

Kia Mau te Kahu Whakamauru:

Health Literacy in Palliative Care

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He Mihimihi

He hōnore, he korōria ki te Atua

He maungarongo ki te whenua

He whakaaro pai ki ngā tāngata katoa

Tēnā rā koutou, e te iwi nui tonu, ka whakakorōria tonu i te Atua Kaha Rawa. Kia tau tonu ōna manaakitanga maha ki runga i Te Arikinui Kīngi Tūheitia, me te Whare o te Kāhui Ariki.

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Whakarāpopototanga - Executive Summary

The New Zealand Palliative Care Strategy (Minister of Health 2001) recognised the need for local and national policies that support the specific needs of Māori, including linkages with Māori organisations and care coordinators. While there are increasing numbers of research studies about access to palliative care for Māori and others (Frey et al 2013; Robinson et al 2013), this is the first to have taken a health literacy perspective.

Health literacy is described as “the degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions” (Nielsen-Bohlman et al 2004; Ministry of Health 2010a). For health professionals, health literacy is about their ability to communicate health information and build skills and knowledge. For health organisations, health literacy is about the appropriateness of the health information and services they provide for patients and their families as well as the organisational systems and processes to support health professionals to build health literacy.

The Health Research Council of New Zealand (HRC) and the Ministry of Health as the Māori Health Joint Venture, contracted UniServices to identify, from a health literacy perspective, issues for Māori and their whānau in accessing palliative care services.

Four key areas in the Request for Proposal of interest were identified, including:

1. Ways in which Māori access palliative care services
2. The current level of Māori health literacy with regards to palliative care
3. The way in which different factors within whānau influence the ability of Māori to obtain, process and understand palliative care information and services
4. Identification of communication models which are effective in enhancing this ability.

Method

The study used a qualitative kaupapa Māori methodology. Following ethics approval, study participants for the palliative care expert focus groups were recruited through hui in Auckland and the Bay of Plenty. Patients and whānau were recruited after approaches by their palliative care services provider.

Semi structured interviews were held with 21 patients and whānau to identify how they accessed palliative care services, the information they received, their experiences and suggestions for improvement. All patient and whānau participants were in receipt of specialist palliative care.

Semi structured interviews were completed with six key informants: a medical specialist, a service leader involved in developing culturally specific responses to patients, two Māori service managers, and two Māori health team leaders. In the key

informant interviews and focus groups, we sought perspectives about palliative care services provided for Māori patients and whānau; health literacy in palliative care; the health literacy demands of palliative care; and how health professionals take into account the health literacy skills of patients and whānau.

Focus groups were held with a total of 54 health professionals providing palliative care services. Focus group participants came from a range of disciplines: nurses (including cancer nurses, students, palliative care nurses, clinical nurse specialists, team leaders and nurse practitioners); General Practitioners (GPs) and clinicians; health psychologists, counsellors, social workers and chaplains; kaumātua, kaiāwhina, kaitakawaenga, kaiatawhai and navigators; and managers, administrators and coordinators.

Data analysis

The interview transcripts were analysed to elicit key concepts and recurrent themes, using a general inductive approach (Thomas 2006). Data from each participant group—patients and whānau, health professionals, and key informants, were viewed as equally authoritative during the analyses, with the same process followed for all. As the themes were developed, it became clear that there was a measure of general consistency across all three groups. The trustworthiness and reliability of the general inductive approach was supported by sharing analysis of transcripts among the research team, using a consistent analytic template, and reviewing analysed texts amongst team members and at hui on the findings. Member checking or respondent validation was used in presenting analyses at five hui with the research communities involved, where there was participant engagement with, and agreement on, the categories and themes that had been developed from the data.

Written resource analysis

Palliative care providers were asked at focus group and key informant interviews to supply written information about palliative care services that providers gave to Māori patients and whānau. A total of 42 written resources from participating palliative care providers were reviewed, in terms of aspects such as purpose, audience, readability, and use of Māori concepts.

Findings

Late access to palliative care, including difficulties with access and referrals to palliative care that occurred late in the life-limiting illness process were identified in this study as issues for the participants. The outcome of these was similar, with inadequate time for patients, whānau and their service providers to engage, negotiate any health literacy demands, access satisfactory support, or make arrangements for the patients' preferred death experience. Late referrals to palliative care were also reported to increase distress for health professionals.

The mechanisms around late access and late referral variously related to tikanga, lack of knowledge or misunderstandings about the availability and uses of palliative care (low health literacy), lack of availability of services, the clarity and timeliness of 'hard conversations' with health professionals about the shift from treatment to palliative care, and the cultural character of palliative care services.

This study found that some patients and whānau were reluctant to accept palliative care because they believed that such services were only available as inpatients; that the purpose of hospice care was to hasten death; and that to accept palliative care was to accept that death was imminent.

This study found that the willingness and ability of health professionals to have the 'hard conversations' that accompany illness and death had an impact on the health literacy of patients and whānau. Where those conversations were not held or lacked clarity, whānau reported feeling overwhelmed and under-informed about their options and how to help their family member.

This study found a clear perception by all participants that Hospice, the Cancer Society, and the wider health care system in general were Pākehā organisations. Yet, interestingly, none of the patient and whānau interviewees identified culture as a barrier to receiving palliative care once the services had been accessed.

The health literacy demands on patients and whānau were found to be substantial and complex, requiring problem solving and resourcefulness.

Three categories of health literacy demands were developed. These included the disease management focus of medicines and patient care, and the wider focus of navigating the palliative care system.

The emotional climate of palliative care may add another dimension to health literacy demands. The participants acknowledged the additional health literacy difficulties for patients and whānau that arose because of the shock, grief and anxiety associated with receiving palliative care services. These emotions, combined with the health literacy demands associated with intensive physical health care needs, created a complex health literacy environment.

Whānau caregiving was another factor that influenced the emotional climate in which health literacy occurred. Having a single spokesperson for the whānau increased the responsibility and workload for that person, and had the potential to create problems for that person. However, it was the perception of most non-Māori health care professionals that this was the method of communication preferred by patients and their whānau.

This study identified that some health professionals consciously used health literacy practices to ensure that patients and whānau felt able to access information and

support. These practices tended to have been developed by the individual and were not generally utilised in a systemic way, or recognised at an organisational level.

Patients and whānau used complex health literacy practices, which utilised a range of literacy and numeracy skills and included critical thinking and decision-making. These health literacy practices were used in spite of significant barriers generally related to a lack of effective communication. Utilising the skills and expertise of other whānau members was a way of ‘working around’ barriers and obstacles posed either by the system itself or by people working within the system.

Patients and whānau experienced poor communication on a number of occasions. However, whānau also identified aspects of good communication practices in palliative care settings which assisted whānau in providing optimal support to their loved one. Effective communication greatly enhanced the whānau experience of palliative care. Generally the whānau participants identified that individual health professionals were open and honest and tried to advise whānau of the reality of the situation. Patients and whānau found the following communication processes used by health care professionals effective in supporting them:

- ability to communicate 24/7 with health professionals, to ask questions and have their fears allayed
- established respectful rapport with patients
- practical training provided for whānau caregivers
- opportunity to have regular meetings with people providing care to patient to discuss progress
- whānau and health professionals all using a ‘communication book’ to record what was happening
- help with predicting future care needs.

Whānaungatanga, kanohi ki te kanohi, wairuatanga, and the availability of Māori kaimahi (health professionals or allied staff) were all identified as important components of an effective communication model for Māori patients and whānau.

A common theme from this research was the importance of effective navigation and/or advocacy roles to address some of the health literacy and access barriers. Called variously a navigator, kaiāwhina, or simply an extension of an existing role such as a nurse or social worker, where they had been involved in the care team, these people had made a big impression on the quality of care whānau experienced and received.

A research agenda which identifies and prioritises future research directions accompanies this document, to build on the insights from this qualitative exploratory study.

Nga Kitenga Matua - Key Points

- This was a qualitative, exploratory study that utilised a relatively small purposive sample that was broadly accessed and minimally defined; its purpose was to develop an understanding of health literacy in palliative care for Māori and to identify future research priorities.
- Māori patients tend to face barriers to accessing palliative care services for reasons relating to tikanga (customs and traditions, protocol), low health literacy, availability of services, health professionals avoiding or mismanaging the 'hard conversations' around the shift from treatment to palliative care, and the cultural character of specialist palliative care services.
- Māori patients and whānau had a range of health literacy practices that were effective and wide-ranging. However, health literacy demands are considerable and complex for Māori in the palliative care context and more research is required.
- Health professionals utilise effective individual strategies to help patients and whānau manage the palliative care environment, but these are not generally adopted at an organisational level.
- This study found that patients and whānau experienced poor communication on a number of occasions, but aspects of good communication were identified and could be built on, including being open and honest and advising whānau of the reality of the situation.
- This study found that there is inconsistency about whether palliative care is a positive experience for Māori, with patients, whānau and health professionals all reporting both positive and negative experiences.
- This, along with the reality that Māori are a diverse, flexible and changeable people (Reid 2005), means that generalisations about culturally effective healthcare cannot be made.
- A research agenda which identifies and prioritises future research directions is presented in Section Five in this document.

Section 1: Kupu Whakataki - Introduction

Health disparities for Māori have long been featured in health literature (Davis et al., 2006; Howden-Chapman, Blakely, Blaiklock, & Kiro, 2000), with strong evidence that Māori have disproportionately high incidences and mortality from life-limiting diseases such as cancer, cardiovascular, and respiratory diseases (Robson & Harris, 2007). Further, Māori rates for chronic 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).

Notwithstanding these statistics, Māori life expectancy is improving, and an increasing proportion of Māori are aged 65 years and older (Statistics New Zealand 2012). However the combination of high life-limiting disease rates and the predictions of an increasing aged Māori population suggest that Māori access to palliative care should also be increasing. This is compounded by the relatively recent development of primary palliative care services and a change in focus that extends palliative care beyond its previous focus on cancer care (Bellamy & Gott, 2013; Frey et al., 2013; Robinson, Gott, & Ingleton, 2013).

Addressing inequalities in Māori access to palliative care has been the focus of national policy (Minister of Health, 2001), but recent research has shown that the increased availability of culturally appropriate services has not increased access and utilisation by Māori (Moeke-Maxwell, Nikora, & Te Awekotuku, 2010).

The identification of low Māori health literacy (Ministry of Health, 2010) adds a new dimension to questions about Māori access to and utilisation of palliative care, particularly in terms of how such services are presented to Māori, and how they are perceived.

The research focus for this project was to identify, from a health literacy perspective, issues for Māori and their whānau in accessing palliative care services. This section provides a brief introduction to health literacy and palliative care (see Appendix One for a full literature review), and the set-up for the study. In Section 2, the methodology and research design are presented, followed by the research findings in Section 3, and discussion and conclusions in Section 4.

1.1 Palliative care

The World Health Organization (2011) defines palliative care as an approach that aims to improve the quality of life of patients and their whānau facing problems associated with life-threatening illness. It does this through the prevention and relief of suffering by means of early identification and applicable assessment and treatment of pain and other physical, psychosocial and spiritual problems.

Palliative care:

- provides relief from pain and other distressing symptoms
- affirms life and regards dying as a normal process
- intends neither to hasten nor postpone death
- integrates the psychological and spiritual aspects of patient care
- offers a support system to help patients live as actively as possible until death
- offers a support system to help family/whānau cope during the patient's illness and in their own bereavement
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated
- will enhance quality of life, and may also positively influence the course of illness
- is applicable early in the course of life-limiting illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

The New Zealand Palliative Care Strategy (Minister of Health 2001) recognised the need for:

- accessible and appropriate services for Māori
- strategy that builds on current service arrangements
- more responsive systems to support the choice of dying at home
- care coordination of services in conjunction with Māori providers of culturally appropriate palliative care services
- formal links with relevant service providers
- development of plans with local Māori to ensure appropriate access to services
- linkages between palliative care providers and Māori development organisations
- workforce planning.

The New Zealand definition of palliative care (Palliative Care subcommittee: NZ Cancer Treatment Working Party 2007) is:

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

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

Palliative care is further defined in terms of who is providing the care and to whom. This falls into two categories (Naylor 2012):

1. *Primary palliative care* (also called generalist palliative care, used in New Zealand since 2012) is care provided by individuals and organisations that

deliver palliative care as a component of their services, but their substantive work is not in the care of people who are dying. The key components are that the individual has a life-limiting or life-threatening condition and they are receiving palliative care as an integral part of standard clinical care by any health professional who is not part of a specialist palliative care team.

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

Internationally, palliative care has historically focused on the end-of-life stage for people who have cancer, but has been revised to recognise the applicability of palliative care early in the trajectory of all life-limiting illnesses (Sepúlveda et al 2002).

1.2 Health literacy

Health literacy is defined as “the degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions” (Kickbusch et al 2006, p.4). This implies rightly that the effects of health literacy relate to how an individual perceives messages. However, individuals do not operate in isolation from the context in which health messages are delivered, received and processed. Many skills are required for individuals to function effectively in the health care environment and act appropriately on health care information. These skills include the ability to interpret documents, read and write prose (print literacy), use quantitative information (numeracy), and speak and listen effectively (oral literacy) (Berkman et al 2011). Both content and context are important; for example, a person with advanced literacy skills may, in a different health context, have poor health literacy (Nutbeam 2009). The exchange of health information has been described as a complex process involving the provider, the health professional and the recipient, with consumers of health services seen as active receivers and seekers of information who also generate and synthesise information of their own (European Health Policy Forum 2005).

Health literacy has been conceptualised within two different approaches: seen either as a risk factor or as an asset. In the risk model, health literacy is conceptualised as a potential risk factor; for example, that lack of health literacy will act as a barrier to patients becoming compliant with treatment. Alternatively, it can be seen as an asset, where improved health literacy is an outcome of personal empowerment in decision making (Nutbeam 2008). The use of the risk model was prevalent in the United States, meaning there was an emphasis on more assessment of individual health literacy, but

recent literature pertains more to the use of an asset model which aligns closely with principles of adult education, where the patient's prior knowledge and experience is recognised (Workbase 2013).

People with poor health literacy skills are thought to be at greater risk of experiencing poor health status and poor health outcomes. Conversely, high levels of health literacy are likely to enable patients and whānau to take more responsibility for the management of their health throughout the continuum of care (Nutbeam 2000).

In New Zealand, *Kōrero Mārama* (Ministry of Health 2010a) has provided the background data that demonstrates, on a population basis, that Māori have poorer health literacy skills compared to non-Māori across all socioeconomic markers.

As health care systems become more complex, the health literacy demands placed on patients and whānau also become increasingly complex. The changing face of health care means that patients are now expected to have a more active role in their care, develop new skills to find and manage information, understand and manage their rights and responsibilities and make the best health decisions for themselves (Nielsen-Bohlman et al 2004). International evidence shows that patients' knowledge and skills are usually below those demanded of them by their health system (Rudd et al 1999; Rudd et al 2007). As Koh et al (2012, p.435) state, "a wide chasm often separates what providers intend to convey in written and oral communication and what patients understand".

The content and context of health messages is so complex that a person with high health literacy skills in one context may experience moments of poor health literacy in another. These episodes occur when patients and whānau find themselves dealing with a new context particularly where the patient is in very poor health (Nutbeam 2009). The physical and social environment of health care settings also influences the efficacy of health literacy (Rudd 2013).

This study drew on Rudd's schema of health literacy (Rudd et al 2004), which examines 'health activity' and 'focus' across the health spectrum, from 'health promotion' to 'systems navigation'. In her more recent work, Rudd (2013) identified the key components of health literacy as individual skills, health tasks undertaken, health materials used, skills of providers (including the 'oral exchange'), and the reciprocal physical and social environment (Rudd 2013). The identification of specific health literacy demands in a particular context can require a full evaluation of the range of activities involved in accessing information and resources, how decisions are made and actions taken, how procedures and protocols are implemented, as well as assessing the health literacy skill levels of the patients, whānau, and health professionals, and of the health service providers systems. This was outside the scope of this study, and also ethically inappropriate, in relation to the circumstances of people facing life-limiting illnesses.

Instead, this study seeks to provide an appropriate and meaningful exploratory analysis of the health literacy context for Māori in the palliative care environment. We have talked to Māori patients and whānau, health care professionals, and key informants about the level of knowledge of palliative care services within Māori communities; the characteristics of the communication of palliative care with Māori patients and their whānau; and the key factors which affect the ability of these patients and whānau to obtain, process and understand palliative care information and services and make informed decisions. We were interested in health professionals' perspectives on health literacy and palliative care for Māori patients and whānau, and what the health literacy demands of palliative care are as a snapshot of those demands. We collected examples of written information provided by different palliative care services providers and analysed these using a health literacy framework.

1.3 Literature review

A literature review was undertaken to address issues related to indigenous health literacy and palliative care. This review is based on literature pertaining to adults and utilises a person-centred, rather than system-oriented, view. The key findings of the review are presented here; the complete literature review is attached as Appendix One.

Assumptions

The Ministry of Health's *Statement of Intent 2010–2013* has a key priority area to “work on issues emerging as a result of New Zealand's ageing population: improving the health and independence of older New Zealanders” (Ministry of Health 2010b, p.12). This report focuses mainly on literature in the adult population.

Scope and methods

While Māori are reported from a population basis to have low health literacy (Ministry of Health 2010a) and low utilisation of palliative care (Minister of Health 2001), the approach in the literature review acknowledges the historical shift in health literacy literature from a concept of the individual ‘risky patient’ to a view that acknowledges health professionals, health service providers, and the health system as having a critical role to play in building health literacy (Nutbeam 2009).

The literature review focused on three aspects:

1. Identify systemic and professional barriers that inhibit utilisation of palliative care services by Māori
2. Explore how health literacy principles are incorporated into palliative care materials (including written resources, such as pamphlets, and resources on the internet, video, etc)
3. Examine health literacy interventions in palliative care for Māori and their whānau.

This section summarises the findings in each area.

1. Identify systemic and professional barriers that inhibit utilisation of palliative care services by Māori

It is recognised that generally indigenous peoples wish to die at home for a number of reasons. A home environment is related to the familiarity of being cared for by their family members, the 'circle of life' where they are born and die, gaining energy from family and community in moving across to the other side, and in receiving support for the family to enable caring to take place (Ngata 2005; Kelly et al 2009; DeCourtney, et al 2010; Hampton et al 2010). The move to palliative care units and hospices is identified as alien in terms of having rules and structures which may not effectively accommodate the needs of the indigenous patient (McGrath 2008; Hampton et al 2010). Notwithstanding visiting hours, the ability of specialist palliative care services to address the needs of indigenous populations is dependent on the knowledge and willingness of staff to 'allow' care to be provided in a culturally sensitive manner. The provision of caregiving by a family member in a hospital-like environment may conflict with health professionals who are reluctant to relinquish care or medical staff who may feel a sense of failure if supposed life-prolonging treatments are discontinued (Bellamy and Gott 2013). In addition, the availability of space for family members who wish to provide care is limited in some institutional settings. There remains a strong call for more indigenous health workers to be available to support health professionals who care for indigenous patients. The use of members of the target ethnic community in working alongside palliative care services has been successfully modelled in the US (Yeo 2009).

