Literacy	Political Health Literacy
Kaimahi Focus Groups			Kaimahi need to listen and collaborate with patients to meet their needs.	Kaimahi should use cultural sensitivity and demonstrate respect for tikanga	
			Kaimahi need to work to build relationships with kaumātua and whānau.	Kaimahi shouldn't assume cultural or personal wishes of patients	
			Kaimahi shouldn't assume personal wishes of patients (ask and listen).		
			Kaimahi need to coordinate care with community rōpū whakahaere and kaimahi.		



Health literacy → ↓ Data-source	Functional Health Literacy	Technical Health Literacy	Interactive Health Literacy	Cultural Health Literacy	Political Health Literacy
Kaimahi Focus Groups (cont.)			Community kaimahi and community rōpū whakahaere can continue to provide strong emotional support.		
Brochure Analysis	Informational material needs to use the principles of plain English and active writing styles.	Informational material that takes account of health knowledge of intended audiences; avoid technical, medical and other complex terms; and explain such terms when used.	Informational material needs attend to relational domains of writing; using personal pronouns with clear relational intentions eg, 'you', 'we', 'us' etc	Palliative care rōpū whakahaere work with kaumātua and whānau in developing informational material.	Palliative care rōpū whakahaere, kaumātua and whānau work together to critically analyse how presentation of important information may impact on decisions in the wider community.



Health literacy → Data-source	Functional Health Literacy	Technical Health Literacy	Interactive Health Literacy	Cultural Health Literacy	Political Health Literacy
Brochure Analysis (cont.)			Palliative care rōpū whakahaere work with kaumātua and whānau in developing informational material.	Hospice and hospitals should engage kaumātua and whānau (perhaps through focus groups) to design culturally appropriate brochures. This would include evaluating images in view of the nature of the topic.	
ED Audit	Kaumātua should seek services with GPs and hospice rather than present at the ED	Kaimahi need to provide better information and networks for kaumātua to get care outside of the ED	Palliative care kaimahi need to better understand the reasons for patients using EDs		Palliative care Rōpū whakahaere need to critically analyse service use and gaps to better serve patients and their whānau using palliative care service.

Recommendations for Kaumātua

If you are a kaumātua and interested in improving health literacy about palliative care (ie, achieve the ideal in Communication Model Three), you should consider the following:

Prior to needing services

- a) Build relationships with community rōpū whakahaere that provide health and social services for kaumātua so you they help later if you need palliative care.
- b) Seek out information about palliative care to understand what you are entitled to and what services you think are relevant for you and your whānau.
- c) Plan with your whānau about your wishes should you need palliative care services.
- d) Talk with your mates about your (and their) palliative care experience.
- e) Take on whakaruruhau (peer-mentor) roles to share knowledge of palliative care.

During the palliative care pathway

- f) Assert your wishes with kaimahi—makes sure you get what you need.
- g) Consider teaching kaimahi about your culture and how they can interact with you in a culturally appropriate manner.
- h) Ask questions of kaimahi and keep asking until you understand what your options are and why.

Recommendations for Whānau

If you are a whānau member and wanting to meet the needs of loved ones who may need palliative care services (ie, achieve the ideal in Communication Model Three), consider the following:



Prior to needing services

- a) Build relationships with community rōpū whakahaere that provide health and social services so you they help later if whānau members need palliative care.
- b) Plan with your loved ones about their wishes—tino rangatiratanga—should they need palliative care services.
- c) Seek out information about palliative care to understand what you whānau is entitled to and what services you think are relevant for your loved one.
- d) Talk with your mates about your (and their) palliative care experience.
- e) Take on whakaruruhau (peer-mentor) roles to share knowledge of palliative care.

During the palliative care pathway

- f) Seek out kaitautoko (advocates) who can help you navigate the palliative care pathway.
- g) Assert your wishes with kaimahi—makes sure you get what you need.
- h) Consider teaching kaimahi about your culture and how they can interact with you and your loved one in a culturally appropriate manner.
- i) Ask questions of kaimahi and keep asking until you understand what your options are and why.
- j) Provide emotional support and physical care to your loved one.
- k) Make sure to respect the mana and dignity of your loved one—let them know they are still a revered leader in the whānau.
- l) Makes sure to get your own needs met (emotional, spiritual, and physical).
- m) Ask for help from your whānau.
- n) Manage the conflicts among the whānau in a cooperative way.



Recommendations for Kaimahi

If you are a kaimahi and want to enhance your health literacy working with kaumātua and whānau (ie, avoid the problems in Communication Model One and achieve the ideal in Communication Model Two), consider the following:

- a) Work to enhance your cultural literacy—ask for help from those who know the culture and seek out training and supervision about culture.
- b) Use clear information to reduce uncertainty.
- c) Provide easy to understand instructions and make sure to explain any technical terms (better yet, try to avoid technical terms in the first place).
- d) Ask kaumātua and whānau what they expect and need.
- e) Listen with your whole heart (not just to the words, but to the feelings and meanings being expressed).
- f) Provide emotional as well as physical support in a caring manner.
- g) Make sure whānau understand all the services they are entitled to and make sure they have care well organised.
- h) Hospice and hospital kaimahi: partner with community kaimahi to help meet the full needs of kaumātua and whānau.
- i) Community kaimahi: make sure that you are an advocate for kaumātua and whānau.

Recommendations for Rōpū Whakahaere

Many approaches to health literacy involve putting the burden on individuals to change. Certainly, individual kaumātua and whānau can work to improve their health literacy about palliative care. However, we feel that rōpū whakahaere-centred efforts will have a stronger impact on kaumātua and whānau health literacy and individually-centred efforts because they help to

change the system and not just individuals. Therefore, we provide more depth to the following recommendations:

1. Awheawhe (interactive workshops);
2. Whakaruruhau whānau (peer-mentors) trained in kanohi ki te kanohi support (face-to-face);
3. Improving quality of brochures; and
4. Training and cultural supervision for palliative care kaimahi.

Recommendation One: Wānanga, hui, awheawhe (seminars, meetings, and workshops)

First, rōpū whakahaere can work to engage kaumātua and whānau prior to palliative care events. A core health literacy related finding from this project is a lack of awareness about palliative care services from some kaumātua/whānau. Some palliative care kaimahi, and some kaumātua, noted that when Māori become aware of what services are available, how the services are tailored to the needs of the family, and that the services are free, they are quite pleased with palliative care services. To address this lack of awareness, rōpū whakahaere should use multiple communication hongere (channels) to engage in two-way communication about palliative care services. Critically, kaimahi from Māori community groups, comfortable in kanohi ki te kanohi (face-to-face) and preferred communication processes of Māori (eg, karakia, whakawhānaungatanga) should be included at the rōpū whakahaere level.

One channel for such efforts is to identify the network of rōpū whakahaere already working with kaumātua and whānau, and then to assess options for them working together. Another involves wānanga (seminar, forum), hui (meetings) and awheawhe (workshops, people working together) focused on palliative care. Significantly, these should be held at marae and other locations where kaumātua and whānau are involved and feel comfortable about participating. The purpose of rōpū whakahaere wānanga, hui and

awheawhe is to share information about palliative care and increase awareness of the services. These awheawhe should also work to make the communication two-and-three way so that kaimahi can learn more about cultural practices and kaumātua and whānau expectations, so they can improve the ways in which they deliver services.

Recommendation Two: Whakaruruhau kaumātua, whakaruruhau whānau (peer mentors)

Despite a multichannel effort to convey information, some kaumātua/whānau will still be missed. Thus, rōpū whakahaere should work to train kaumātua and whānau as whakaruruhau about palliative care. Kaumātua who are well informed about palliative care can be ideal conduits for conveying health information about palliative care as they are from the same culture and age group (ie, role models). Whakaruruhau should be trained not only about palliative care services, but also about how to use their cultural knowledge to effectively communicate about behaviour change. People are not always ready to change their behaviour; even when peers are the ones delivering the message. While the training of whakaruruhau may involve adaptations of tauwi (foreign) communication techniques designed for such purposes (eg, motivational interviewing, Miller and Rollnick 2002), it is critically important that whakaruruhau are enabled to draw on their cultural capital and Te Ao Māori worldview to benefit those needing to know about palliative care services. Using this approach could be a fruitful avenue for enhancing health literacy for kaumātua and whānau and effective when driven by an rōpū whakahaere.