2. Explore how health literacy principles are incorporated into palliative care materials (including written resources, such as pamphlets, and resources on the internet, video etc)

Materials in palliative care, although only a small part of the health literacy context, were deemed to rate poorly due to the overuse of medical terminology. However, while using direct explanations and other cues to make the design more readable, such as bullet points and bold lettering, it is acknowledged that replacing medical jargon with plain language alone is not sufficient to improve health literacy (Kehl and McCarty 2012; Ministry of Health 2012). There were references to the use of additional forms of media such as video or the internet (Vollandes et al 2011). Videos/DVDs have some health literacy potential in the ability to view them more than once or share amongst family to also view. However, health information may focus primarily on tinana (physical manifestations of illness) and exclude information in relation to wairua (spiritual aspects), hinengaro (thoughts and feelings) and whānau (family/community aspects) which are of importance to indigenous populations. Internet use is increasing in younger populations and while an older person may not be familiar with internet technology, a younger relative may be able to support them. In addition, there is anecdotal evidence that the younger generation are using online communication

methods to advocate for older people, although the older person may be reluctant to complain/comment (M Parsons, personal communication, April 2013).

Depending on health literacy levels, using internet search engines may provide users with the answers to their questions or enable refinement of their questions. For health professionals, the use of the internet has the potential to allow users to be in charge of when, how and in which format information is received (Knapp et al 2011), although the inaccuracy of some internet material can create problems for health professionals who need to correct misleading information patients have found online (Lo and Parham 2010).

3. Examine health literacy interventions in palliative care for Māori and their whānau

Although we intended to view health literacy interventions through the lens of an asset model, no articles measured information flow as a two-way process (European Health Policy Forum 2005). There was a lack of research measuring the way in which health information was delivered, apart from some exploration of the usability of materials provided. Strategies were measured based on readability or numeracy or on health literacy levels of individuals. Further research is required to understand the skill base of health professionals when they convey health messages.

In drawing on the findings of this review, it is evident that the study of health literacy is still in its infancy in New Zealand. The understanding of how to better address health literacy from a health services perspective has been identified as a practical step towards improvement. Further studies are required to investigate the capacity and capability of health professionals and health care providers, and to support the development of skills based on adult learning principles and assessing the outcomes of these.

1.4 This study

In New Zealand, the Ministry of Health's (2010a) *Kōrero Mārama* survey report on Māori and health literacy argued that instead of viewing health literacy as an issue for individuals, with the responsibility on individuals to build their skills, the solution required a concerted effort from all sectors, including schools, government agencies and the healthcare system.

The overall objective of this research was to identify access issues for Māori and their whānau to palliative care services, from a health literacy perspective. By identifying these issues, this project was designed to contribute to better service delivery of palliative care and improved access to palliative care for Māori and their whānau.

Key areas of interest for the research were:

1. The ways in which Māori access palliative care services
2. Current levels of Māori health literacy with regards to palliative care

3. How different factors within whānau influence the ability of Māori to obtain, process and understand palliative care information and services
4. Identification of communication models which are effective in enhancing this ability.

Advisory group

An advisory group of Professor Ross Lawrenson, Associate Professor Merryn Gott, and Associate Professor Robyn Dixon provided expertise and support for the study, including feedback on this report.

Sister project

Another Māori health literacy and palliative care research study *Hei Manaaki Ngā Kaumātua* was carried out by Rauawaawa Kaumātua Charitable Trust Research Team.

Both projects were part of a Palliative National Joint Work Programme 2012 for Hospice New Zealand, the Ministry of Health and Palliative Care Council.

Section 2: Rautaki Mahi - Methodology

2.1 Research design

This project uses a qualitative kaupapa Māori methodology, a methodological approach that incorporates a set of principles that reflects the theoretical approach underpinning and informing the research process (Bishop 2005; Smith 2005; Cram et al 2006). The principles are:

- location within the wider context of tino rangatiratanga (self-determination). In the context of research this principle encompasses control of research and research processes, participation in all levels of research, and the delivery of information that will contribute to Māori development and autonomy
- connection with Māori philosophy and values and the incorporation of Māori attitudes, language, and ways of living in the world
- awareness and critique of the dominant accepted norms, assumptions, and power relationships and how these serve to maintain the 'status quo' that privileges the dominant (non-Māori) community and maintains disparities between Māori and non-Māori
- the legitimacy and validity of Māori world views are taken for granted and seen as the norm; kaupapa Māori research seeks to understand Māori knowledge and experience on its own terms
- that research moves Māori from the margin to the centre, allowing Māori concerns to be addressed, and providing information that addresses our self-identified priorities.

2.2 Recruitment

In September 2012, hui were held at the Whakatane Palliative Care Forum, Waipuna Hospice (Tauranga), Mercy Hospice (Auckland), Hospice Eastern Bay of Plenty and Hospice West Auckland to introduce the study and ask for support to identify Māori patients and whānau who could be approached to participate in the study. At the same time, we asked health professionals to participate in focus groups, and as part of that process we also identified key informants amongst the health professionals. Additional health professionals were recruited through formal and informal workplace networks. Details of the participants follow.

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

Patients and whānau, whose details were supplied to us or who indicated to their palliative care service provider that they wished to participate in the study, were individually contacted by a Māori interviewer to consent to their participation. The participant information sheet, and consent form (in both English and te reo Māori) are attached in Appendix Four.

2.3 Data collection

Interview questions for all participants (patients, whānau, focus groups and key informants) were based on the objective and four key areas of focus identified in the Request for Proposal. Interview schedules are attached in Appendices Four and Five.

Patients and whānau

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

Where patient and whānau quotes have been included in this report, each participant who participated in the group is named by their relationship to the patient; for example (wife and daughter). In all cases the quote refers to one palliative event about which the whānau carers were talking.

Interviews were conducted by Māori researchers. The semi-structured interviews generally took place in the homes of participants, whether in Auckland or the Bay of Plenty, and took between 30 minutes and 2 hours. All but one of the interviews were recorded and transcribed.

During the patient and whānau interviews, we gathered information on the way they used palliative care services, how they obtained information about the services, what the positive aspects of the palliative care services provided were and what could be improved.

The term 'health literacy' was not used with patients and whānau as it is a new term and not well known by the general public. Instead, proxy terms such as 'communication' and 'information' were used.

All but one of the interviews were recorded and transcribed.

Palliative Care Providers

Ten focus groups were held involving 54 people from organisations providing palliative care services. Focus groups were facilitated by both Māori and non-Māori researchers.

Focus groups took place with staff from four hospices, two Māori palliative care providers, one primary healthcare service, GP practices, the Cancer Society, and one general hospital. Of these groups, seven provided specialist palliative care services and three were primary palliative care providers.

The focus groups were well attended, with 15 participants in one group. Generally the focus group size was approximately five people. In all the focus groups except one, there was a mixture of nurses and other health professionals. One focus group was exclusively comprised of specialist nurses working in a secondary palliative care service.

The main criterion for participating in a focus group was that the health professionals participating were involved in providing primary or specialist palliative care.

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

A copy of the focus group information letter, consent form and interview schedule are attached in Appendix Five.

All focus group interviews were recorded and transcribed.

Data about the 54 participants in the focus groups are set out in Table 2.

Table 1: Health professional participants

Number of People in Focus Group	Service Type
9	Māori provider
8	Hospice
6	Māori provider
5	Hospice
3	Māori provider
1	Medical centre
4	Hospice
5	Hospice
8	Hospital specialist team
5	Cancer Society

Focus group participants came from a range of disciplines. There were nurses, including cancer nurses, students, palliative care nurses, clinical nurse specialists, team leaders and nurse practitioners; General Practitioners (GPs) and clinicians; health psychologists, counsellors, social workers and chaplains; kaumātua, kaiāwhina,

kaitakawaenga, kaiatawhai and navigators; and managers, administrators and coordinators.

During the focus groups, some participants who were health professionals also spoke of their experiences of providing palliative care as whānau carers rather than as health professionals. From a kaupapa Māori perspective, this reflects that whānau have a number of roles, including as professional carers, members of a whānau providing care for another whānau member who is dying and/or as advisors to other whānau carers in similar situations. One patient attended a Māori service focus group with her caregiver.

Key informants

Semi structured interviews were completed with six key informants: a medical specialist, a service leader involved in developing culturally specific responses to patients, two Māori service managers, and two Māori health team leaders. These participants were chosen to bring a management focus and a broader overview of the palliative care service environment to the research.

The semi-structured interviews were carried out by Māori and non-Māori researchers. A copy of the interview schedule is attached in Appendix Five. All key informant interviews were recorded and transcribed. Key informants were asked similar questions to the focus groups: perspectives and understanding about Māori access to palliative care services; perspectives on health literacy demands; and how services and health professionals took these demands into account when delivering palliative care services to Māori patients and whānau.

Data about the key informants is set out in Table 3.

Table 2: Key informants

Key Informant	Discipline
1	Māori service manager
2	Non-Māori service leader
3	Māori health team leader
4	Māori service manager
5	Māori health team leader
6	Non-Māori medical specialist

Key informants came from a range of service providers including District Health Boards (DHBs), hospices and cancer services.

Written resources

Written resources are used by palliative care providers to inform patients and whānau of the range of services available. These resources represent a critical health literacy

demand placed on patients and whānau. Palliative care providers were asked at focus groups and key informant interviews to supply written information about palliative care services that providers give to Māori patients and whānau. This information was used as a snapshot of the health literacy demands placed on patients and whānau when accessing palliative care services.

A total of 42 written resources from palliative care providers located in the Bay of Plenty and Auckland were reviewed. The following provided information:

- 4 hospice organisations
- 1 DHB
- 1 Whānau Ora provider
- 1 nursing services provider.

A list of the resources assessed is attached as Appendix Two. The resources aimed to explain palliative care services and consumer rights to patients and whānau, and were evaluated according to criteria such as vocabulary, apparent purpose and audience, inclusion of Māori concepts, readability and resource type. The evaluation process is outlined below in 'Written resource analysis'.

2.4 Data analysis

Interviews were transcribed and anonymised for analysis. A general inductive approach was taken to analysing the interview and focus group data (Thomas 2006) to allow the dominant and significant themes to be interpreted. This approach was chosen because of its specific focus on analysing exploratory and evaluative data which have been shaped by a straightforward set of aims and objectives. Our analysis was guided by the research aim of understanding Māori patient and whānau access to primary and specialist palliative care services from a health literacy perspective.

The interview transcripts were analysed to elicit key concepts and recurrent themes. The key concepts and themes were drawn out by referencing the main objective and key areas of interest of the study, as well as new issues that were noted in the data. A detailed index of codes (categories with short text descriptors) was developed and the transcripts coded and re-coded manually until all the transcripts had been completed satisfactorily. The codes were then organised into themes reflecting the key areas of focus.

Data from each participant group, patients and whānau, health professionals, and key informants were given equal weight during the analysis with the same process followed for all. As the themes were developed, it became clear that there was generally consistency across all three groups. Where differences emerged, this has been highlighted in the findings section.

As mentioned earlier, during the focus groups some health care professionals spoke of their experiences as whānau carers and one patient attended a focus group with her caregiver. Throughout the report, we have identified whether data came from Māori health professionals or Māori health services wherever this was clearly identified by the participants, but Māori also attended the hospice and hospital focus groups so quotes from those sources cannot be presumed to be non-Māori.

Rigour

Trustworthiness and reliability of the general inductive approach was tested by sharing transcripts among the research team, and using an agreed framework of codes and definitions to ensure coding consistency. This was further tested by sharing analysed texts among some of the research team both individually and through two hui to discuss the findings.

The categories and themes were taken back to the research communities in a series of five hui for discussion and validation in March and April 2013. These hui were well attended, and generated more stories, which were consistent with the categories rather than producing additional data. None of the categories were challenged by the hui attendees, who generally approved of the themes that had been developed from the data.

Written resource analysis

The 42 written resources that had been collected from palliative care providers located in the Bay of Plenty and Auckland were analysed using criteria derived from Ministry of Health (2012) and Workbase (2013) reports on aspects of health literacy and education. These focused on aspects such as:

- how clear, or implied, the purpose of the resource was
- the audience for the resource, whether specified or implied
- resource type
- the point in the palliative care process at which the resource was accessed
- readability
- vocabulary
- language and text features e.g. layout, white space as well as use of visuals (which help create contextual meaning)
- inclusion of Māori concepts and values, such as referring to Te Whare Tapa Whā.

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

For some resource writers, the cornerstone of resource development is readability. A number of writers refer to adult New Zealanders reading at the 'reading level' of a 7 to 10 year old. These sorts of generalisations are neither accurate nor helpful. Adults are not children and using children's reading ages to determine how to write patient

materials gives a false sense of security. These reading ages are based on vocabulary, for example what vocabulary a 7 year old might be expected to read. Adults with low literacy skills may have smaller reading vocabularies than some children. However, adults have greater life experience than children, and therefore are more likely to understand conceptual matters involving complex vocabulary if properly explained to them.

Readability formulae produce readability scores which measure two things – sentence length and number of multisyllabic words. Readability formulae are based on the premise that long sentences and words with multiple syllables are harder to understand. To reduce readability scores (the higher the readability score, the harder to read the document is thought to be), short sentences and single syllable words are recommended.

In health situations, it is not possible to eliminate commonly used multiple syllable words such as palliative, services, and information. Shortening sentences and replacing multiple syllable words will not guarantee that a reader will make sense of the text. In a health context, it may be more useful and relevant to have a ‘higher’ readability score because required terminology is included and explanations of those terms are provided. Readability has a place in reviewing documents. Using everyday language and common words where appropriate is a good idea. However, readability alone will not ensure that a resource is easier to understand or is useful.

Assessing health literacy

The health literacy skills of individual patients and whānau who participated in this research were not formally assessed. However, we did identify a list of health literacy demands (generated by data collected from patients, whānau, focus group participants and key informants), which need to be confirmed with further research.

The decision not to assess individual health literacy levels was based on a number of factors. The most commonly used assessment tests (Rapid Estimate of Adult Literacy in Medicine and Test of Functional Health Literacy Assessment) have been critiqued for being generic, focused on reading only, and for taking a deficit view of patients (Workbase 2013). The deficit model of health literacy, where patients are judged as posing risks to health professionals and health care organisations, has been largely overtaken by a systems approach, defined as an understanding that health literacy is ‘an interaction between the demands of the system and the skills of the individual’ (Nielsen-Bohlman et al 2004) and that health professionals and healthcare organisations have a role in building health literacy, both by reducing the health literacy demands placed on individuals and by building individuals’ health literacy skills (Koh et al 2012).

The Single Item Literacy Screener (how frequently people get assistance with reading written materials) (Morris et al 2006) was used as part of the patient and whānau interviews. However, we decided not to use the data collected from this question as

palliative care service providers had already advised us that their written materials were not easy to read and we had confirmed this when analysing the materials supplied.

We also had a proxy measure of health literacy in that, from a population basis, 75% of Māori women and 80% of Māori men have low health literacy (Ministry of Health, 2010a).

2.5 Ethics

Ethical approval was given to this project by the Multi-Region Ethics Committee, reference MEC/12/EXP/050.

2.6 Limitations

This was a qualitative, exploratory study that utilised an appropriately small purposive sample that was broadly accessed and minimally defined. This means that:

- There was no assumption of ‘representative’ or ‘population sampling’; the research was specifically aimed at in-depth exploration of the views of participants in the palliative care system, especially in relation to Māori, not at trying to make ‘objective’ generalisations. Further research may build on this qualitative base to explore larger group samples.
- The ‘opt-in’ recruitment strategy used for patient and whānau participants (in that participants chose to respond to information about the research and opt in to participating) means that it is possible that the whānau who responded to a request to participate in the study had extreme experiences (either good or bad) of palliative care services.
- Focus group participants were not specifically asked to identify their ethnicity or profession, so conclusions cannot be drawn about Māori-specific or profession-specific viewpoints among the health professionals. In hindsight, collecting such data would have been useful for the analysis, although transcribing with this level of accuracy about each speaker would have been challenging.
- Primary and specialist health professionals were not identified separately, which has reduced the clarity around access and practice issues.
- Some focus group participants spoke about their experiences as whānau carers, but this was not always able to be captured separately. Furthermore, a patient and caregiver attended one focus group as participants. These were not counted in our patient and whānau numbers.
- This study did not involve direct observation of interactions between palliative care providers and patients and whānau. This was not the purpose of the research, and would have required very different ethical and logistical considerations, but may have added to the richness of the findings.
- Recommendations from the study require further research to confirm.

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

Uniformity of focus group data

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

Section 3: Nga Kitenga - Findings

The findings from this study have been organised into the following themes: accessing and utilising palliative care services; health literacy demands; health literacy practices; barriers; and navigating the palliative care system. In addition, three areas of findings were identified as ‘stand-alone’ categories: the discussions that took place among health professionals about the concept of health literacy in practice (section 3.1), the analysis of written resources (3.2), and communication processes (3.8).

Verbatim quotes from anonymised transcripts are included to illustrate themes and categories, from numbered patient and whānau interviews (denoted with relationship of carer to patient included), focus groups (denoted with type of service and location included), or from key informant interviews (denoted with role and location).

This study did not seek to evaluate Māori satisfaction with palliative care services, and there was just a single sub-question that asked patients and whānau to comment on the strengths of their involvement with palliative care services. However, it is interesting to note, to set the scene of the findings, that most of the patients and whānau reported positive experiences with their provider(s), particularly in relation to particular health professionals and the provision of equipment.

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

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

But they immediately – it was almost like “Well, grab your supermarket trolley, we’re going out the back and we’re piling everything we can fit in your truck.” Every possible thing that we think you’ll need or will need, or might need, we’re gonna put in there and . . . our sun room became the ‘any-sort-of-medical-equipment-you-could-get room’ for about, it must have only been about three weeks. (Wife & step daughter)

Three whānau discussed very distressing experiences of poor care, all of which involved general hospital care rather than specialist palliative care.

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

It is noteworthy that although the patients and whānau identified a generally positive palliative care experience, many of the findings indicate that care was less than ideal. This is discussed further in the final section of this report, and is identified as a topic requiring further research.