Recommendation Three: Improving cultural and technical literacy of brochures

Third, rōpū whakahaere can work to improve the quality of information to kaumātua and whānau about palliative care. Our research identified a lack of cultural resonance with written palliative care information (ie, brochures). The lack of resonance related directly to the quality of brochures. Rōpū

whakahaere and health care kaimahi should directly engage their local kaumātua and whānau, and/or community groups working with kaumātua and whānau in health, to develop high-quality and culturally-appropriate brochures. This is likely to involve allocating resources to those involved.

One general principle of health promotion is that messages need to be tailored directly to the audience to which the message is targeted. Brochures and other media can be developed to meet the communication needs of kaumātua and whānau if providers can involve them in their creation, production, and dissemination. Such involvement would include ensuring appropriate use of images and te reo Māori, as well as representation of Te Ao Māori worldviews. However, as implied by the above recommendations, palliative care rōpū whakahaere and services themselves may also need to adapt—rather than simply change formal messages about the services.

The development of reading material written in te reo Māori was supported by participants. However, it was also recognised that not all kaumātua and whānau can read Māori. The most critical issues for participants was that text and symbolic images should be speaking to the same message; and the Māori symbols should be used correctly and with consideration to the other images and messages conveyed. These principles apply to any text-based messages including web-pages, podcasts, and social media. One suggestion was that rōpū whakahaere need to be creative in sharing information in media. Younger whānau may benefit with the use of social media, interactive chats, and podcasts. Kaumātua and whānau may like to watch take-home DVDs. These communication technologies can be effective at reaching some audience members provided they maintain cultural integrity.

Recommendation Four: Cultural Supervision for Palliative Care Kaimahi

The fourth recommendation is to provide continual training for palliative care kaimahi on cultural and interactive health literacy. This is another opportunity for kaumātua and whānau, and Māori health kaimahi to develop

and manage training and cultural supervision programmes for palliative care kaimahi.

Some kaimahi are highly skilled in cultural and interactive health literacy and others are not. Those with low health literacy need basic level training workshops lead by kaiawhina skilled in cultural supervision—cultural liaisons. Ideally, there would be opportunities to role play and practice cultural and interactive literacy skills prior to interacting with patients and whānau. As kaimahi become culturally literate, monitoring of skills becomes important. All kaimahi have supervision in two areas: clinical and cultural supervision. Clinical supervision ensures continued training to keep sharp on medical training. Cultural supervision ensures continued develops of cultural and communication skills (eg, Ake and Calvert 2012). We recommend group supervision hui so that all kaimahi can learn from others and talk about what works and what doesn't.

We anticipate that resourcing could be an issue, but would recommend that Māori community agencies involved with kaumātua and mainstream palliative care rōpū whakahaere investigate ways for them to develop programmes utilising their respective skills and knowledge. Part of the conversation would involve resourcing: Education and cultural supervision depend on cultural knowledge, and access to cultural knowledge requires pūtea (funds).

Recommendations for the Health Sector

The final recommendations are for the health sector. The health sector (eg, District Health Boards, Ministry of Health) has a responsibility for assuring the health of kaumātua and whānau. We identify two recommendations to facilitate the improvement of the health literacy of kaumātua and whānau (and thus enhance health outcomes) around palliative care: a) Set up guidelines for rōpū whakahaere around interactive and cultural health literacy; and b) Provide resources/balance for community health kaimahi.

Recommendation One: Provide Guidelines/Standards for Rōpū Whakahaere

The first recommendation is to provide guidelines/standards for rōpū whakahaere, particularly around the recommendations provided to rōpū whakahaere. The health sector can create expectations for practices that maximise health literacy around palliative care such as the following:

- a) hosting informational events about palliative care, b) developing peer-mentoring programmes, c) implementing cultural training and supervision, and d) designing effective brochures. In addition, the health sector should encourage and require improved levels of coordination of palliative care rōpū whakahaere.