3.1 Health professionals' concepts of health literacy in practice

During the focus groups and key informant interviews, healthcare professionals engaged in conversations about their understanding of health literacy. Discussions included health literacy as a component of communication between the health care professional and the patient and whānau, and particularly the need to engage effectively:

. . . engage where they're at or their level of education and understanding and knowledge . . . and that's different for each person. (Hospital-based service Auckland)

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

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

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

Some health care professionals reflected on the challenges to their existing practice, particularly:

. . . developing our own ability around communication skills. (Hospital-based service Auckland)

. . . learning to listen, not always talk . . . (Māori health professional Auckland).

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

The participants acknowledged the additional health literacy difficulties for patients and whānau that arise because of the shock, grief and anxiety associated with receiving palliative care services. These emotions, combined with the health literacy demands associated with intensive physical health care needs, create a complex health literacy environment.

In this next quote, a participant describes very well the complex health literacy demands placed on patients and whānau and the role of the health professional:

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

3.2 Written resource analysis

The review of the written resources supplied by palliative care providers found that the resources reviewed used formal language and structures (e.g. did not use direct language such as 'you' or 'we'), were passive in tone, included unfamiliar vocabulary without explanations, had high readability scores and contained large blocks of text. Sometimes the audience and the purpose of the resource were clear. In other resources, they were implied or absent.

Some texts had good headings and subheadings which assisted in navigating the text to find particular information. However, in some cases, the lack of white space and the difficult vocabulary made the resource difficult to read, notwithstanding good headings.

A number of terms, such as 'complementary therapies', were used in materials without explanation. Other terms were conceptual or required whānau to infer what the terms might mean—for example, integrity, respect, 'circles of support', and 'practical matters'.

Few publications referred to Māori values and concepts. Those that did were resources developed by two organisations, one a Māori provider and the other a palliative care services provider which had a Māori staff member.

A number of hospices provided 'communication books', which were supposed to help facilitate clear communication processes by enabling all health care professionals, patients and their whānau write notes and questions in the one place. One had a sticker on the front cover with the 24 hour contact numbers for the staff. None of the books included examples of how whānau could use the communication book.

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

But all the handouts and everything, the booklet and that came well before he was diagnosed. Yeah, so that when they first came out to assess him, when they first got the call, that's when all the information came. (Wife & daughter)

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

Consent forms were evaluated as being particularly difficult to understand. Some of the forms contained information about services the hospice did not provide, including information about social services and enduring power of attorney.

Participants generally agreed that the efficacy of written resources relied on the quality of the relationship between the patient and whānau and the health professional, which needs to be characterised by effective communication (discussed further in section 3.8).

Health professional and key informant interviews suggested that providing an opportunity to discuss resources at times might be quite difficult.

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

Yeah I mean education is a huge component of our work. . . . therefore one could assume that we should be spending the majority of our time educating, but the clinical demands [are too high]. . . (Hospital-based service Auckland)

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

The nurse does the initial visit and she will give the patient and whānau an information booklet, or folder with lots of different – It will have the agreement to care in it and it will have information about the service and they will talk about all the different aspects of the service and do an initial assessment. (Social worker Auckland)

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

Often you give people lots of stuff to read, but when you go back the next time, not only can they not find it, they don't even know that they've had it and I do feel as though it's a burden for them often. It's a really big ask for them to get through a

whole lot of written material when they're struggling with complexity and often sudden bad news. (Hospice BoP)

The findings from these two categories are revisited throughout the following themes, and are particularly useful in understanding the context of health literacy demands and patient and whānau responses to these.

3.3 Accessing and utilising palliative care services

This theme includes the pathways experienced by our patient and whānau participants, the timeliness of their referral to palliative care, health literacy demands, and disease management literacy. This latter term refers to the specific knowledge and skills required to carry out assessments and tasks related to the patient's medical needs.

Access pathways

As already noted, the New Zealand definition of palliative care is:

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

1. Optimise an individual's quality of life until death by addressing the person's physical, psychosocial, spiritual and cultural needs.
2. Support the individual's family, whānau and other caregivers where needed, through the illness and after death. (Palliative Care subcommittee: NZ Cancer Treatment Working Party 2007)

Achieving these aspirations relies on a number of factors, including access to palliative care and the timeliness of referrals, as well as the overall provision of palliative care services. This part of the report looks at access and timeliness of referrals.

An overview of the details of referrals and services accessed by 15 of the participants is set out in Table 4. Not all participants wanted to discuss access pathways, and the interviewers did not insist on the information.

Table 3: Individual patient pathways and services accessed

Source of Referral to Palliative Services	Community-based Palliative Services accessed	Hospital-based Palliative Services accessed
Hospital	Hospice home visits Patient already had equipment	Specialist care
Self-referral	Hospice home visits, respite, 24/7 availability and equipment Pastoral community nursing in hospice	Specialist care
Hospital	Limited hospice care, as ineligible whilst under specialist care Pastoral Community nursing	Specialist care, no referral for home follow-up after discharge from hospital
Hospital	Hospice initial home visits, 24/7 availability and equipment – bed, wheelchair, and walking frame Ambulance – 24/7 availability Rest home for final month of life	Oncologist Chemotherapy
General Practitioner (GP) /Hospital	GP consultation and advice Hospice home visits, 24/7 availability and equipment Home help	Specialist care Chemotherapy
Cancer navigator	GP consultation but poor advice Chiropractor advice Nebuliser (Asthma Foundation) Hospice provided some equipment, and made 2 home visits Other equipment hired by whānau	Specialist care
Whānau member a health professional	Hospice daily home visits – pain relief injections, 2 hour day stay and longer respite options offered Equipment: chair, mattress, personal care item provided, shower rail procured from other whānau Physiotherapist home visit, exercises but no home assessment.	Specialist care

Source of Referral to Palliative Services	Community-based Palliative Services accessed	Hospital-based Palliative Services accessed
Established relationship with Hospice service	Hospice initial home visits daily then twice daily, 24/7 availability and equipment – bed, ripple mattress, training for primary caregiver, journal writer provided	Surgeon – specialist care Use of bathing facilities in the hospital
Hospital	Hospice home visit to support caregiver	Team of specialists
Self-referral	Hospice provides social activities, 24/7 advice, Social service support on-site Home help Equipment already provided by other services	Team of specialists
Nurse	Hospice provides social activities, 24/7 advice, community nurse	Unknown
Emergency Department admission, referral to Palliative Care nurse then to Hospice	Hospice 24/7 advice, home visits, pain relief medication, equipment although bed did not arrive in time, and cultural advice and support	Unknown
Hospital referred to Hospice in an effort to avoid hospital admissions	Hospice in-patient care, monitor and control nutrition and exercise, provided training in administering medication Community programme provided regular social interaction	Unknown
Official referral was too late, but Hospice were notified by Hospital	Hospice home visits, 24/7 availability and equipment – chair lift and bathroom equipment Whānau purchased walking frame	Specialist care
Hospital Social Worker	Hospice provided some equipment, but this was returned when patient improved. Later, GP made referral for more equipment – bed with monkey bars, trolley, wheelchair, bed pans.	Specialist care

Timeliness of referral

Most whānau and health care professionals expressed frustration and grief at the lack of timeliness of patient engagement with palliative care services. Some whānau were referred very late to palliative care services and the patient often died within a short period of time following the referral. This occurred in one case notwithstanding the fact that the patient had a long term condition and was frequently hospitalised. The following quotes illustrate three different scenarios related to late access to palliative care. The first relates to a delay in the initial diagnosis of life-limiting illness, the second quote refers to a lack of referral from a tertiary medical service, and the third refers to whānau resistance to receiving palliative care.

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

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

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

The reasons for these delays were not discussed within this study, but indicate the need for further research into the points where timeliness is affected.

This finding of late referral is consistent with the literature (Davis 2006; Ministry of Health 2013), but requires further analysis to ascertain the systemic, organisational, individual and whānau influences on lack of timely access to health services for Māori. Some of these are discussed later in the report as internal factors that act as barriers for whānau.

3.4 Health literacy demands

We did not directly ask patients and whānau what health literacy demands were placed on patients and whānau because the term is relatively unknown. We did ask patients and whānau what they had to do to find out information. We directly asked health professionals about the health literacy demands placed on patients and whānau. Three categories of health literacy demands, based on Rudd and colleagues (2004) schema, were developed from both explicit statements made by patients and whānau, health professionals and palliative care service providers, as well as implicit references from

patients and whānau. The categories were medicines, providing care to the patient, and navigating the palliative care system.

Each category was divided into knowledge and tasks. The knowledge component is where patients and whānau had to “obtain, process and understand information” (Ministry of Health 2010a) about palliative care, either from health professionals, palliative care services providers or other sources. The task components were the tasks that patients and whānau reported they had to do to meet the health literacy demands of palliative care services.

The health literacy demands were found to be substantial and complex, requiring problem solving and resourcefulness on the part of patients and whānau. A full list is provided in Appendix Three.

The emotional climate

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

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

I was trying not to cry. There was a stage I said, “It’s not the nurses’ fault. I’m not blaming them.” I’m exhausted and am struggling to look at the nurse. I’ve become teary. I’ve tried so hard not to cry in front of my beautiful father. (Daughter)

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

How the whānau choose to approach the responsibilities of caregiving is another factor that influences the emotional climate in which health literacy occurs. This is particularly important during communication with health professionals about the care and treatment of the patient. Having a single spokesperson for the whānau increases the responsibility and workload for that person, and has the potential to create problems for that person. However, it is the perception of some health care professionals that this is the method of communication preferred by patients and their whānau.

And I said to her, "Really you cannot do it on your own. You need the whole lot of ya . . . I've been through there. I've been through it. I've done it, and I'm telling you, involve as many as you can. Don't take it on yourself." Yeah, but it's a hard yakka. (Daughter)

Yeah well I would personally ask who's the spokesperson and try and find that person each time . . . and I've spoken to the wrong person inadvertently. And because that person identified themselves as a spokesperson but the actual whānau hadn't, so that's a challenge as well. Yeah. (Hospice Auckland)

Very recently we had this woman who was the spokesperson for the whānau who was an in-law and she felt really responsible and she had to make a decision and I can't remember what it was, but we said to her, "Our role here is to support you. If you feel – you could blame us, you could blame us – that whatever was decided, you could bring it back to the hospital as the outlet." But she was really relieved and you could almost see the tension on her face, particularly being an in-law. (Hospice BoP)

I did think about what you were saying before about information filtering through the family and I think often for us in the larger whānau especially that we do try and identify one spokesperson to then filter that information through to others. And obviously we're only speaking to one person, but identifying the person that the whānau identifying the person that is to be the main spokesperson and then giving them a lot of information, but then encouraging them to talk with the rest of the whānau (Hospice BoP)

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

In the whānau context, all members are potential caregivers. This first quote below refers to a mokopuna helping the whānau to come to terms with the new reality of a kuia with cancer, while the second quote refers to practical care provided by a mokopuna to a koroua in hospital.

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

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

These next quotes provide some information about the challenges faced by whānau and the levels of resiliency that are needed when responding to health literacy demands.

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

Hard as. Hard, hard, hard. And when I think back in the days when we did it [caregiving] 10 years ago or so – we had the big whānau that would come and give you a day. Everyone was around. Now everybody's so busy trying to work and keep their jobs, I find that the whānau are smaller now, so that support is not there. (Māori health professional BoP)

I try and go to sleep but then people come in and then especially you've got to keep an eye on for the ones that she. . . Cos she's one that wouldn't let anyone just touch her, even her hand, and so if certain people visited, you have to stay up. And then they had to come and get me cos the family got to a stage they wouldn't give her medication, cos she was saying, "No, no," rejecting all of them. So I says, "Oh well, I'll just do it." So they left that to me and when she got in pain quite a bit, so I had to kind of stay up. (Cousin)

The tension around whānau caregiving in the home, and wanting support but also needing to respect the patient's desire to remain independent is highlighted by this comment:

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

Reducing health literacy demands

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

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

Sometimes you can get a bit engrossed in your paperwork and not be sort of looking . . .but I think it is really important to just be aware of how they're feeling and know when to push on and when to draw back really. (Hospice BoP)

They say in hospice that you have to be really careful, you can't just throw all the information at people . . .Our nurses are really good at not forcing information that they don't want. (Hospice Auckland)

Many of the health professionals, Māori and non-Māori, described individually adapting their practice in a culturally competent way to help patients and whānau achieve greater confidence in their service provider and greater skill in utilising the service.

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

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

Health professionals and key informants discussed their understanding of the health literacy demands on patients and whānau, with some actively making efforts to build health literacy.

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

Reducing health literacy demands needs to be an active, purposeful process driven by the health care organisation (Rudd 2013). These health care professionals have demonstrated ways in which they worked as individuals, but there were only a few examples in this research to demonstrate that the building of health literacy skills by health professionals was supported by their health care organisations.

3.5 Health literacy practices

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

Patients and whānau reported the use of a wide range of health literacy practices required in order to meet the health literacy demands placed on them in the context of palliative care services. These health literacy practices were identified from explicit statements made by patients and whānau. The health literacy practices most commonly used by patients and whānau in this study were that they sought support from whānau and friends, maintained written records, researched information, read written information, dispensed medicines, advocated on behalf of patients, and interpreted unspoken messages. Each will now be outlined in more detail. .

Seeking support from whānau and friends

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

I was just full on, 24 hours, and I ended up sleeping right through to about half past nine I think it was and mum needed to go toilet and I wasn't up, she couldn't wake me up. So it was pretty much then I called one of my mates . . . She was an ex-nurse at a Medical Centre . . . she come over and she brought a social worker over to have an interview with me and then I was telling her and sharing with her, this is what I do, and I hadn't slept and I ended up sleeping and my mum needed to be cared for and she couldn't wake me up. And then we had a meeting and they ended up bringing in another person. (Daughter)

There was some evidence in this study to show that whānau members were used in this way because whānau carers felt more comfortable talking to someone they knew and who they perceived was more knowledgeable about the system. There was also

evidence that patients and whānau used other whānau members for advice because the patients and whānau were not provided with information to enable them to understand how the different parts and players in the palliative care system worked together.

There's always somebody that knows somebody who's just been through it. It's that sort of korero, and you look after each other. And there's sometime . . . they'll find often it's the nurses in the whānau or an advocate in the whānau. "Ah, yeah, I'll ring up the blah blah – she'll know what to do." . . . and they say, "Oh, no, no, no, no," you know, "we did this. You got to go try this, this and this." "Yeah, we'll do that," and they're talking to each other and they're looking after each other. Our whānau have been through it. If you've been through it, you've got all the information to share. And we all know who's doing what at the marae. They'll say, "What did you do when this happened?" So we are talking to each other now and giving each other advice, sharing – sharing the love, sharing the resources, sharing the care. (Māori health professional BoP)

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

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

Maintained written records

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

- to inform other whānau members who were living at a distance and so were not intimately involved in caring for the patient
- to make sense of the different information that was being provided to whānau

I kept a diary every day of what the doctors and nurses said. I needed to do that to make sense for me and my family. (Wife)

- to keep records of medications and other treatments

Yeah, somebody taught me how to – it was my sister-in-law again, this is what . . . And because everything had to be, before the blister packs . . . Everything had to be written down so you knew what pill it was, which – how many, yeah. (Daughter)

We had a red big folder, bag thing, where if you asked us for any medical records, anything, prescription slips, we got it all organised in tabs. So what do you want? Okay, we'll find you those results. If H studies anything, he studies it to down to the point where he could perform surgery on himself. (Wife & daughter)

- to prevent health professionals from giving incorrect medicines

Because they got to read it and note who was coming in to see mum and what were they saying about mum and how she was reacting. Even writing down what she looked like. [laughs] . . . They'd switch the nurses. Yeah. The staff nurses had been switched. So a new lot would come in and they were trying to give her something else, some other medication, but it wasn't for her – it wasn't for that time, it was for later on. So I could say, "Oh no no, that's not her medication. That's not what she's supposed to be having right now. (Daughter)

- as a whānau resource for others who might take on a carer role

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

When my mum passed away, my mum's sister ended up getting cancer too, so I passed the book [diary] on to my cousin saying, "Take notes from here cousin, so that you know . . ." (Wife)

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

When Dad's fistula popped open, we went to the A and E and waiting . . . Waiting, waiting, and the registrar comes in. And he said, "Oh Dr R's in a meeting. I've just come here to just check . . . All the surgeons have got a meeting right now. I'll be back in an hour". And we said, "Is Dad going to be okay?" . . . He goes, "Oh, look, I've got my meeting and I've got to go. He should be okay". And so my sister, I mean, we were exhausted and here she's like, "Should be okay? What does that mean? Is somebody going to help us here at the hospital or what?" So I started writing down and I think I looked at the time and I wrote down the time and he goes, "Oh, what are you writing from me? You make people nervous when you write." And actually I had that said to me by about three people at the hospital. And he goes out and he come back in and he goes, "Oh, it's 2 o'clock now. I'm having my lunch. Do you want to write that down too?" (Daughter)

Researched information

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

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

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

There is the potential for such internet information to lead to more informed dialogue between patients and doctors (Knapp et al 2011), however the literature also suggests that doctors have concerns about the accuracy of information gleaned from the internet, which can change consultations to include debunking inaccurate or misleading information (Lo and Parham 2010).

Read written information

Most of the patient and whānau participants did not report that they received information from the written resources. This health literacy practice was specifically mentioned by only two whānau, and the second whānau read the information in retrospect.

I picked up [pamphlets] in the hospital while I was caring for mum. I just started reading them. Yeah, most of the services that we had, I had gotten from pamphlets or had asked . . . (Daughter)

It's quite funny, because a couple of weeks ago my sister asked me to come over – she didn't know whether we needed to keep all this information [after Mum's death] and there was a file there from hospice. We were looking at it and I actually started to read it there and then, but I didn't read it at the time. (Daughter)

Dispensed medicines and used medical equipment

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

He developed a chest infection and it got so bad he would be in agony and we'd be calling [the GP] on the phone saying, "Should we be calling the ambulance, should we do something?" and he's like "Well give some paracetamol," . . . In the end we got the ambulance . . . We took him up to the hospital and during that process we got in contact with the Asthma Foundation and got him a nebuliser . . . we did this

ourselves. Not through the hospital, or [the GP], not through anyone. (Wife & step daughter)

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

Advocated on behalf of patient, with health professionals and healthcare providers

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

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

Interpreted unspoken messages

An aspect of health literacy that is not discussed in the literature is the ability of patients and whānau to draw inferences from events and actions taken by health professionals. In this first quote, the whānau used the proposed appointment as an indication of life expectancy when they felt otherwise uninformed about when death might occur.

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

It was more what they weren't saying as opposed to what they were saying. (Wife & daughter)

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

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

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

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

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

These quotes indicate the importance of health professionals understanding the power and uses of non-verbal communication, and the interpretations patients and whānau can place on apparently routine actions such as arranging a future appointment. This is an area which requires further research to understand.

Some of the patients and whānau used these health literacy practices in spite of significant barriers put in their way by both individual health professionals and healthcare providers. Generally these barriers related to failing to communicate fully with whānau and failing to acknowledge the considerable knowledge and expertise about the patient which whānau had developed through providing continuous intimate care to the patient.

3.6 Barriers

This study identified barriers experienced by patients and whānau, and reported by health professionals, while navigating the palliative care system. These barriers were generally grounded in poor health literacy and had the effect of restricting access or utilisation of palliative care.

Access barriers for whānau

Previously we described the ways patients and whānau access palliative care services. This study also explored potential barriers to accessing these services.

As demonstrated in Table 4, access to palliative care services occurred through a variety of means for this sample. Further to these pathways, participants noted that patient and whānau perceptions of palliative care and hospice impacted on their ability and willingness to access services. These two whānau had their concerns allayed once they had agreed to access hospice care:

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

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

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

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

But to take them into hospice, they prefer not to. They prefer to look after them at home. That is what I'm trying to say here. Nine times out of 10 . . . [the whānau] would prefer to take them home and look after them, not go in to hospice. (Māori health professional Auckland)

Reasons for the reluctance included the “misconception that palliative care is very much inside a hospice or inside a hospital – not something that can be delivered in the community” (Māori health service BoP), and that to accept palliative care was to accept that death was imminent.

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

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

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

Other perceived reasons for avoiding palliative care included stigma and a lack of accurate information about what was involved.

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

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

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

Sometimes going to palliative care was just too complicated; patients were confused by increasing amounts of information that was often inconsistent or incomprehensible, and were too ill to have the energy to do something new.

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

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

Interviews with health professionals explored perceptions of what might make it difficult for Māori patients and whānau to access palliative care services. Some of these were based on personal and/or work experiences, and others were put forward as perceived barriers given the complexities of working in this field and with this cohort. A common theme was that their colleagues in non-palliative care settings such as hospital wards, specialists, and primary care avoided having 'hard conversations' with patients and whānau about the change in focus from treatment to palliation. This created situations where patients and whānau were poorly prepared for palliative care.

Many of the nurses who participated in the focus groups had stories about helping patients to overcome a fear of hospice as 'the place to die'.

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

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

Cultural barriers

During discussions about the cultural identity of services among all the health professionals and key informants, there was a clear perception that Hospice, the Cancer Society, and the wider health care system in general are Pākehā organisations; 'white, female and middle-class'. Although this perception is demonstrated to be inaccurate in some aspects of this report, the statement was clearly articulated in all the hospice focus

groups, the Cancer Society and the GP focus group. It was also discussed as a barrier to access in the Māori service focus groups and among the key informants.

I can understand some seeing hospice as very sort of European middle-classed-focused, and I strongly believe that we have to break that down, not only in terms of inpatient hospice but right through the community. (Medical specialist BoP)

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

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

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

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

The perceptions of Māori communities and whānau about the ability of hospice and other palliative care service providers to deliver care which is culturally competent and appropriate for Māori was also in doubt.

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

Processes and environments that acknowledge a Māori worldview were seen as largely absent from many palliative care services. For example there was little reciprocity in the relationship, and attendance at groups was controlled by the service provider.

Like you say, when Māori come into a situation like this, they are very mindful of the fact that this is, well, being in a Pākehā world where hospice is concerned and Māori have their own protocols, so when hospice comes into play with Māori in this sort of way, Māori tend to take a back step and sort of nut things out before they commit themselves to doing anything. (Kaiatawhai, Hospice Auckland)

I think if it was an open house type thing, and let people know that, then you can just drop in for a cup of tea, instead of having to belong to a group. . . And you see hospice gets everything. They get baking done for them . . . Well you know, when I was growing up, we had to take a plate, whether it be a bread and a butter, and that's the thing. I think hospice has got to let them bring what they want to bring,

instead of saying, "Oh no no, it's alright, they've got it all here." That's not the issue. The issue is, this is something I brought to share. (Patient & husband)

Many of the health professionals demonstrated a level of helplessness about effecting changes that would benefit Māori. This extended to service-level issues where Māori staff were either not recruited or were not viewed as intrinsically important to the service.

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

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

I think one of the barriers is that our workforce is not culturally diverse enough in palliative care, and yeah, I've spoken to a few nursing leaders about this over the years and I think that we should be doing some sort of purposeful recruitment, because I think our workforce lacks cultural diversity. (Hospital-based service Auckland)

Some of the focus group discussions demonstrated a lack of empathy that could be considered structural racism. All of the following quotes originated from different focus group participants.

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

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

I think there is a difference for Māori. . . I think health literacy for everyone's really important, it's about ensuring the other person understands, it's about talking in a simple language . . . But for Māori sometimes I think it's ignorance of wanting to

know, by not going to the doctor hence late presentations – the fear of what is, yeah. (Hospice BoP)

It was also clear that some palliative care organisations were not collecting ethnicity data as per census guidelines which was a barrier to provision of culturally competent care.

That is another thing to take into consideration, working with whānau. You are going to get blue eyed, blond headed Māori and that is the way it is now, so never underestimate the whānau values. (Māori health service BoP)

For me it's very, very limited because I can't identify sometimes whether these people are Māori or not . . . I don't get that information because it's not in our access sheet. (Hospice Auckland)

Interestingly, none of the patient and whānau interviews identified culture as a barrier to receiving palliative care once the services had been accessed. This is discussed further in the next section.

External barriers to health literacy

Earlier sections in this report focused on factors within (internal to) whānau which influenced their health literacy skills around palliative care. However, this study also identified that there were a number of factors external to whānau (either generated by health professionals, palliative care service providers or the palliative care system itself) which directly interfered with and acted as barriers to whānau building their health literacy skills around palliative care. Of key importance were communication barriers:

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

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

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

In summary, the findings from this study suggest that patients and whānau who are motivated for a range of reasons will develop health literacy in particular contexts (in this case palliative care) which are relevant and important to them. These findings are consistent with both adult education principles (Knowles et al 2005) and adult literacy studies (Sticht et al 1987)

We did not specifically ask patients and whānau whether they were already using these practices in other contexts before transferring the practices to the palliative care context. Nor did we ask patients and whānau whether they had transferred these practices into other health care contexts e.g. optimal use of asthma medication and devices.

3.7 Navigating the palliative care system

A common theme from this research was the importance of effective advocacy/navigation to address some of the health literacy and access barriers. While advocacy was discussed above as a health literacy practice involving utilising whānau and friends, this section relates to a specific function provided by palliative care services. Called variously a navigator, kaiāwhina, or simply an extension of an existing role such as a nurse or social worker, these people act as advocates and system navigators and appeared to have made a big impression on the quality of care whānau experienced and received. The following quotes illustrate the range of perspectives from whānau experiencing a navigator role, to a health professional observing a navigator, a navigator service describing what they do, and another health professional noting the full extent of what the navigator offers.

[The navigator] took – like I was trying to take notes and then she just took my book and she just – so I could listen, she did all the notes for us and I really appreciated that. And by the time I got my book back she had all the phone numbers in it, she had everything I needed, yeah. . .always like keeping a step ahead of us. Like she knew what questions we didn't know to ask, and she knew that soon we would be needing certain services, and she would make sure that contact either had been made by herself to set up contact – so that they would contact us or she would give us the information and we would contact them. . .She was saying, "Do this now, don't wait till it gets worse, so that you've got a rapport with these people before you need them". (Wife & step daughter)

[The navigator] was actually talking to the rest of the team and documenting that [the treatment plan] is something that is distressing to the family. (Hospital-based service Auckland)

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

The role of the navigator involves being called at home at 8 o'clock at night or at 10 o'clock at night and being told we're having trouble and being expected to access care. (Medical specialist BoP)

Attending appointments with patients and whānau formed a key part of advocacy, ensuring that information was effectively communicated because “people feel overwhelmingly intimidated by health professionals and the language that’s being used and may not really understand what’s going on” (Hospital-based service Auckland).

Sometimes you go with them to their appointments, to their GP, oncologist or whoever and it’s about translating the information for them, generally what the diagnosis is and what the prognosis is. (Māori health service BoP)

They like to read a [pamphlet] so we take them information on that [chemotherapy and radiotherapy] and I mean that is pretty hard to understand so we sit there and go through it with them. They are terrified of going to their first treatment, so we go with them. We meet them before they walk in the door. (Māori health service BoP)

Advocacy was extended to accessing social support such as Work and Income appointments, and intervening when schools became concerned about a child’s absence during the final stages of life for a parent or grandparent.

3.8 Communication processes

Many aspects of the themes above have some relationship to the topic of communication. It is an important topic, so is included as a separate theme here. Patients and whānau found the following communication processes used by health care professionals were effective in supporting them:

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

The good thing about it is that they had this whiteboard and it told you who was on, and like from the social worker right down . . . we could talk to any of them about if we had like a question or anything. They were nice. . . And the thing about them was that they were quite straight up with you, which was even better. That’s what you sort of need when you – so you can sort of prepare yourself and all of that sort of stuff so yeah. Even though it was scary, it was still good. (Daughter)

There were certain times that I needed [the nurse] to explain to the family. And they were pretty much there within half an hour. (Cousin)

- established respectful rapport with patients

Oh the way she spoke, the way she interacted with us . . . she was really lovely, really informative . . . He was happy with her. She went right through the medication . . . saying that he can increase that whenever; there won’t be any problems with it. (Wife & daughter)

- training provided for carers

So the nurses taught T what to do [morphine], which is really good, cos it was one on one so it was easy for her to understand as well. (Daughter)

The people from hospice came out and explained [to the whānau] what needed to be done and what I found was the fact that they showed them how to handle the patient, what to do, and how they should be treated and even how to wash them, and they took all that in and that helped my family heaps, it was fantastic. (Hospice Auckland kaumātua)

- opportunity to have regular meetings with people providing care to patient to discuss progress

Once a week you could call a meeting with everybody who's looked after mum and then we can all group together and see what's going on and how's it all going? (Daughter)

- communication book to record what was happening

Because they got to read it and note who was coming in to see mum and what were they saying about mum and how she was reacting. Even writing down what she looked like [laughs]. (Daughter)

- help with predicting future care needs

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

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

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

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

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

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

During the discussions and descriptions related to communication processes there was considerable overlap among accounts from patients and whānau, and health professionals. There was general agreement that finding ways to effectively communicate within each extended care team was a key part of having a good palliative care experience for Māori.

Culturally appropriate communication

Māori health professionals and some of the patients and whānau participants identified dimensions of culturally appropriate communication and care that were critically important for Māori. It is interesting to note that few patients and whānau discussed the detail of culturally appropriate communication; their attention remained on the more clinically focused points described above. It is the impression of the interviewers that the cultural component of whānau-health professional communication was inherent in the successful processes described above. This impression could be tested in future research. The dimensions of culturally appropriate communication that were identified by Māori health professionals are outlined in the following section.

Whānaungatanga

Whānaungatanga contains many aspects; our participants particularly discussed two of them. The first was the process of becoming known to one another, which was discussed as a key factor in the acceptability and cultural safety of service delivery. The second aspect of whānaungatanga mentioned was the development of an ongoing relationship between the patient, whānau, and health professionals.

When we meet, it's whānaungatanga – whakawhānaungatanga is the most important thing. (Māori health professional Auckland)

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

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

You can't, with a new referral go in and talk cancer straight away in the first thing. It might not be until the third or even the fourth visit that you can start talking about the cancer. You have to develop that trust and respect first before you can start talking about their mamae, their hurt, before you can talk about it. (KI1: Māori manager BoP)

Kanohi ki te kanohi

The most common means of communicating among all the participants was through kanohi ki te kanohi (face-to-face conversation). This was identified as being particularly important for whānau.

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

Kanohi ki te kanohi . . . so vital for Māori. It is really important that you sit and talk to someone. (Māori health professional Auckland)

Te hora o te whānau i te māramatanga - Whānau sharing knowledge

Participants acknowledged the strength to be found in sharing knowledge and experiences.

There's always somebody that knows somebody who's just been through it. It's that sort of kōrero, and you look after each other. And there's sometime . . . they'll find often it's the nurses in the whānau or an advocate in the whānau. "I'll ring up blah blah – she'll know what to do." . . . Our whānau have been through it. If you've been through it, you've got all the information to share. And we all know who's doing what at the marae. They'll say, "What did you do when this happened?" So we are talking to each other now and giving each other advice, sharing – sharing the love, sharing the resources, sharing the care. (Māori health professional BoP)

Oranga wairua - Spiritual care

Spiritual care or wairuatanga is a dimension of care that was included by whānau as key to their engagement in healthcare.

When [the chaplain] came, dad had been fighting death, fighting for every breath, not giving in. The chaplain asked what type of karakia did we want? I knew there would be no miracle. I asked for a karakia to give my father a safe journey to heaven. The karakia or prayer began and I felt my father's body ease. I felt him relax. I believed this karakia helped my dad pass over and I am grateful for this. (Daughter)

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

The spiritual aspects of Māori health, Māori death, and of palliative care have been well addressed in the literature (for example, see Durie 1994; Fairbairn 2002; Paley 2008; Moeke-Maxwell et al 2010). The relevance of spirituality to the health literacy context has not yet been researched. Rudd (2013) calls for careful examination of impact of the social environment on health literacy; this research and the literature suggests that wairuatanga should be viewed as an area of potential impact on health literacy for Māori.

Nā Māori, mā Māori - By Māori, for Māori

Palliative care provided by Māori afforded patients and whānau a different level of engagement. Participants agreed that there was a “*cultural divide there . . . care is better managed by Māori for Māori. . . So much of what we do is about relationships, and if you've got a relationship with somebody, if they've got the relationship with [Māori], you've got that conduit.*” (GP BoP)

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

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

Sometimes you hear, “I wish there were more Māori nurses”, “I wish there were Māori . . .” . . . for Māori sometimes there's just a look and it's an understanding that words cannot say and you just, I don't know, have that connection. I'm not saying it happens in all cases. I mean even I get challenged, even from kuias, the old, yeah. But I think if your heart's in the right place and you know why you're there . . . (Māori health professional at a Hospice focus group BoP)

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

Māori care did provide challenges, however, in terms of the close connections of whānau.

For myself as Māori, some [patients] are family and I've had to say several times that what's said between you and I stays here. Yes I know that you might be related to my family, but I'm working here and what we say stays here unless there's some safety thing for you, then I need to talk to somebody. And that conversation I have to have quite often . . . that's the other side of Māori. (Hospice, Māori nurse BoP)

The communication processes identified by these participants is consistent with much of the literature that examines culturally appropriate healthcare for Māori (Durie 1998; Cram et al 2003; Cormack et al 2005; Jansen et al 2008; Kidd et al 2013).

3.9 Summary

Māori access to palliative care took many forms, from self-referral through to high level specialist referrals. Some whānau experienced significant difficulties with access to appropriate care. Whānau and health professionals reported that when referrals occurred very late in the illness process, the patients, whānau and service providers did not have time to engage, negotiate the health literacy demands, access satisfactory support, or make arrangements for their preferred death experience. Late referrals to palliative care were also reported to increase distress for health professionals.

Reasons for late access and/or late referrals included individual patient and whānau perceptions that accepting palliative care was synonymous with accepting imminent death, and that hospice might hasten death.

Patients and whānau demonstrated a wide range of health literacy practices in order to meet the health literacy demands placed on them in the context of palliative care services. Some of the patients and whānau used these health literacy practices in spite of significant barriers put in their way by individual health professionals, palliative care providers, and referring services. Practices which improved health literacy included those categorised as internal to the whānau, such as accessing friends and resource people who could assist with navigating the palliative care environment, and initiating and maintaining written information records that were passed on to health professionals and extended whānau.

The health literacy demands associated with palliative care were acknowledged to be wide ranging and complex. Whānau were negotiating the acquisition of new knowledge and skills within a context of shock, grief and loss. While recent research suggests that

Māori have low health literacy, whānau who participated in this study demonstrated high level health literacy practices including finding and understanding information, navigating the health care system by utilising resource people, and keeping written records of their experiences. Whānau were often faced with complex health care systems and barriers with health professionals, which may have at times undermined the effectiveness of their health literacy practices.

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

External barriers influencing health literacy in palliative care settings included the quality and context of information transmitted by health professionals, cultural considerations including the perception of hospice and the Cancer Society as non-Māori organisations, and the presence or absence of advocates or navigators.

Effective communication for whānau participants involved respect for the knowledge held by whānau, plain speech, and a willingness to have the 'hard conversations' that accompanied the move from treatment focused care to palliative care.

Whānaungatanga, kanohi ki te kanohi, wairuatanga, and Māori service providers were all identified as important components of an effective communication model for Māori patients and whānau.

Section 4: He matapakinga me he whakatepe - Discussion and conclusion

Health literacy is a function of the demands and expectations placed on the patient by the health care system as well as by the patient's disease processes (Sudore et al 2009), and has been described as an interactive practice rather than an individual skill set (Workbase 2013). Health professionals and health service providers have a critical role to play in health literacy. In this section we discuss the findings with reference to the literature, maintaining a broad focus on patient and whānau, health professional, and organisational or systemic views.

4.1 Access

Late access, difficulties with access, and late referral to palliative care were all identified in this study as issues for the participants. The outcome of these was similar, with inadequate time for patients and whānau and their service provider to engage, negotiate the health literacy demands, access satisfactory support, or make arrangements for the patients' preferred death experience. Late referrals to palliative care were also reported to increase distress for health professionals.

The mechanisms around late access and late referral may variously relate to tikanga, lack of knowledge or misunderstandings about the availability and uses of palliative care (low health literacy), availability of services, the clarity and timeliness of 'hard conversations' with health professionals about the shift from treatment to palliative care, and the cultural character of palliative care services.

Tikanga

Tikanga (cultural values) such as restrictions on who may physically touch the body can lead to Māori patients and whānau to resist or refuse health care (Kidd et al 2013). Although there is no large scale or generalisable research into Māori preferences about dying at home, these participants and international literature tend to suggest agreement with the view that dying at home is a preferred option for Māori. For example, Canadian and Alaskan research identified that indigenous people prefer to be cared for by relatives (Kelly et al 2009; DeCourtney et al 2010), and a New Zealand study highlighted the necessity for spiritual, emotional, moral and physical support for the dying person and their family (Ngata 2005). The odds of Māori dying at hospice are lower than for NZ Europeans (Frey et al 2012), but the exact reasons for this are not clear. The place of tikanga in health care, and the preferences for place of death for Māori are areas that require further research.

Attributes of blame for having a terminal illness are attributed to self or ancestral wrongdoings – a sort of payback (Ngata 2005) which may inhibit family from seeking palliative care. This may lead to additional stress on the patient who may be unwilling to talk about their disease for fear of bringing shame to the family and community

(Shahid and Thompson 2009). Furthermore, refusing care may be as a result of acceptance; that they are bearing the pain to protect their families from further suffering caused by a 'curse' or payback.