Recommendation Two: Resource Community Health Kaimahi

The second recommendation is to provide resources and funding to Māori community groups so that they can develop culturally driven palliative care services. The current structures and resources for palliative care services are based largely with mainstream District Health Board regional services that work with local district nurses, community hospices (ie, charitable trusts), and sometimes Māori health providers. So that change is brought about at a structural level, we suggest that pūtea (funding) address rauemi (resources), skills, and kaimahi development within Māori health and Māori community rōpū whakahaere to enable them to work effectively with mainstream palliative care services. Thus, rather than only existing palliative care rōpū whakahaere building resources and staff capacity to offer culturally relevant and meaningful palliative care services for kaumātua and whānau, that existing services with the cultural capital be included in the service.

Summary

In summary, health literacy is a core facet to effective palliative care service. The models we present display a number of intersections and communication strategies to address health literacy in the palliative care pathway. The first model illustrates the intersection of interactive health literacy for

kaumātua/whānau and cultural health literacy of kaimahi in palliative care. It demonstrates that the ideal situation is when both parties are high in health literacy and yet what can happen when there is low health literacy for one or both parties. The model helps to explain why some kaumātua/ whānau struggle and have resentment with the palliative care pathway.

The second model provides a summary of the entire research project and centres on the relationships of the four main parties in the palliative care pathway. It emphasises the interaction elements during palliative care and illustrates the communication responsibilities the parties have.

The third model provides a summary of the research project from a Māori cultural perspective. Te Tōtara model includes ten core elements of the palliative care pathway that need to come together to keep Te Tōtara strong. It emphasises the cultural dimensions while still including clinical aspects. This model is a symbol of the palliative care pathway that we hope resonates with kaumātua and whānau.

In addition, the recommendations have the potential to enhance health literacy in the palliative care pathway for the health sector, rōpū whakahaere, palliative care kaimahi and kaumātua and whānau. The recommendations include some focus on addressing individual health literacy needs (interactive, functional and technical) of kaumātua and whānau and also health literacy (cultural and interactive) of palliative care kaimahi. Additionally, because some of these recommendations are centred on the rōpū whakahaere-level, we feel that they are sustainable and likely to lead to long-term change—that is, by addressing political health literacy. Finally, addressing the larger structural issues of how palliative care is funded (recommendation five) could help to better address the cultural needs of kaumātua and whānau, as well as account for political health literacy issues within the system.

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**Chapter 9: Ngā Tuhituhinga me Ngā Kōrero—Making connections:
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Ngā Apitihanga—Appendices

Appendix 1.1: Research tasks, task leaders, key supporters

Note that many team members contributed, but as holder of the research contract, Rauawaawa Kaumātua Charitable Trust considered it important to acknowledge the task leaders and key support/s in the various roles and tasks of the research.

Tasks	Task Leader	Key Supporters
<i>Foundations</i>		
Advisory Group	Rauawaawa Kaumātua Charitable Trust	
Project Administration	Rauawaawa Kaumātua Charitable Trust	All
Stakeholders Network	Rauawaawa Kaumātua Charitable Trust	All
<i>Research Capacity Building: Training</i>		
Team Workshop: Cultural Training, Kaupapa Māori Research, Community Based Participatory Research	Te Rūnanga o Kirikiriroa	Te Kotahi Research Institute and Management Communication Department, Te Raupapa/Management School, Te Whare Wānanga o Waikato/University of Waikato
Team Workshop: Thematic Analysis Training	Management Communication Department, Te Raupapa/Management School, Te Whare Wānanga o Waikato/University of Waikato	
<i>Research Capacity Building: Whakaruruhau-Mentoring</i>		
Academic and Kaupapa Māori Research Mentoring	Te Kotahi Research Institute, Te Whare Wānanga o Waikato/University of Waikato	