The extent of Māori refusing or avoiding palliative care for reasons of tikanga is not known; culturally appropriate research is required to increase understanding and to enable services to adapt their care accordingly.

Low health literacy

This study found that some patients and whānau were reluctant to accept palliative care because they understood that such services were only available as an inpatient; believed that the purpose of hospice care was to hasten death; and believed that to accept palliative care was to accept that death was imminent. Many of the health professionals had stories about helping patients to overcome a fear of hospice as 'the place to die', which were consistent with New Zealand research (Frey et al 2012). This perception may be a barrier to utilising the services provided, especially where families are still wishing to remain positive (Bellamy and Gott 2013).

The study also found that some patients and whānau did not know of the existence of such services until they were confronted with a referral. The level of health literacy is likely to be a factor in whether a referral to palliative care is accepted, with people who have low or marginal health literacy more likely to prefer treatment focused care than palliative care (Volandes et al 2008). A recent New Zealand study confirms that this finding occurs across other cultures in addition to Māori, and recommends public profiling of hospice with education and information provision to strengthen community involvement (Bray and Goodyear-Smith 2013).

Service availability

All our patient and whānau participants were in receipt of specialist palliative care, even those who lived in relatively remote areas of the Bay of Plenty, largely because of the mobility of hospice care in the region. GP and Māori primary care providers in both regions were also involved in care delivery. However, access to specialist palliative care services in rural areas has been acknowledged as a concern (Minister of Health 2001). Many Māori live in rural areas of NZ or return to their ancestral/tribal home when terminally ill, meaning they may be disadvantaged in their access to specialist palliative care services (Lawrenson et al 2010).

The full extent of the impact of regional gaps in palliative care for Māori is not known.

'Hard conversations'

This study found that the willingness and ability of health professionals to have the 'hard conversations' that accompany illness and death had an impact on the health literacy of patients and whānau. Where those conversations were not held or lacked clarity, whānau reported feeling overwhelmed and under-informed about their options and how to help their family member. This also had an impact on their access to

services, with some whānau not realising that choices were being offered, and others resisting palliative care referrals because of preconceived ideas.

The move from active treatment to palliative care has been described as transitioning from a space of closed awareness, to one focusing on treatment and side effects only, to open awareness where the limits of medicine are acknowledged and end-of-life planning is openly discussed (Wittenberg-Lyles et al 2011).

This study did not explore whether these hard conversations occur (or do not occur) in the same way in primary, specialist or general (pre-referral) health care settings.

Although a NZ study found that a traditional Māori belief system about the inevitability of death made conversations about end-of-life care less difficult for staff (Bellamy and Gott 2013), health professionals can struggle with decisions to change the direction of care from active management to palliative care (Morita et al. 2005; Wittenberg-Lyles et al 2011; Bellamy and Gott 2013). An Australian study suggested that GPs lack confidence in talking about death and dying (Burgess et al 2004), while another New Zealand study found a lack of knowledge among acute hospital staff about how to care for a dying patient (Sheward et al 2011).

For health professionals, caring for a person of a different culture can bring about its own anxiety (McGrath 2000). A lack of physician and nurse awareness of traditional beliefs held by the community regarding death was a barrier to care in a study of remote communities in Canada (Westlake Van Winkle 2000; Hotson et al 2004).

This finding highlights the need to understand how to teach and support health professionals to work with people who have life-limiting illnesses, particularly at the point where active treatment changes to palliative care.

Cultural character

This study found a clear perception by all participants that Hospice, the Cancer Society, and the wider health care system in general were Pākehā organisations; 'white, female and middle-class'. The perceptions of Māori communities (reported by Māori health professionals and key informants) and whānau about the ability of hospice and other palliative care service providers to deliver care which was culturally competent and appropriate for Māori was also in doubt.

Some of the focus group discussions demonstrated a lack of empathy that could be considered structural racism (Jones 2000), while many of the health professionals demonstrated a level of helplessness about effecting changes that would benefit Māori.

Certain rules were evident in some hospital or hospice settings which may conflict with the cultural requirements towards the end of life. For example, visiting hours and policy around whom and how many can visit could be at odds with this concept. For Māori, seeing people while they are still alive is important: extended family brings with them their spirit, life spark, collective concern, love and sympathy (Ngata 2005). While none

of the organisations in this study imposed visiting hours for people receiving palliative care, most of the participants from inpatient settings reported difficulties with space and resources for extended whānau over time.

Interestingly, none of the patient and whānau interviews identified culture as a barrier to receiving palliative care once the services had been accessed. This may reflect a bias in our sample because all the patient and whānau participants were identified by hospices. However, the perceptions and importance of culture for patients and whānau who either choose to engage or avoid engaging with palliative care services is not known and requires further research to understand.

The overall finding of late referral or late presentation is consistent with the literature (Davis et al 2006; Ministry of Health 2013), but requires further analysis to ascertain the systemic, organisational, individual, whānau and cultural influences on timely access to health services for Māori.

4.2 Health literacy demands

The health literacy demands were found to be substantial and complex, requiring problem solving and resourcefulness on the part of patients and whānau.

Three categories of health literacy demands, based on Rudd and colleagues (2004) schema, were developed. These are the knowledge and task components of the disease management focus of medicines, patient care, and the wider focus of navigating the palliative care system. A larger, more targeted study is required to confirm these categories.

The emotional climate of palliative care may add another dimension to health literacy demands. The participants acknowledged the additional health literacy difficulties for patients and whānau that arose because of the shock, grief and anxiety associated with receiving palliative care services. These emotions, combined with the health literacy demands associated with intensive physical health care needs, created a complex health literacy environment.

Whānau caregiving was another factor that influenced the emotional climate in which health literacy occurred. Having a single spokesperson for the whānau increased the responsibility and workload for that person, and had the potential to create problems for that person. However, it was the perception of most non-Māori health care professionals that this was the method of communication preferred by patients and their whānau.

A survey of New Zealand GPs identified the need to involve whānau in the management of Māori patients needing palliative care by identifying the key people within the family (Lawrenson et al 2010). In some cases, identifying the decision-maker in the family is a matter of health professionals simply asking who it is (DeCourtney et al 2010). In contrast, whānau caregivers discussed how stressful and difficult it could be to be the

‘identified person’. Larger multi-dimensional studies may help to identify appropriate ways for health professionals to work with whānau.

4.3 Reducing health literacy demands

This study identified that some health professionals used individual processes to ensure that patients and whānau would feel able to access information and support. In particular, they described ‘front-loading’ time to ensure that when patients were first referred, relationships were actively created to support an effective learning environment when patients were first referred.

The perceptions of some health professionals were that decision making was easier and more effective when patients and whānau already had some knowledge about palliative care.

Providing education is a fundamental health professional intervention that is ideally both empowering and culturally sensitive for those in hospice and other end-of-life care settings (Cagle and Kovacs 2009). However, many health professionals are likely to have been taught to provide education in a ‘top-down’ fashion (with health professional as powerful expert) that bears little resemblance to the principles of adult education (including shared collaborative knowledge) that form the foundation of health literacy (Nutbeam 2008).

Studies of current health literacy content in professional training programmes and assessment of their efficacy would ensure that future generations of health professionals are competent at recognising and reducing health literacy demands for patients and whānau.

4.4 Health literacy practices

Health literacy practices are the actions that patients and whānau take to meet the health literacy demands. Health literacy practices involve the use of health literacy skills such as reading, writing, speaking, listening and numeracy as well as critical thinking and decision-making (Nutbeam 2009).

This study found evidence of patients and whānau using complex health literacy practices, which utilised a range of literacy and numeracy skills and included critical thinking and decision-making. These included:

- Seeking out and utilising whānau and friends for information, support and advocacy
- Researching information, especially on the internet
- Reading written information
- Maintaining written records
- Dispensing medicines (including using syringe drivers and naso-gastric tubes)

- Advocating on behalf of patient with health professionals and healthcare providers

These health literacy practices were used in spite of significant barriers generally related to a lack of effective communication. Utilising the skills and expertise of other whānau members was a way of ‘working around’ barriers and obstacles posed either by the system itself or by people working within the system.

Some participants described feeling frustrated at the lack of clear explanations from health professionals, and turned to the internet to find the information they needed. There is the potential for such internet information to lead to more informed dialogue between patients and doctors (Knapp et al. 2011), however the literature also suggests that doctors have concerns about the accuracy of information gleaned from the internet, which can change consultations to include debunking inaccurate or misleading information (Lo and Parham 2010). Research shows a positive correlation between internet searching and health literacy for older people (Lam and Lam 2012), so it would be useful to understand how the internet is changing the health professional-patient dynamic and how health professionals can take advantage of the increasing availability of health information. It is not known how the internet could affect Māori health literacy in palliative care, but clearly a number of whānau participants in this study were accomplished internet users.

These palliative health care literacy practices could be viewed as being in contrast to the finding of low levels of general health literacy for Māori found in *Kōrero Marama* (Ministry of Health 2010a). Explanations for this could include that people receiving or caring for people in palliative care may be more motivated by the presence of life-limiting illness to develop health literacy; that the motivation of these particular participants had resulted in high levels of health literacy and would have been measured as such (sample bias); or alternatively that there are systemic barriers in the health care system that prevent the translation of health literacy practices into high levels of measureable health literacy, so no matter how many health literacy practices the whānau employ there is a barrier to achieving measurable health literacy for Māori.

The suggestion that patients and whānau are motivated to improve their health literacy by the important diagnosis of life-limiting illness is consistent with both adult education principles (Knowles et al 2005) and adult literacy studies (Sticht et al 1987). Further studies are required to engage health professionals and health care providers in developing skills based on adult learning principles and assessing the outcomes of these.

It is not known whether patients and whānau were already using these practices in other contexts before transferring the practices to the palliative care context. Nor do we know whether they subsequently transferred these practices into other health care contexts, although given the value placed on information from other whānau members or friends who had been through palliative care situations, we might assume they were

also transferring information and health literacy practices to others facing palliative care.

A systematic review of health literacy identified that health literacy can be a mediator of racial disparities in health outcomes (Berkman et al 2011). Despite a plethora of health literacy literature emerging in the past decade, this area remains emergent in New Zealand and requires further research.

No patients and whānau reported using an advanced care planning directive or living will, nor did health professionals discuss these. This is an area for further research to establish the usefulness of such devices.

4.5 Communication

This study found that patients and whānau did not always experience good communication and, in fact, experienced poor communication on a number of occasions. A recent New Zealand study identified patients' and families' dissatisfaction with the quality and type of information provided; understanding of language used; ways of being informed about patient's condition; poor communication of 'bad news'; staff lacking the skills to have these difficult conversations; staff not available to provide updates; and always being reactive rather than proactive around providing information (Robinson et al 2013). The experiences of patients and whānau in this study were consistent with all these examples of poor communication.

However, whānau also identified aspects of good communication practices in palliative care settings which assisted whānau in providing optimal support to their loved one. Effective communication greatly enhanced the whānau experience of palliative care. Generally, the whānau participants identified that individual health professionals were open and honest and tried to advise whānau of the reality of the situation.

Patients and whānau found the following communication processes used by health care professionals were effective in supporting them:

- ability to communicate 24/7 with health professionals, to ask questions and have their fears allayed
- established respectful rapport with patients
- practical training provided for whānau caregivers
- opportunity to have regular meetings with people providing care to patient to discuss progress
- communication book to record what was happening
- help with predicting future care needs.

Whānaungatanga, kanohi ki te kanohi, wairuatanga, and the availability of Māori kaimahi (health professionals or allied staff) were all identified as important components of an effective communication model for Māori patients and whānau. The

spiritual aspects of Māori health, Māori death, and of palliative care have been well addressed in the literature (for example, see Durie 1994; Fairbairn 2002; Paley 2008; Moeke-Maxwell et al 2010). The relevance of spirituality to the health literacy context has not yet been researched. Rudd (2013) calls for careful examination of impact of the social environment on health literacy; this research and the literature suggests that wairuatanga should also be viewed as an area of potential impact on health literacy for Māori.

The communication processes identified by these participants was consistent with much of the literature that examines culturally appropriate healthcare for Māori (Durie 1998; Cram et al 2003; Cormack et al 2005; Jansen et al 2008; Kidd et al 2013).

Written resources

The review of the written resources supplied by palliative care providers found multiple problems. For example, they tended to use formal language and structures, were passive in tone, included unfamiliar vocabulary without explanations, had high readability scores and contained large blocks of text. Few publications referred to Māori values and concepts.

Some services provided a lot of information to whānau all at one time (in a folder or envelope), and often different types of documents (e.g. information and instructions) were combined without making it clear when there was a transition from one type to the other.

Health professional and key informant interviews suggested that there were often conflicting needs to engage with the patient and whānau, conduct an initial assessment, and provide mandatory information such as Health and Disability literature as well as an agreement to receive care. Finding an opportunity to discuss resources at times could be quite difficult. A systematic review that focused on single or multiple literacy-directed interventions (Sheridan et al 2011) reported that presenting only essential information improved comprehension in individuals with low literacy and numeracy compared with providing essential and non-essential information.

In this study, the combination of effective, culturally relevant communication processes along with written materials was found to be the most valuable means of improving health literacy, although further research is recommended to confirm this finding.

4.6 Systemic or organisational health literacy practices

This study found that some health professionals were individually building health literacy with their patients, but there was little evidence of palliative care service providers using systemic approaches to reducing health literacy problems (DeWalt et al 2011).

There is a growing appreciation that health literacy does not focus solely on individual skill (Nielsen-Bohlman et al 2004), so reducing health literacy demands needs to be an active, purposeful process driven by the health care organisation (Rudd 2013).

Researchers have argued that the interventions required to ensure organisations have the attributes to be health literate include: having health literacy integral to core values; integrating health literacy into planning, evaluation, and quality improvement; workforce preparedness; allowing and integrating population input; meeting the needs of the population; using health literacy strategies in communication and confirmation; providing easy access to navigate health information and services; utilising easy to understand design and distribution of materials; prior identification of high risk situations for health literacy; and communicating clearly about costs (Brach et al 2012).

Individual practices to build health literacy could be systematised and applied on an organisational level, although further research would be required to evaluate their efficacy for patients and whānau.

Navigators

A common theme from this research was the importance of effective navigation and/or advocacy to address some of the health literacy and access barriers, whether by whānau and friends or as a specific palliative care services function, provided by navigators, kaiāwhina, or out of existing roles as nurses or social workers. The systemic provision of a navigator role has the potential to improve health literacy and reduce health literacy demands for patients and whānau. Variations of the navigator role have been successfully implemented in a range of New Zealand health care settings (Dohan and Schrag 2005; Freeman 2006; Doolan-Noble et al 2013). A trial of such a role would provide evidence of efficacy and satisfaction levels for Māori in the palliative care context.

4.7 Conclusion

This was a qualitative, exploratory study that utilised a purposive sample that was broadly accessed and minimally defined; its purpose was to develop an understanding of health literacy in palliative care for Māori and to identify future research priorities.

Māori patients tend to struggle with access to palliative care services for reasons relating to the importance of maintaining tikanga whilst accepting health care, low health literacy, availability of services, health professionals avoiding or mismanaging the 'hard conversations' around the shift from treatment to palliative care, and the (sometimes misperceived) cultural character of specialist palliative care services.

Health literacy for Māori in the palliative care context is a complex topic which can be more effectively understood with further research. Health literacy demands are considerable, with patients and whānau utilising varied health literacy practices to meet the demands. Health professionals utilise individual strategies to help patients and

whānau manage the palliative care environment, but these are not generally adopted at an organisational level.

This study found that patients and whānau experienced poor communication on a number of occasions. However, whānau also identified aspects of good communication practices in palliative care settings which assisted whānau in providing optimal support to their loved one. Effective communication greatly enhanced the whānau experience of palliative care. Generally the whānau participants identified that individual nurses were open and honest and tried to advise whānau of the reality of the situations they faced.

This study found that there was inconsistency about whether palliative care was a positive experience for Māori, with patients, whānau and health professionals all reporting both positive and negative experiences. This, along with the reality that Māori are a diverse, flexible and changeable people (Reid 2005), means that generalisations about culturally effective healthcare cannot be made.

A research agenda which identifies and prioritises future research directions is presented in the next section.

Section 5: Research Agenda

Life-limiting illnesses do not have to mean the end of being involved with whānau and enjoying day to day life. Palliative care services exist to improve the quality of life of patients and whānau facing the problems associated with life-limiting illnesses. Their focus is on affirming life and providing relief from pain and other distressing symptoms. Palliative care is provided according to an individual's need, and may be suitable whether death is days, weeks, months or occasionally even years away.

Palliative care aims to optimise an individual's quality of life until death by addressing the person's physical, psychosocial, spiritual and cultural needs, and support the individual's family, whānau and other caregivers where needed, through the illness and after death (Palliative Care subcommittee: NZ Cancer Treatment Working Party, 2007).

Māori life expectancy is improving, and an increasing proportion of Māori are aged 65 years and older (Statistics New Zealand 2012). This, combined with high rates of chronic and life-limiting illnesses (Robson and Harris 2007), low levels of health literacy (Ministry of Health 2010a), and inequalities around healthcare access (Cormack et al 2005; Crengle, et al 2005), means there is a growing need to understand access to palliative care provision for Māori.

Experiencing a life-limiting illness does not remove the patient from the national strategic aim for improved wellbeing for Māori (Minister of Health and Associate Minister of Health, 2002), or from the need to involve patients and whānau in service delivery planning.

Two projects were commissioned by the Ministry of Health and the Health Research Council of New Zealand Māori Health Joint Venture programme to explore the issue of Māori, palliative care and health literacy, and to determine the health research priorities that will contribute to improved access for Māori to palliative care services and to improved palliative care health literacy.

This project was led by the University of Auckland in partnership with UniServices, Workbase, and the Māori and palliative care communities in the Bay of Plenty and Auckland. Organisations that supported and contributed to the research included Waipuna Hospice, Kaitiaki Nursing Service, Hospice Eastern Bay of Plenty, Kimihauora, Western Bay of Plenty PHO, Mercy Hospice, Hospice West Auckland, Te Whānau O Waipareira, Auckland DHB Palliative Care Team, and the Auckland Cancer Society.

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

The vision that informed the research was of patients and whānau receiving timely and effective palliative care in a way that suits their needs and feels safe to access. **Principles** underpinning the research included 1) an integrative approach to the problem of low health literacy for Māori that views health organisations, health professionals, whānau and patients as contributors to the health literacy context, and 2) a strengths-based focus that assumes that Māori have successful strategies for negotiating health care and seeks to highlight and work with those strategies.

The sister project was conducted by Rauawaawa Kaumātua Charitable Trust in partnership with Waikato University. Organisations that contributed to the study included Hospice Waikato and the Palliative Care Unit at Waikato Hospital, Te Rūnanga o Kirikiriroa, Waikato District Health Board, and the University of Auckland Waikato Clinical School.

The central focus of that 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 the 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). **The 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.

The research design included the establishment of an advisory group and a stakeholder end users group, a systematic review of New Zealand and international literature, interviews kaumātua, whānau hui (focus groups) and focus groups with palliative health care kaimahi (workers), an analysis of promotional brochures from providers of palliative care services, and a document audit of palliative care patients' use of Emergency Departments within Waikato District Health Board (Rauawaawa Kaumātua Charitable Trust Research Project Team, 2013).

Key areas of interest for both projects research were:

1. The ways in which Māori access palliative care services
2. Current levels of Māori health literacy with regards to palliative care
3. How different factors within whānau influence the ability of Māori to obtain, process and understand palliative care information and services
4. Identification of communication models which are effective in enhancing this ability

The research agenda aims to prioritise translational research that can change or influence palliative care provision and health literacy for Māori.

Figure 1: Research agenda¹

Vision	Patients and whānau receiving timely and effective palliative care in a way that suits their needs and feels safe to access			
Principles	A strengths-based focus that assumes Māori have successful strategies for negotiating health care and seeks to highlight and work with those strategies			
Scope	An integrative and intergenerational approach that views health organisations, health staff, iwi, hapu, whānau and patients as contributors to the health literacy context			
Theme	Health organisation	Health staff	Health literacy: demands, practices and reducing demands	Access
Translational research projects	<p>Develop and evaluate ways to systematically embed health literacy into specialist and primary palliative care.</p> <p>How can palliative care organisations embed the teaching and support of staff to improve their health literacy skills?</p> <p>How can systemic racism be identified and addressed in primary and specialist palliative care service delivery?</p>	<p>What are health staff attitudes, beliefs and knowledge about Māori palliative care needs?</p> <p>What is the most effective way to develop staff capacity and capability for supporting Māori health literacy?</p> <p>What are the skills, knowledge and attitudes required to have 'hard conversations' with Māori who are being referred to palliative care services or discussing death plans?</p> <p>How these can be taught to multidisciplinary health staff across specialist, primary, and pre-referral</p>	<p>Measure and evaluate the health literacy demands for Māori in palliative care. Is there a relationship between high or low health literacy and Māori access to and experiences of palliative care?</p> <p>What is the relationship between health literacy practices and levels of health literacy for Māori in palliative care settings?</p> <p>What would constitute an effective Māori navigator role to support Māori health literacy for patients and</p>	<p>What is the extent of late access to palliative care for Māori? At what points in the health journey are there delays, and why do these occur?</p> <p>What are the reasons that some Māori refuse or avoid palliative care? Is there a connection between resisting or refusing palliative care and health literacy?</p> <p>What is the prevalence for wishing to die at home among Māori with life-limiting illness? What are the reasons behind choosing home,</p>

¹ This table has been modelled on Robson B, Koopu P, Gilmour J, et al. (2011). Oranga waha – oral health research priorities for Māori: Low-income adults, kaumātua, and Māori with disabilities, special needs and chronic health conditions. Wellington, New Zealand, Te Rōpū Rangahau Hauora a Eru Pōmare.

	<p>How could specialist palliative care organisations improve their balance of Māori and non-Māori staff?</p> <p>What are the most effective ways to transmit organisational information to Māori patients and prospective patients?</p> <p>What are rural Māori experiences of palliative care? Are there gaps in palliative care delivery that are impacting Māori access to services?</p>	<p>palliative care health services?</p> <p>How can necessary information (e.g. service information, consent forms and Health & Disability information) be effectively transmitted to patients and whānau entering palliative care?</p>	whānau?	hospice or hospital?
Research, monitoring and evaluation	<p>What are Māori aspirations for palliative care?</p> <p>What are the current care pathways for Māori with life-limiting illnesses who do not access specialist palliative care?</p> <p>How can ethnicity data collection and utilisation be improved?</p> <p>What data are required in order to evaluate effective palliative care service provision for Māori patients <u>and</u> whānau?</p> <p>How should health literacy for Māori be measured in palliative care contexts?</p>			

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Glossary²

Advance Directive: Instructions that consent to, or refuse, specified medical treatment or procedure in the future.

Advance directives are defined in the Code of Health and Disability Services Consumers' Rights (the Code) as written or oral directives in which the patient makes a choice about a possible future health care procedure, and this choice is intended to be effective only when the patient is no longer competent. For this reason, advance directives are also, though less frequently, referred to as 'living wills'.

Right 7(5) of the Code gives every consumer the legal right to use an advance directive in accordance with common law.

Death: The cessation of all vital functions of the body, including the heartbeat, breathing and brain activity (including the brain stem).

Dying: A person is considered to be dying when they are in the process of passing from life to death. It is characterised by a gradual failing of vital functions including the cardiac, respiratory and central nervous systems, followed by an absence of criteria that define life (spontaneous heartbeat, breathing and brain function). The dying phase is generally considered to be minutes to hours in duration, but can occasionally be just seconds.

End-of-Life Care: End-of-life care is the provision of supportive and palliative care in response to the assessed needs of the patient and family/whānau during the end-of-life phase. It focuses on preparing for an anticipated death and managing the end stage of a life-limiting or life-threatening condition. This includes care during and around the time of death, and immediately afterwards. It enables the supportive and palliative care needs of both the person and the family/whānau to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support and support for the family.

Generalist Palliative Care: Refer to 'Primary Palliative Care'.

Hinengaro: Mind, thinking process.

Hospice: Hospice is not only a building; it is a philosophy of care. The goal of hospice care is to help people with life-limiting and life-threatening conditions make the most of their lives by providing high quality palliative and supportive care.

Hospices provide care for the whole person, not just their physical needs but also their emotional, spiritual, and social needs. They also care for families and friends, both

² This glossary has been adapted from the *New Zealand Palliative Care Glossary* (2013) published by the New Zealand Palliative Care Council, Hospice New Zealand & the Ministry of Health, and Kidd, Gibbons, et al. (2013).

before and after a death. Irrespective of where a hospice service is, this philosophy of care does not change. In New Zealand all aspects of hospice care are provided free of charge.

Hui: Meeting.

Kaumātua: Elders. In some areas, including Waikato, this term refers to male and female elders.

Kaupapa Māori: Māori ideology.

Life-Limiting Condition: A life-limiting condition is one for which there is no reasonable hope of cure and from which the person will die. Some of these conditions cause progressive deterioration rendering the person increasingly dependent on family and carers.

Liverpool Care Pathway (LCP): The LCP is an evidence-based, integrated care pathway that was developed to transfer the hospice model of care into other care settings. The LCP guides health care professionals to deliver best-practice care to dying patients and their families/whānau in the last days and hours of life, irrespective of diagnosis or care setting.

Mirimiri: Massage.

Mokopuna: Grandchildren (sometimes abbreviated to moko).

Palliative Care: The World Health Organization (2011) defines palliative care as: “an approach that improves the quality of life of patients and their families facing the problems associated with life-limiting or life-threatening conditions, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten nor postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patient’s illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.”

A New Zealand-specific definition of palliative care is: Care for people of all ages with a life-limiting or life-threatening condition which aims to:

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

Palliative care is provided according to an individual's need, and may be suitable whether death is days, weeks, months or occasionally even years away. It may be suitable sometimes when treatments are being given aimed at improving quantity of life.

It should be available wherever the person may be.

It should be provided by all health care professionals supported, where necessary, by specialist palliative care services.

Palliative care should be provided in such a way as to meet the unique needs of individuals from particular communities or groups. These include Māori, children and young people, immigrants, refugees, and those in isolated communities.

Palliative Care Services: This term refers to any individual, team or organisation whose core work focuses on delivering palliative care, for example a hospice or hospital palliative care team.

Palliative Care System: This refers to palliative care services, primary palliative care providers and the other factors that enable them to deliver palliative care, such as communication and coordination between providers. Without these 'other factors' palliative care providers cannot function as part of a 'system'.

It is not simply the existence of primary palliative care providers and palliative care services that comprises the palliative care system; it is the links that exist between them that tie together 'a system'.

Patient: A patient is the primary recipient of care. In the practice of palliative care, the patient together with their family and carers are the focus of care.

Primary Palliative Care: Primary palliative care is provided by all individuals and organisations that deliver palliative care as a component of their service, but their substantive work is not in the care of people who are dying. It is palliative care provided for those affected by a life-limiting or life-threatening condition as an integral part of standard clinical practice by any healthcare professional who is not part of a specialist palliative care team.

In the context of end-of-life care, a primary palliative care provider is the principal medical, nursing or allied health professional who undertakes an ongoing role in the care of patients with a life-limiting or life-threatening condition. A primary palliative care provider may have a broad health focus or be specialised in a particular field of medicine. It is provided in the community by general practice teams, Māori health

providers, allied health teams, district nurses, and residential care staff etc. It is provided in hospitals by general ward staff, as well as disease-specific teams – for instance oncology, respiratory, renal and cardiac teams.

Primary palliative care providers assess and refer patients to specialist palliative care services when the patient's needs exceed their services capability.

Quality care at the end of life is realised when strong networks exist between specialist palliative care providers, primary palliative care providers, support care providers and the community – working together to meet the needs of all people.

Specialist Palliative Care: Specialist palliative care is palliative care provided by those who have undergone specific training and/or accreditation in palliative care/medicine, working in the context of an expert interdisciplinary team of palliative care health professionals. Specialist palliative care may be provided by hospice or hospital based palliative care services where patients have access to at least medical and nursing palliative care specialists.

Specialist palliative care is delivered in two key ways in accordance with the New Zealand definition of palliative care.

- Directly – to provide direct management and support of patients and families/whānau where more complex palliative care need exceeds the resources of the primary provider. Specialist palliative care involvement with any patient and the family/ whānau can be continuous or episodic depending on the changing need.
Complex need in this context is defined as a level of need that exceeds the resources of the primary team – this may be in any of the domains of care – physical, psychological, spiritual, etc.
- Indirectly – to provide advice, support, education and training of other health professionals and volunteers to support the primary provision of palliative care provision.

Tikanga: Customs and traditions, protocols.

Tinana: Physical self, body.

Wairua: Spirit, soul, spirit of a person. Wairuatanga refers to the spiritual wellbeing of the individual.

Whānau: Whānau means the extended family, family group, a familiar term of address to a number of people—in the modern context the term is sometimes used to include friends who may not have any kinship ties to other members.

Whānaungatanga: Forming connections, relationships.

Appendix One: Literature Review

Review Team

This report was authored by Dr Veronique Gibbons, Research Fellow at Waikato Clinical School, The University of Auckland, who developed and undertook the literature search, extracted the data, conducted the critical appraisals and prepared the report.

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Purpose

The purpose of this literature review is to support better service delivery of palliative care and improved access to palliative care for Māori and their whānau. The review needs to identify access issues for Māori and their whānau from a health literacy perspective.

A Māori Health Joint Venture request for proposal sought to establish a project which focused broadly within the context of health literacy in palliative care. The Steering Committee identified four key areas of interest:

1. The ways in which Māori access palliative care services;
2. The current level of Māori health literacy with regards to palliative care;
3. The way in which different factors within whānau influence the ability of Māori to obtain, process and understand palliative care information and services; and,
4. The identification of communication models which are effective in enhancing this ability.

This literature review informs the accompanying research agenda to include gaps in current knowledge and policy implications across palliative care from a health literacy and Māori context.

Assumptions

The Ministry of Health *Statement of Intent 2010–2013* has a key priority area to ‘work on issues emerging as a result of New Zealand’s ageing population: improving the health and independence of older New Zealanders’ (p12) (Ministry of Health 2010). This report focuses mainly on literature in the adult population.

Scope and methods

While Māori are reported from a population basis to have low health literacy (Ministry of Health 2010) and low utilisation of palliative care (Minister of Health 2001), this

literature review seeks to move away from a sole focus on patients and acknowledges health professionals and health service providers as having a critical role to play in health literacy.

This literature review sought to:

1. Identify systemic and professional barriers that inhibit utilisation of palliative care services for Māori
2. Explore how health literacy principles are incorporated into materials (written resources such as pamphlets, internet, videos etc) in palliative care
3. Examine health literacy interventions in palliative care for Māori and their whānau.

Searches were carried out using Scopus which is the largest abstract and citation database of peer-reviewed research literature with more than 20,500 titles from more than 5,000 international publishers. In addition, it covers PubMed (includes MEDLINE) and Embase.

Free text searches were used to identify key words in the title, abstract and keywords. A search of all fields was too resource intensive and, as an example, picked up words that may only appear in the reference titles rather than in the body of the text. In addition, only articles or review articles were requested. In relation to the choice of search terms, Scopus relies on free text rounded by quotation marks and therefore does not relate these to Medical Subject Headings (MESH) as would be found in a database like MEDLINE. However, viewing these terms in MEDLINE we could ascertain the usefulness of each criterion.

This review did not seek to write a comprehensive review of the literature on health literacy or palliative care as single search terms. These have been done elsewhere and have been used utilised in policy documents (Nutbeam 2000; Minister of Health 2001; Nutbeam 2008; Ministry of Health 2009; Ministry of Health 2010; Naylor 2010). The following steps were used to conduct this review.

Identifying search terms

This section identifies how each group of terms relating to palliative care, indigenous peoples and health literacy was developed.

- #1. For palliative care: palliative care or hospice care or terminal care or end-of-life care (26,913 articles);

Palliative care became a search term on MEDLINE in 1996; prior to this, palliative treatment was the term used (1964–1995). This change related to the concept of care alleviating symptoms without curing the underlying disease (Stedman, 25th edition, quoted by MEDLINE). Terminal care relates to medical and nursing care of patients in the terminal stage of an illness and has been a search term since 1968. Hospice care is a more broad term relating to specialised health care, supportive in nature, provided to a

dying person. This concept has been a MEDLINE term since 1992 and includes bereavement care for the family.

#2. For Indigenous populations: Native American or American Indian or Indigenous or First Nations or Alaska Native or Canadian Indian or Canadian Native or Inuit or Aboriginal or Māori or Torres Strait Island or Metís) (50,603 articles);

Indigenous peoples were identified using the United Nations modern understanding which includes: self-identification as indigenous peoples at the individual level and acceptance by the community as their member; historical continuity or common ancestry with pre-colonial and/or pre-settler societies; strong links to territories and surrounding natural resources (primordial); distinct social, economic or political systems; distinct language, culture and beliefs; former non-dominant groups of society; and, resolve to maintain and reproduce their ancestral environments and systems as distinctive peoples and communities (United Nations 2008). We utilised articles for this review from specific countries whose colonisation histories are similar to New Zealand's: Canada, North America and Australia.

#3. Health literacy: Health literacy or literacy (19,516 articles).

The term Health Literacy has been in existence in the United States since the early 1970s; however, it is identified as a newer search term on MEDLINE, as recently as 2010. In addition, the MESH terms 'Patient Education as Topic' and 'Consumer Health information' were added in 2008. These latter terms relate to the provision of health information to consumers or patients concerning their own health needs and/or with an emphasis on self-care and preventive approaches. In Scopus, using the term 'health literacy' alone identified 2,763 articles, probably reflecting this relatively new terminology. The search was extended to include health and literacy where the words appeared within 15 words of each other; this added more publications which sought to address this area (3,896 articles).

Search results

The initial searches revolved around the three search strands of palliative care (#1), Indigenous Peoples (#2) and health literacy (#3). The combined searches yielded the following number of articles:

Search strategy	No. of articles SCOPUS
#1 AND #2 AND #3	1
#1 AND #2	96
#1 AND #3	39
#2 AND #3	330

The numbers of articles was an indication of the workload required to effectively sort, review and synthesise the literature review in the given timeframe.

Inclusion criteria

All articles were restricted to the English language, published from 2000 until May 2013. In addition, we identified secondary references from reference lists of published literature. Unpublished literature was sourced from the NZ Palliative Care Council and Hospice NZ, and through word of mouth from palliative care and health literacy colleagues.

Potentially relevant studies were identified by reviewing titles and abstracts retrieved from the bibliographic databases. Studies that were potentially relevant were retrieved in full text and screened for inclusion.

Focus

This literature review is focused on the three questions as outlined in the scope. These are:

1. Identify systemic and professional barriers that inhibit utilisation of palliative care services for Māori

The terms that reflected barriers were defined from identifying MESH terms for the word 'barriers' and capturing common words used in titles and abstracts in MEDLINE. This strategy found three MESH headings which were fit for purpose. The search terms in MEDLINE included Communication Barriers/ or Patient Acceptance of Health Care/ or Health Services Accessibility/ or Attitude to Health. In Scopus, the free text terms used were: barriers or acceptance or accessibility or attitude (1,051,884). This search was labelled #4.

Search strategy	No. of articles SCOPUS
#1 AND #2 AND #4	51
Full text retrieved	22

A total of 22 full-text articles were retrieved for further review from the Scopus search. A further five articles were identified from reference lists which may have been outside the time period but provided information referred to in primary articles. Reasons for excluding articles included not meeting our definition of indigenous populations, focusing on quantitative outcomes, commentaries to already identified full-text articles, service evaluation, end-of-life in relation to critical care rather than palliative care, opinion pieces and policy directives. The majority of studies were qualitative studies, the methodology of which lends itself to studies on palliation due to its social phenomenon, non-quantifiable outcomes and a limited number of participants (Hotson et al 2004).

Dying at home is a common thread for indigenous peoples for a number of reasons. Of those who died from cancer in 1996, Māori were more likely to die at home than non-Māori (53.2% and 30.8% respectively) (Minister of Health 2001). Often identified in literature was the desire to be cared for by relatives (Kelly et al 2009; DeCourtney et al

2010). Research on Aboriginal peoples of Canada highlighted the tradition of caring for the person who raised them to the end of their life and the views held that by not doing this you were appearing ungrateful (DeCourtney et al 2010). This circle of life and death was part of the expectation that family members would care for elders at home. This caring process identified the role that carers played in helping the dying person and also in supporting family members by providing 'energy' to help the person pass from this world to the next (Hampton et al 2010). Not only is support needed in providing energy for the dying person's transition, carers needed emotional as well as practical support (McGrath 2008). For Māori, likewise, relatives and friends are reported as gathering at the bedside of Māori to provide spiritual, emotional, moral and physical support for the dying person and their family (Ngata 2005). As with Canadian Aboriginal peoples, Māori 'energies', both unseen and unspoken, are described which connect the physical and spiritual environments (Muircroft et al 2010). The centrality of family and community was demonstrated strongly in the literature (Ngata 2005; Kelly et al 2009; DeCourtney et al 2010).