Tasks	Task Leader	Key Supporters
Community Based and Kaupapa Māori Research Mentoring	Te Rūnanga o Kirikiriroa	
Communication and Health Literacy Mentoring	Management Communication Department, Te Raupapa/Management School, Te Whare Wānanga o Waikato/University of Waikato	
Palliative Care Services Mentoring	Palliative Care Unit, Waikato District Health Board	
<i>Mahi Rangahau-Research Tasks: Stage 1</i>		
Proposal Development	Rauawaawa Kaumātua Charitable Trust	Management Communication Department, Te Raupapa/Management School, Te Whare Wānanga o Waikato/University of Waikato Te Rūnanga o Kirikiriroa
Kaupapa Māori Research Methodology Development	Te Rūnanga o Kirikiriroa Te Kotahi Research Institute, Te Whare Wānanga o Waikato/University of Waikato	Rauawaawa Kaumātua Charitable Trust
Ethics Application (excluding ED Document Audit)	Te Rūnanga o Kirikiriroa	Rauawaawa Kaumātua Charitable Trust
Ethics Application Emergency Department Audit	Waikato Clinical School, Faculty of Medical and Health Science, The University of Auckland	
Literature Review	Management Communication Department, Te Raupapa/Management School, Te Whare Wānanga o Waikato/University of Waikato	

Tasks	Task Leader	Key Supporters
<i>Mahi Rangahau-Research Tasks: Stage 2 - Working with Participants and Documents</i>		
Kaumātua Individual Interviews	Te Rūnanga o Kirikiriroa Rauawaawa Kaumātua Charitable Trust	Management Communication Department, Te Raupapa/Management School, Te Whare Wānanga o Waikato/University of Waikato Te Puna Oranga, Waikato District Health Board
Whānau hui	Te Puna Oranga, Waikato District Health Board Management Communication Department, Te Raupapa/Management School, Te Whare Wānanga o Waikato/University of Waikato	Rauawaawa Kaumātua Charitable Trust
Kaumātua Focus Group	Te Puna Oranga, Waikato District Health Board Management Communication Department, Te Raupapa/Management School, Te Whare Wānanga o Waikato/University of Waikato	Rauawaawa Kaumātua Charitable Trust
Palliative Care Kaimahi Focus Groups	Management Communication Department, Te Raupapa/Management School, Te Whare Wānanga o Waikato/University of Waikato	Te Puna Oranga, Waikato District Health Board
Māori Community Kaimahi Focus Group	Te Puna Oranga, Waikato District Health Board	
Brochure Analysis	Management Communication Department, Te Raupapa/Management School, Te Whare Wānanga o Waikato/University of Waikato	Te Puna Oranga, Waikato District Health Board Rauawaawa Kaumātua Charitable Trust

Tasks	Task Leader	Key Supporters
Transcription	Te Rūnanga o Kirikiriroa	Rauawaawa Kaumātua Charitable Trust
Thematic Analysis (interviews, whānau hui, kaimahi focus groups and brochure analysis)	Management Communication Department, Te Raupapa/Management School, Te Whare Wānanga o Waikato/University of Waikato	Te Puna Oranga, Waikato District Health Board
Waikato Emergency Department Document Audit	Waikato Clinical School, Faculty of Medical and Health Sciences, The University of Auckland	Palliative Care Unit, Waikato District Health Board
<i>Mahi Rangahau-Research Tasks: Stage 3 – Reporting and Dissemination</i>		
Final Report Writing	Management Communication Department, Te Raupapa/Management School, Te Whare Wānanga o Waikato/University of Waikato	All
Final Report Review	Management Communication Department, Te Raupapa/Management School, Te Whare Wānanga o Waikato/University of Waikato Te Rūnanga o Kirikiriroa	All

Appendix 1.2: Rārangi kupu—Glossary of te reo Māori—English terms

Te Reo Māori	English Translation/Approximation
aroaha	love, compassion, affection, empathy (verb and noun)
atua	god, deity, ancestor with continuing influence
awheawhe	workshop/s, working together
awhi	embrace, surround, care about/for
haere mai	welcome; a greeting
haka	performance, dance (verb and noun)
hākari	feast
hapū	to be pregnant
hinengaro	mind, thought
hongere	channel/s
hui	meeting; discussion
inoi	prayer (noun); pray (verb)
iwi	tribe
kai	food
kai hākari	feast
kaiako	teacher, instructor; singular and plural
kaiāwhina	supporter, assistant, helper
kaimahi	worker or workers; singular and plural
kaitautoko	advocate
kaitiaki	protector, guardian/s
kākano	seeds
kanohi ki te kanohi	face-to-face communication
karakia	prayer
kaumātua	elder or elders
kaupapa	agenda, philosophy, focus
kaupēkapeka	branch or branches of a tree
kawa	governing protocol

Te Reo Māori	English Translation/Approximation
kiri	tree bark
koha	gift (to be reciprocated), contribution
kōrero	talk, narrative
koroua	male elder or elders
koru	curled new fern shoot; symbol of new growth
kotahitanga	unity
kuia	female elder or elders
kupu	word
mahi	work
mahitahi	coordination
manaakititanga	hospitality, kindness, care, nurturing
mana	prestige, authority, influence, status, spiritual power; the supernatural force in a person
manu	bird or birds
manuhiri	guest/s, visitor/s
marae	place of belonging for given hapū; Place set aside for give hui, gatherings, celebrations.
mātauranga	knowledge
matemate	be sickly, ailing
matua	father, uncle, man senior to self
māuiui	be sick, weary, tired
mohiotanga	knowledge
mokopuna	grandchild; grandchildren
ngaungau	point of discussion; getting at the nitty gritty; ‘chewing things over’
paepae	speakers’ bench or seat usually at a marae
Pākehā	New Zealander/s usually of European

Te Reo Māori	English Translation/Approximation
	settler heritage
pakiaka	roots
Papatūānuku	Earth mother and wife of Ranginui from whose union all living things originate.
pounamu	New Zealand greenstone
pōwhiri	formal welcome
pūtea	funds
rangatahi	young person; young people; teenager/s
rangatiratanga	self determination
Ranginui	Atua of the sky and husband of Papatūānuku, from whose union all living things originate.
rauemi	resource
rohe	boundary, territory (of an iwi)
rōpū whakahaere	organisation or organisations; singular and plural
tamariki	children
tane	man singular
tāne	men plural
tangata	person
Tangata Whenua	Māori; people of the land
tangi	mourn, weep
taonga	treasures, highly prized object/s; singular and plural
tapu	be sacred, restricted, under <i>atua</i> protection
tauiwi	non-Māori; foreign people; immigrants
tautoko	support, advocacy
Te Ao Mārama	The realm of being
Te Ao Māori	Māori world; worldview
Te Kore	The primal energy of potential
Te Po	The realm of becoming

Te Reo Māori	English Translation/Approximation
Te Reo Māori	The Māori language
tētahi	One . . . the other
Te Tiriti o Waitangi	The Treaty of Waitangi; the Māori version of it
Te Whai Ao	The emerging world
teina	younger sibling of older sibling of same gender
tikanga	cultural customs, practices, values, beliefs,
tinana	body, physical
tino rangatiratanga	self determination; full chieftainship
tōtara rakau	tōtara trees
tuitui	coordinate
tupuranga	growing generations
tūroro	patient
waiata	song, singing
wairua	spirit
wānanga	seminar, forum
waihotanga	bequest
whaea	mother, aunty, woman senior to self
Whakāro	thoughts
whakaruruhau	mentor, guide
whakatauki	proverb
whakawhānaungatanga	process of establishing relationships
whakawhitiwhiti whakaaro	debrief
whānau	kin
whānaunga	relative
whānaungatanga	Relationships, connections

* These definitions are derived from multiple sources including kaumātua involved with the research and from Rauawaawa Advisory Group, and *Te Aka Māori-English, English-Māori Dictionary* (online).

Appendix 4.1: Question guide for kaumātua interviews

Tell me your story of why you were willing to be interviewed for this topic.