Dying at home was also related to cultural factors. The geographical concept of 'Home' reflects the Australian Aboriginal's 'death country', where the soul and spirit are tied to the land (McGrath 2007). Geographic isolation presented its own issues in relation to provision of community-based palliative care (Hotson et al 2004). These included limited specialist medical treatment, the absence of a committed primary caregiver in an isolated location, and the lack of inpatient care for patients requiring admission at the terminal phase of illness.

While the literature appears to be inclusive in the view that indigenous peoples would reject hospital palliative care services due to the wish (and/or expectation) for family to be part of the caregiving, there were occasions in literature which described situations where services have not been rejected. Firstly, in one community, there was a belief that dying at home would be negative for the family due to part of the dying person's spirit being left behind (Hotson et al 2004). In another study, there was stigma attached to a person dying at home; the family did not want to be held responsible for the death (blame) (McGrath 2008). Secondly, palliative care services were a necessity, to enable family to have 'time off' (respite). However, a barrier to this was that for families wanting temporary relief from caring there was confusion around the utilisation of hospice care concerning its availability for respite or its use during an acute episode (Frey et al 2012).

A lack of resources in the community, often cited in rural and remote communities, was a barrier for families in not being able to look after a family member. Services were commonly located in the city, often quite far from their home (McGrath 2008).

Finally, the breakdown of the family structure impacted on the use of hospice/hospital palliative care services (Weeramanthri 1997).

Over a three-year period (2008–2010), an increase had been reported in the numbers of Māori dying at one hospice when compared to the local hospital, suggesting an increase in hospice as a place of death for Māori. However, on further analysis, the odds of Māori dying at hospice remained lower than for NZ Europeans and was not statistically significant ($p = .744$) (Frey et al 2012). Larger studies would be needed to test this finding and to model future behaviour.

Research has looked at certain rules evident in some hospital or hospice settings which may conflict with the cultural requirements towards the end of life. For example, the concept of visiting hours as they are imposed in some settings was described as alien to people who, during the final days, wanted to ensure the environment remained upbeat so that the energy to pass to the next world was done positively (Hampton et al 2010). The number of visitors, as a person is dying, depended on extended kinship networks of people who came to pay their last respects before death (McGrath 2008). Visiting hours and policy around who and how many can visit could be at odds with this concept. For Māori, seeing people while they were still alive was reported to be important: extended family brought with them their spirit, life spark, collective concern, love and sympathy to promote healing and recovery (Ngata 2005). At death, Māori have been reported as identifying the need to ensure the deceased “is kept warm and comforted by the presence of kinfolk to calm the soul and assist it on its journey to the spirit world” (Ngata 2005, p.33). A lack of primary palliative care services and respite facilities in rural and remote locations has been cited as a barrier to providing support at the end of life for those who wish to remain with their communities (McGrath et al 2007; Lawrenson et al 2010). Culturally sensitive care required access to family supports and traditional services if requested (Hotson et al 2004).

Beliefs about the causes of illness are often cited when the mechanisms of disease are given without the meaning as to why a person had a particular disease (McGrath et al 2006). Attributes of blame for having a terminal illness were reported as being attributed to self or ancestral wrongdoings – a sort of payback (Maddocks and Rayner 2003; McGrath 2008) and this might inhibit family from seeking palliative care. The concept of ‘blame’ in Aboriginal Australians was strongly related to the reasons for the illness and links to kinship ties and traditional law (Weeramanthri 1997). The idea of payback was also a feature of Māori culture (Ngata 2005). Researchers have identified that this may lead to additional stress on the patient who may be unwilling to talk about their disease for fear of bringing shame to the family and community (Shahid and Thompson 2009). Furthermore, refusing care may be as a result of acceptance; that they are bearing the pain to protect their families from further suffering caused by a ‘curse’ or payback.

In research with health professionals, it was pointed out that caring for a person of a different culture could bring about its own anxiety (McGrath 2000). A lack of physician and nurse awareness of traditional beliefs held by the community regarding death was a barrier to care in a study of remote communities in Canada (Westlake Van Winkle 2000;

Hotson et al 2004). It was recommended that health professionals who provide palliative care in multicultural societies must “set aside our own beliefs and seek to understand the needs of the other person” (Taylor and Box 1999, p.13). It was argued that there was a need for health professionals to recognise that each person was unique and that part of following protocols was recognising that each individual was different, “because the Creator made us so unique that even that way of going is unique. So there’s not one way of doing it. Everyone will have their own” (Hampton et al 2010, p.12). These differences were also attributed to ‘traditional, acculturated or religious practice’ (Westlake Van Winkle 2000; Hotson, et al 2004). In addition, for a group such as Māori, who were described by Reid (2005) as being diverse, flexible and changeable, there was a danger in making generalisations about cultural identity based on what Reid called “museum exhibits of past behaviours” (Reid 2005, p.47).

The construct of death was highlighted in research as different within western medicine-oriented models (where death is the enemy) and Canadian Aboriginal understandings of death as a transition from Mother Earth (Hampton et al 2010). In addition, it was argued that it must be recognised that egalitarian principles to provide quality care to all people might cause harm to cultures whose needs and expectations differ from the dominant culture (McGrath 2000).

Five articles focused solely on the perspectives of health professionals who provide palliative care, as opposed to including the views of patients or their families/whānau. The articles were identified specifically for their inclusion of discussion about indigenous populations. Three articles were from New Zealand, one from Canada and one from Australia.

GP focus groups in Australia suggested that GPs needed to develop confidence in talking about death and dying, with one GP noting that the reluctance of GPs to work with dying patients may reflect their own fear of death (Burgess et al 2004). These focus groups were made up of GPs who had an interest in palliative care; however, GPs were particularly concerned with having access to support [for themselves] when caring for dying patients from ‘other cultures’, a comment which strongly identified that the GPs were from the ‘dominant’ culture. This study might have been strengthened with discussion of different views about the needs of indigenous peoples, not solely on medical needs.

A survey of hospital staff perceptions of current end-of-life care was conducted in an acute hospital setting to gather a baseline understanding of challenges facing NZ palliative care services (Sheward et al 2011). Nurses described assessment, advocacy and a form of brokerage on behalf of patients, even though at times different perceptions led to conflict with medical staff. A barrier to achieving good symptom control for patients, identified predominantly by nursing respondents, was the lack of knowledge among health professionals about how to care for a dying patient. Other barriers which contributed to challenging dynamics included professional differences,

staff cultural backgrounds and personal values and beliefs stemming from attitudes to death and dying.

Access to specialist palliative care services in rural areas has been acknowledged as a concern (Minister of Health 2001). Many Māori live in rural areas of NZ or return to their ancestral/tribal home when terminally ill; researchers have argued this means they are disadvantaged in their access to specialist palliative care services (Lawrenson, et al 2010). A survey of 186 rural New Zealand GPs aimed to identify their perspectives of the needs of Māori patients receiving palliative care and to discover what GPs did to meet these needs (Lawrenson et al 2010). The strongest theme from GPs was the need to involve whānau in the management of Māori patients needing palliative care, including the need for more time for interaction and communication and to identify the key people within the family. Identifying the decision-maker in the family was highlighted as being important. In some cases it is a matter for health professionals to simply ask who it is (DeCourtney et al 2010); in others, kinship ties may make identifying the 'kinship network' more difficult but holding family meetings has been suggested as a means to ensure a way of 'sharing the story' about the person's illness with the most appropriate family members (McGrath 2000).

A New Zealand study exploring the views of primary and specialist palliative care providers regarding the provisions of culturally appropriate palliative and end-of-life care for older non-Pākehā people demonstrated a number of identified barriers (Bellamy and Gott 2013). In agreement with other studies, it was acknowledged that the involvement of family was fundamental to the provision of palliative care and for Māori, allowing family members to provide 'hands-on' care. Again, the lack of space to accommodate family members who were providing care or who were there to support the family spiritually impacted on a difficult but potentially rewarding time. In response, the hospice setting provided adjoining rooms where families could be close to and provide care to their sick relative, while the residential setting housed groups away from the other residents but were close enough at hand to provide support but not intrude on other patients who may be present.

Discord around health professionals' decisions to change the direction of care from active management to palliative care appeared to cause a 'sense of struggle' with a reluctance to 'abandon' treatment being perceived as failure by some medical respondents (Morita et al 2005; Wittenberg-Lyles et al 2011; Bellamy and Gott 2013). Health professionals experienced ethical dilemmas associated with continuing treatments that were perceived to not be in the best interest of the patient. The families reported that they received insufficient preparation from health professionals for changing the treatment focus from active management to palliative care (Morita et al 2005). This move from active treatment to palliative care was described as transitioning from a space of closed awareness (isolated journey), focusing on treatment and side effects only, to open awareness (rescued journey), where the limits of medicine were

acknowledged and end-of-life planning was openly discussed (Wittenberg-Lyles et al 2011).

A NZ study addressing the development of priorities for culturally appropriate palliative care and end-of-life care for older Māori, Pacific and Chinese people in Auckland reported that caring for Māori (and Pacific) peoples in a hospice setting was easier than providing the same service to Chinese people, due to Māori and Pacific belief systems about being more able to talk about death and dying which reduced barriers for staff (Bellamy and Gott 2013). The researchers reported that some Chinese families wished to keep the prognosis from a patient, which comprised a risk to staff of being in breach of the Health and Disability Commissioner (Code of Health and Disability Services Consumers' Rights) Regulations 1996. It was recognised that a more proactive approach would be a 'comforted journey' which situated palliative care at the point of diagnosis; therein supporting patients and families through diagnosis and side effects of treatment by focusing care on quality of life and patient goals (Ferrell 2005). It has been argued that Māori patients and families may, therefore, be more receptive to the comforted journey at an early stage (Wittenberg-Lyles et al 2011). In identifying palliative care journeys, there were limitations of placing the research in the setting of a hospice or hospital palliative care service and it is not known whether these journeys from 'isolation' to 'rescued' occurred in the same way in a community setting. A hospital or hospice was seen as a place to go to die (Frey et al 2012) and this perception may be a barrier to utilising the services provided there especially where families were still wishing to remain positive (Bellamy and Gott 2013) or wished to remain close to their communities (McGrath 2007).

A qualitative case study to explore challenges of delivering culturally sensitive and safe palliative care was undertaken with a small minority Aboriginal population in rural British Columbia where there was a lack of formal palliative care services (Castleden et al 2010). Participants included nurses, doctors, health care administrators, hospice volunteers and employees, allied health care workers and a family caregiver. Much was discussed on whether there was an Aboriginal population in that area to the point that as services became increasingly difficult to access, 'they just return to the place familiar to them'. One participant described service provision on an individual basis yet this was contradicted by another who stated that cultural differences were set aside so patients received equal access and care. However, an example of observed racism was expressed. Talking in a manner that conveyed a generalist view, a person was reported as saying, 'You people are always. . .' in an elevated voice, which left the patient (with additional chronic disease needs) scared, distrustful and without dignity – likely never to return for much needed care. For this study, the lack of visibility of the indigenous population and their traditions was a barrier to addressing cultural and conceptual differences and in providing culturally sensitive care practices to this population.

In summary, in identifying barriers that inhibited utilisation of palliative care services for Māori, it was recognised that generally indigenous peoples wish to die at home. A

home environment was related to the familiarity of being cared for by their family members, the 'circle of life' where they were born and die, gaining energy from family and community in moving across to the other side, and in receiving support for the family to enable caring to take place. Due to a lack of specialist palliative care services in many rural areas and the limitations of primary palliative care services, the move to specialist palliative care services was often away from the community, thus isolating the patient from their support structures of family and community at an important time towards the end of their life. The move to palliative care units and hospices was identified as alien—in terms of having rules and structures which may not effectively accommodate the needs of the indigenous patient. Notwithstanding visiting hours, the ability of specialist palliative care services to address the needs of indigenous populations was reported as being dependent on the knowledge and willingness of staff to 'allow' care to be provided in a culturally sensitive manner. The provision of caregiving by a family member in a hospital-like environment was argued as potentially in conflict with health professionals who were reluctant to relinquish care or medical staff who may feel a sense of failure if supposed life-prolonging treatments were discontinued. In addition, the availability of space for family members, who wish to provide care, was reported to be limited. The ability to provide comprehensive care was called to question when health professionals within specialist palliative care services support the notion that some staff may be better at caring for patients towards the end-of-life than others. It is worth considering the turnover of workforce within palliative care services which may impact on the relationship between families and the service. Furthermore, there remained a strong call for more indigenous health workers to be available to support health professionals who care for indigenous patients. The use of members of the target ethnic community in working alongside palliative care services was successfully modelled in the US (Yeo 2009).

Table 4: Search #1 Identify barriers that inhibit utilisation of palliative care services for Māori

Type of study	Title	First author/ Year	Population, Location	Barriers to Palliative Care services identified
Culturally modified qualitative focus groups	Gathering information to develop palliative care programs for Alaska's Aboriginal peoples	DeCourtney, 2010	84 Aboriginal elders representing 6 groups of Aboriginal peoples, Canada	<ul style="list-style-type: none"> • Use of facial expressions were inappropriate as measures of pain • A wish to go to die at home/ within the community cared for by family members • Loss of traditional healers • Lack of palliative care services remotely • Not identifying one decision-maker for the family (although community and family may also want a say)
Purposive sampling	Completing the Circle: Elders speak about end-of-life care with Aboriginal families in Canada	Hampton, 2010	Five elders in Saskatchewan, Canada	<ul style="list-style-type: none"> • Policy restrictions when gathering around a community member dying in hospital • No provision of family rooms in hospitals • Disrespect and racist treatment by health care providers • Western perspective on the visitor role • Health care provider needs education in order to work with Aboriginal persons who are dying • Not being permitted to bring traditional food to comfort the dying person
Qualitative interviewing	<p>Family care-giving for Aboriginal peoples during end-of-life Findings from the Northern Territory</p> <p>'I don't want to be in that big city; this is my country here': Research findings on Aboriginal peoples' preference to die at home</p> <p>"They should come out here. . ."</p> <p>Research findings on lack of local palliative care services for Australian Aboriginal people</p> <p>Insights on Aboriginal peoples' views of cancer in Australia</p>	<p>McGrath, 2008</p> <p>McGrath, 2007</p> <p>McGrath, 2007</p> <p>McGrath, 2006</p>	72 Aboriginal patients, caregivers, health care workers, interpreters, non-indigenous health care workers, Australia	<ul style="list-style-type: none"> • Traditional value of caring for their own people (locality specific) • Hospital rooms designed to accommodate ONLY a few visitors • Fear of blame and payback/ a curse • Fear of 'contagion' – lack of understanding of disease process • Do not wish to relocate to hospital/strong community bond • Strong connection with land and community, 'death' place

Type of study	Title	First author/ Year	Population, Location	Barriers to Palliative Care services identified
Literature review	End-of-Life issues for aboriginal people	Kelly, 2007	Aboriginal, Canada	<ul style="list-style-type: none"> • Respect for personal independence – advising, persuading or instructing is undesirable behaviour • Modern healing practices focusing purely on physical may not be accepted, preferring balancing mind, body and spirit • Discussing terminal illness or sickness may expedite death whereas positive thinking promotes health (protecting) • Translators may alter doctor's messages in order to deliver a positive message • Preference for Aboriginal staff
Perspective	Issues in palliative care for Indigenous communities	Maddocks, 2003	Aboriginal, Australia	<ul style="list-style-type: none"> • Lack of understanding about disease causation • Attributing self-blame to sickness • The importance of dying on traditional lands • Offense in discussing site of illness with person (better with family member) • Gender and culture issues – men talk with men, women with women, Aboriginal with aboriginal.
Review Article	Issues influencing the provision of palliative care services to remote aboriginal communities in the Northern Territory	McGrath, 2000	Aboriginal, Australia	<ul style="list-style-type: none"> • Egalitarian principles of the dominant culture may cause harm • 'Cultural paralysis' – unfamiliar cultural circumstances for staff • Explanations must convey meaning not mechanisms – not only 'what' is happening to the dying person but 'why' it is happening.
Qualitative study – semi-structured interview	Palliative care of First Nations people. A qualitative study of bereaved family members	Kelly, 2009	10 Ojibway and Cree aboriginal families, Canada	<ul style="list-style-type: none"> • Being away from home is an unfamiliar cultural milieu
Perspective	A New Zealand perspective on palliative care for Māori	Muircroft, 2010	Māori, New Zealand	<ul style="list-style-type: none"> • <i>Wairua</i> (spiritual aspects) is the most important requirement of good health. Health relates to unseen and unspoken energies which connect with both the physical and spiritual environments • Family represent the main support for a dying Māori person • Patients and family need help to 'navigate' the health system, to ensure continuity of care and to be made aware of entitlements

Type of study	Title	First author/ Year	Population, Location	Barriers to Palliative Care services identified
Semi-structured interviews	Understanding death and dying in select First Nations communities in Northern Manitoba: issues of culture and remove service delivery in palliative care	Hotson, 2004	Aboriginal communities, Northern Manitoba, Canada – residents, elders and religious leaders, doctors, nurses and allied health care providers	<ul style="list-style-type: none"> • Lack of physician and nurse awareness of traditional beliefs held by the community regarding death • Not all Aboriginal people follow traditional ways, some traditional ways interspersed with conventional religious forms i.e. Catholic, Pentecostal • Unwillingness to relocate, fear of an unfamiliar environment, expressed need to be near friends • Jurisdictional issues and limited resources of health providers
Qualitative interviews – instrumental case studies approach	‘Where do I go from here?’ A cultural perspective on challenges to the use of hospice services	Frey, 2013	37 cancer patients or family (6 Māori) and 15 Health professionals (7 Māori). *only statements particularly pertaining to Māori were included.	<ul style="list-style-type: none"> • Unaware of how hospice can be utilised • Cultural presumptions concerning preferences in hospice service utilisation which limits access to information about services • Misunderstanding about potential financial impact • Hospice seen as a ‘place’ rather than a philosophy of care • Fear of discrimination based on other experiences within the health system • Shyness discussing health issues related to sexuality
Focus groups and joint interviews	What are the priorities for developing culturally appropriate palliative and end-of-life care for older people? The views of health care staff working in New Zealand.	Bellamy, 2013	80 participants working in NZ specialist (n=26) & primary (n=54) palliative care settings incl. 30 working in aged residential care settings	<ul style="list-style-type: none"> • The ability to accommodate large numbers of family members who provide hands-on care • Staff anxieties about relinquishing care to family members
Telephone interviews with purposive sampling and snowball technique	Providers’ perceptions of Aboriginal palliative care in British Columbia’s rural interior	Castleden, 2010	31 formal and informal palliative care providers, Canada.	<ul style="list-style-type: none"> • Lack of awareness of Aboriginal population • Discrimination may have led to ‘invisibility’ of aboriginal cultural needs • Assumption that Aboriginal People ‘<i>take care of their own</i>’ • Services are increasingly difficult to access • Aboriginal peoples who remain in the city have ‘<i>adapted</i>’
Focus groups	Talking to patients about death and dying	Burgess, 2004	13 GPs, Australia	<ul style="list-style-type: none"> • Only 25% of patients are ready to discuss death and dying • GPs require access to support in caring for dying patients from other cultures

Type of study	Title	First author/ Year	Population, Location	Barriers to Palliative Care services identified
Postal survey	Staff perceptions of end-of-life care in an acute setting: A New Zealand perspective	Sherward, 2011	179 staff from medical, surgical, medical, nursing, allied health at a regional hospital, NZ	<ul style="list-style-type: none"> • Needing nurses to broker on behalf of patients • Inadequate knowledge about pain control by staff • Professional differences, multidisciplinary engagement • Staff cultural backgrounds • Personal values and beliefs about death and dying
Postal survey	Rural general practitioner perspectives of the needs of Māori patients requiring palliative care	Lawrenson, 2010	186 rural GPs, NZ	<ul style="list-style-type: none"> • Access to specialist palliative care services • Identifying the decision-maker in the family • Rural GPs looking after new patients who have returned 'home'

2. Explore how health literacy principles are incorporated with materials (written resources such as pamphlets, internet, videos etc) in palliative care

This search strategy utilised the combination of #1 (Palliative care) and #3 (Health Literacy)

Search strategy	No. of articles SCOPUS
#1 AND #3	39
Full text retrieved	9

A total of 39 articles were identified using a combination of the search terms, palliative care and health literacy. On examination of titles, abstracts and keywords, only nine articles fitted the criteria concerning materials in palliative care which related to health literacy. Of these, six articles were suitable for inclusion. The removed articles related to advanced care directives (Melhado and Bushy 2011), cultural deficits based on a group of people with a sensory disability (as a cultural identification) (Maddalena et al 2012) and one using the same cohort and information as an already described article (Vollandes et al 2010).