Potential Probing Areas:

Five Areas of Health Literacy	Question Areas
Interpersonal	<p>Communication with clinicians</p> <p>When were you told about the condition/illness?</p> <p>Where were you told about the condition/illness?</p> <p>Who was involved in your care?</p> <p>What kind of information did you receive?</p> <p>Did anyone explain the information?</p> <p>What support did you receive?</p>
Cultural (will pick up as they tell their story)	<p>Māori workforce present in pathway</p> <p>Any situations where tikanga was used or denied</p> <p>Use of te reo</p> <p>Safety (treatment and advice, environment and surroundings)</p>
Technical (will pick up as they tell their story) – medical processes, diagnosis	<p>How were you told about the condition/illness?</p> <p>Did you understand that information?</p>
Political (focus group) – ability to change the system	<p>Did you try to change the care/system?</p> <p>Did you complain about the process?</p>
Functional (what palliative care is)	<p>What was your understanding of palliative care?</p>
Services/system – what works or not?	
Ideal	
What advice would you give to someone else if they were to go through the same journey?	
How do you want this to look/work for your future mokopuna?	
What would make it work better?	

Appendix 5.1: Discussion statements for whānau hui

- Whānau need to know what's going on.
- Only whānau should care for whānau
- Kanohi ki te kanohi is the best approach
- Whānau and tikanga are the most important things

Appendix 6.1: Palliative care worker focus group question guide

These questions form the area of interest from palliative care/health kaimahi that will be consistent with procedures about how kaumātua and whānau Māori access health service utilisation for a variety of health services. In terms of accessing care services such questions may include the following:

1. Tell me about a typical case when you offer services to kaumātua.
 - a. Probe: What happens to kaumātua and whānau on their journey through the palliative care pathway
 - b. Probe: What services are available to people needing end of life services and how are they delivered
 - c. Probe: How is it different with other elders?
2. Communication: How did you first talk with them about their illness?
 - a. Describe your conversations with kaumātua? Whānau?
 - b. What are the most important things you can say (or not say) to kaumātua? Whānau?
 - c. Are there any cultural issues that you've found in your interaction with kaumātua? Whānau?
3. Rōpū whakahaere factors
 - a. Are there any factors about your services or rōpū whakahaere that prevent or hinder kaumātua and their whānau from seeking services when they need them?
 - b. What factors encourage them to seek services?
 - c. What are the workplace factors that help you in providing services? OR What are the best parts about your job and rōpū whakahaere in providing palliative services?
 - d. What are the workplace factors that hurt you in providing services? OR What are the worst parts about your job and rōpū whakahaere in providing palliative services?
4. What advice would you offer to kaumātua and whānau if they have a need to seek services?
5. What services do you believe that kaumātua and their whānau need but can't get?; and that are hard to get?;
6. What would be the single most important change you would suggest to improve palliative care?

Appendix 7.1: Template email to hospices to request brochures

To: [each hospice]

Subject: Study in Māori health literacy in palliative care: Request for help

Tena koe

I am a member of a research project funded by the Health Research Council and Ministry of Health, ‘Māori health literacy in palliative care: Kaumātua-led models.’ The research aims to identify key communication practices that contribute to Māori health literacy in end-of-life planning and palliative care. This includes experiences of kaumātua and whānau, elders over 50 years and their families, well as clinicians’ and community workers’ delivery of these services.

I am responsible for studying information and promotional material used by palliative care services in New Zealand, including that which is made available to users of palliative care services, their families and whānau. Different aspects of the material will be looked at, for example, content, layout, styles, literacy levels, and so on. We expect the study to result in recommendations for further developments in material for different participant groups that take part in our study.

I am writing to hospice and other palliative care service organisations to obtain copies of printed material. If your organisation uses its own brochures, pamphlets, information sheets/packs, in its service delivery, I would very much appreciate your sending me a copy of each for inclusion in the study.

In sending copies of such documents, your hospice has the right to a summary of the findings from this part of the study when it is concluded (30 June 2012). Meantime, you are welcome to ask any questions about the project by contacting me at the contact details below.

I hope you can help and look forward to hearing from you.

Warm regards

Nga mihi nui

For **electronic** copies please reply to this email [address] and attach

For **printed** copies please FREEPOST to me as per label below (write on, or print label for, any size envelope)