Researchers argued that education could be conceptualised as a fundamental health professional intervention in providing information that was both empowering and culturally sensitive for those in hospice and other end-of-life care settings (Cagle and Kovacs 2009). There were several educational complexities that impacted on the ability to effectively help patients and families to access the information they needed. Health literacy drew on principles of adult education and required educators to draw on the patient's prior knowledge and experience (Nutbeam 2008).

Health professionals are seen as relying heavily on spoken and written forms of communication (Workbase 2013); however, the use of plain language in replacing medical jargon was not seen in itself as sufficient to guarantee readability had been achieved and health messages had been understood (Ministry of Health 2012). In addition, it was argued that caregivers themselves may have co-morbidities that may reduce their literacy levels (Kehl and McCarty 2012) impacting on their ability to advocate for patients. A US study examined written documents used by 170 hospices to prepare families for caregiving at the time of death looking at the languages of the materials, what materials were offered and how materials were distributed and reviewed (Kehl and McCarty 2012). Resources were analysed for readability using three health literacy tools, the Flesch-Kincaid Readability Formula (F-K), the Simple Measure of Gobbledygook (SMOG), and the Colors Label Ease for Adult Readers Instrument (CLEAR). Hospices provided from one to seven documents from providers for review. Few documents were reported as meeting the recommended grade level for adequate comprehension. The number of medical terms ranged from 0 to 20.

Overall it was found that the main reason for poor ratings on literacy tests was the use of medical terminology without adequate and effective explanations. Implications for practice included: highlighting medical terms coupled with the use of direct explanations, improving document design through the use of bullet points, appropriate use of illustrations and appropriately large font size.

Other articles referred to types and presentation of information. The format in which information is provided may have an effect on how it is received, processed and acted upon. A US study of parents who had children with life-threatening illnesses compared whether they were more likely to use the internet as a primary information source for health queries compared with using the doctor as a primary information source, based on their self-identified internet usage. It found that greater internet use was positively associated with an increase in e-health literacy (Knapp et al 2011). Despite parents of Hispanic origin having lesser access to the internet in general, for those that did access the internet, using multivariate analysis, the researchers identified that e-health literacy did not differ by ethnicity. The use of visual content in e-health literacy was seen as helping parents to understand the information provided on the internet. Even those parents who were not able to decipher the content were prompted to follow up what they found on the internet with the doctor, thus leading to new dialogue between parents and their health professional. A further search would be required to understand the consequences of this for patients and health professionals.

An interventional trial assessing health literacy and end-of-life preferences between groups in a rural community compared verbal information about dementia against having the verbal information plus a video decision aid (Vollandes et al 2011). The group that received the video decision-making aid alongside the verbal information were more likely to prefer comfort care compared with the verbal information alone (91% c.f. 72%). Those with higher health literacy also had a greater propensity towards comfort care. In an earlier study by the same author which addressed health literacy as a variable in decision making, it was found that those with low or marginal health literacy were more likely to prefer aggressive care than comfort care after verbal description, but after watching the video decision-making aid there were no significant differences in the distribution of preferences by race or health literacy (Vollandes et al 2008).

An internet survey exploring nurses' attitudes to and use of an online palliative care resource was conducted with staff working in specialist palliative care services (Tieman and Rawlings 2008). While the content was found to be credible, specialist palliative care nurses were more aware of the resource than other nurses.

A systematic review that focused on single or multiple literacy-directed interventions (Sheridan et al 2011) reported that presenting only essential information improved comprehension in individuals with low numeracy compared with providing essential and non-essential information. However, when quality information was presented that put essential information first, comprehension was improved for those with low numeracy.

It is known that there is high correlation between measures of health literacy, print literacy and numeracy (Berkman et al 2011). Studies using intensive self-management intervention to improve heart failure outcomes failed to improve quality of life scores or health literacy scores. In palliative care, self-management recognises stages of illness and informs patients and families of where symptom control or more intense intervention is required. In this review, they found few studies that stratified analysis by health literacy levels. None were ethnicity specific and none related to palliative care.

In summary, in addressing how health literacy is incorporated into materials in palliative care, although only part of the overall health literacy context, materials were deemed to rate poorly due to the overuse of medical terminology. However, while using direct explanations and other cues such as bullet points and bold lettering was argued as possibly making the design more readable, it was acknowledged that focusing on readability alone by replacing medical jargon with plain language was not sufficient in improving health literacy. Other literature referred to the use of additional forms of media such as video or internet use. Videos had potential in their capacity to be viewed again at a later date or shared amongst family to also view. Internet use is increasing in younger populations and anecdotally the younger generation are advocating more for older people where the older person may be reluctant to complain/comment (M Parsons, personal communication, April 2013). Therefore, while an older person may not be au fait with internet technology, a younger relative may be able to support them. Depending on health literacy levels, using internet search engines may provide users with the answers to their questions or enable refinement of their questions.

3. Examine health literacy interventions in palliative care for Māori and their whānau

Using a combination of #1 (Palliative care), #2 (Indigenous Populations) and #3 (Health Literacy), this search strategy provided one article in Scopus which considered the challenges of ethnogeriatrics in the US (Yeo 2009). Several additional articles appeared to meet the criteria which were not found using the Scopus search, as well as non-published literature (book, reports). It was important to keep the focus on the health outcomes for Māori and therefore this final strategy moves to a narrative synthesis to garner a complete picture of the interventions identified that research indicated might support better service outcomes for tāngata māuiui and their whānau. Furthermore, the asset model (Nutbeam

2008) was the lens in which this review was sited. The asset model uses health education as a lever with which personal empowerment in decision making can occur.

Beginning with the one identified article, the authors cited several challenges to high-quality ethnogeriatric care which included disparities in health status and health care, differences of acculturation level and other characteristics within the populations, language and limited English proficiency, health literacy, culturally defined health beliefs and syndromes, and specific beliefs and preferences about long-term and end-of-life care (Yeo 2009). While this article did not focus solely on indigenous populations, the recommendations for ethnically diverse populations appeared to correspond with the barriers to palliative care services identified in the first section of this review.

An Australian study examined individual, social and cultural aspects of health literacy relevant to cancer among Aboriginal patients, carers and their health workers in New South Wales (Treloar et al 2013). It was recognised that differing views of health and illness in indigenous populations were not aligned with western biomedical models (Hampton et al 2010). This qualitative study identified the silence of cancer in which Aboriginal people did not believe they would get cancer due to its portrayal in the media where there was an absence of Aboriginal people in public campaigns; hence the campaign lacked meaning to indigenous people. In addition, priorities were discussed in which cancer may take a back seat to other health issues. Recommendations to address these aspects of health literacy included facilitated community members' awareness of cancer and for cancer education programmes at a number of levels.

A systematic review of interventions to mitigate the effects of low health literacy was performed addressing three factors: improving health literacy for patients and providers, improving utilisation of appropriate services and improving health outcomes compared with usual care (Basu et al 2010). Four systematic reviews and 30 primary studies, that had not been included in any of the previously identified systematic reviews, met the criteria. Twenty-two out of the 30 studies were randomised controlled trials. Five general principles for organising health literacy related interventions were identified as contributing to successful outcomes, however two of these principles (visual materials and readability levels, and multi-component and multi-media) overlapped with one of the other three themes. Therefore, the three main principles included: complex interventions (those that engaged in two or modalities such as combinations of face-to-face interactions, use of multimedia or videotape instruction and the use of textual data); interventions that recognised peoples' different learning styles (recognising that people process information in different ways, and therefore including text-based materials, soundbytes, visualisation (pictorials), debates and verbal exchanges of ideas); and interventions that were personalised and tailored to specific individuals or groups and were outcomes focused. One

key idea was for health professionals and other caregivers to check for understanding by ensuring that 'message sent = the message received'. The teach-back method, where patients and families can restate in their own words what has been told, was one recommended way to ensure the message was understood and remembered, and for practical training, a dummy run was another technique to check for understanding (Kripalani and Weiss 2006).

A rapid evidence review of interventions for improving health literacy relating to communicable diseases found that a diversity in the range of outcomes limited the conclusions in most studies (D'Eath et al 2012). More importantly, the authors reported little evidence of specific inclusion of disadvantaged or hard-to-reach groups. None of the studies focused on palliative care and there was a lack of research which considered interventions based on ethnicity, culture or age. As this report was a review of reviews, its quality was constrained by the quality of reviews. Most literature on health literacy and patient adherence does not seek to investigate culture or ethnicity as variables, despite commonly observed outcomes that low health literacy is more prevalent in ethnic minority, low-income and elderly populations (Shaw et al 2009).

An updated systematic review of health literacy interventions and outcomes that was conducted in the US allowed for increased recognition of numeracy in relation to health literacy, and of oral skills of participants, as well as knowledge, as outcomes (Berkman et al 2011). Variables on the causal pathway between health literacy and health outcomes included knowledge, self-efficacy and social stigma. In this updated review, it was identified that health literacy could be a mediator of racial disparities in health outcomes. Despite a plethora of health literacy literature emerging in the past decade, this area remains emergent in New Zealand. Small sample sizes were reported as making it impossible to determine true effect and inconsistent approaches to creating health literacy and numeracy levels or thresholds in analysis hampered comparisons.

A systematic review which reviewed interventions for individuals with low health literacy recognised several discrete design features that improved patient comprehension (Sheridan et al 2011). The authors concluded that intensive self-management interventions reduced emergency department visits and hospitalisations, and intensive self- and disease-management interventions reduced disease severity. They also reported that multiple interventions showed promise for mitigating the effects of low health literacy.

A framework has been proposed based on best-practice principles for improving care with patients with limited health literacy (Sudore et al 2009). Within it, limited health literacy was described as a function of the demands and expectations placed on the patient by the health care system, as well as by the patient's disease processes. Three main areas of

intervention were identified: Clinical-Patient Level Interventions, focusing on communication, presentation, reinforcement, reconciliation and confirmation of understanding; System-Patient Level Interventions, around materials, labelling, disease management programmes, empowering environments and clinical communication training; and Community-Patient Level Interventions, including adult education and literacy programmes, use of lay health educators and health navigators and harnessing the media. This comprehensive framework cited limitations in the use of some of these interventions as not having been tested in limited health literacy populations. Strategies such as the use of computer kiosks with touch screens have been reported as being used more in large health care organisations and have been shown to be useful and acceptable in well-educated populations; however their use in limited health literacy populations has not been tested. The message was not a 'one-size fits all' approach as other factors such as language barriers, the use of interpreters, learning disabilities and dementia sufferers further inhibited health literacy. The key is for further research to examine how client-patient communication can increase health literacy thereby reducing health disparities (Sudore and Schillinger 2009).










A list of ten attributes of health literate health care organisations were identified by the Institute of Medicine (Nielsen-Bohlman et al 2004). If organisations have these attributes it is argued that it will make it easier for the organisations' patients to navigate, understand and use information and services to take care of their health (Brach et al 2012). There is a growing appreciation that health literacy does not focus solely on individual skill (Nielsen-Bohlman et al 2004). According to research thus far, the interventions which organisations need to ensure they have to gain the attributes of a health literate organisation included: having leadership to allow health literacy to be integral to its core values; integrates health literacy into planning, evaluation, patients safety and quality improvement; workforce preparedness; allows and integrates population input; meets the needs of the population; uses health literacy strategies in communication and confirmation; provides easy access to navigate health information and services; utilises easy to understand design and distribution of materials; prior identification of high risk situations for health literacy; and, communicates clearly about costs (Brach et al 2012).







Despite the intention to view health literacy interventions through a lens of an asset model, no articles measured information flow through a two-way process (European Health Policy Forum 2005). There was a lack of interventions measuring the way in which health information was delivered apart from the usability of materials provided. Strategies were measured based on readability or numeracy or on health literacy levels in individuals. The conveying of health messages requires skill on the part of the health professional. It is likely







that more work needs to occur in assessing the delivery of interventions not only in terms of products and time.







In drawing on the findings of this review, it was evident that the domain of health literacy is still in its infancy in New Zealand. The understanding of how to improve health literacy from a health services perspective has been identified in practical steps for improvement. Further studies are required to engage health professionals and health organisations in developing skills to build health literacy (based on adult learning principles) and assessing the outcomes of these efforts to build health literacy.





Appendix Two: List of resources analysed

	A guide for carers booklet A5 (2nd Edition) Hospice New Zealand
	About us . . . pamphlet DLE Hospice North Shore www.hospicenorthshore.org.nz/site/nshospice/files//ABOUT%20US%20Pamphlet%20FINAL%20PRINT.pdf
	Information pamphlet DLE North Shore Hospice Trust
	Information & Care Communication Book A5 North Shore Hospice Trust
	Family Support Information Pamphlet North Shore Hospice Trust
	Kaitakawaenga Kaiawhina pamphlet DLE North Shore Hospice Trust
	Your introduction to Patient and Family Services booklet A5 Hibiscus Hospice
	Hospice Cares pamphlet DLE Hibiscus Hospice www.hibiscushospice.org.nz/site/hibiscushospice/files/Hospice%20Cares%20(2).pdf
	Welcome to Hospice West Auckland letter A4 Hospice West Auckland

	<p>Information for Patients and Families pamphlet DLE</p> <p>Hospice West Auckland</p>
	<p>An appreciation of hospice care: how you can help pamphlet DLE</p> <p>Mercy Hospice Auckland</p> <p>Other pamphlet DLEs from Mercy Hospice Auckland include:</p> <ul style="list-style-type: none"> • Education for families as carers 2012 • Opening doors • Prevention of Pressure Injuries in the Home • End of life changes (at home): Advice for family members, friends and carers of patients who are dying at home • Morphine – information for first time users
	<p>Give the gift of sight: Eye Donation for Transplantation pamphlet DLE</p> <p>The New Zealand National Eye Bank, Department of Ophthalmology, School of Medicine, University of Auckland</p>
	<p>Mo Wai Te Ora: Māori Health Services pamphlet DLE</p> <p>Mo Wai Te Ora: Māori Health Services, Waitemata District Health Board</p> <p>www.healthpoint.co.nz/specialists/other/waitemata-dhb-Māori-health-services-mo-wai/important-information/</p>
	<p>Mo Wai Te Ora: Māori Health Services Patient Satisfaction Survey leaflet A5 or online</p> <p>Mo Wai Te Ora: Māori Health Services, Waitemata District Health Board</p> <p>www.surveymonkey.com/s/Mo_Wai_Te_Ora_Patient_Satisfaction_Survey</p>
	<p>Kaitiaki Nursing service: What we offer pamphlet DLE</p> <p>Kaitiaki Nursing service, Western Bay of Plenty PHO</p>

	<p>Whānau Ora Navigation Cancer Care Service, comprised of:</p> <ul style="list-style-type: none"> a. Community Health Navigator Background booklet b. Patient and Whānau Communication Journal <p>Waitemata District Health Board and Te Whānau o Waipareira Trust</p>
	<p>How to Claim Carer Support pamphlet DLE</p> <p>Ministry of Health</p> <p>www.health.govt.nz/yourhealth-topics/disability-services/respite-and-carer-support/carers-support</p>
	<p>Code of Health and Disability Services: Consumers' Rights pamphlet + booklet</p> <p>Health & Disability Commissioner</p> <p>www.hdc.org.nz/media/24833/leaflet%20code%20of%20rights.pdf</p> <p>There is also an easy read booklet found on the HDC website here: www.hdc.org.nz/media/52437/you%20have%20rights%20-%20easy%20read%20version.pdf</p>
	<p>Making the most of your final years: Practical and spiritual things to think about and plan for end of life pamphlet DLE</p> <p>Advance Care Planning Cooperative (ACP)</p> <p>www.advancecareplanning.org.nz/Portals/0/Documents/Making%20the%20most%20of%20your%20final%20years%20leaflet.pdf</p>
	<p>Forms in the Hospice North Shore Information Pack</p> <p>North Shore Hospice Trust</p>
	<p>Welcome to the Community Palliative Care Service of Mercy Hospice Auckland</p> <p>Mercy Hospice Auckland</p>
	<p>Because grief happens and support matters: Support to help children, young people and adults pick up the pieces</p> <p>Skylight</p>

	Family Support Team Mercy Hospice Auckland
	Cloud Workshop: Art workshops for bereaved children and those with life threatening illness in their family Sponsored by Mercy Hospice Auckland
	Supporting children and young people through loss and grief: a guide for parents and caregivers Mercy Hospice Auckland
	List of specially chosen books for children with grief in their lives The Women's Bookshop
	Agreement for Care letter A4 Mercy Hospice Auckland
	Being Honest with your Children pamphlet DLE Waipuna Hospice
	Caregiver Education Programme information sheet A4 Waipuna Hospice
	Complaints / Feedback leaflet A5 Waipuna Hospice
	Family Support Services pamphlet DLE Waipuna Hospice

	Loan Equipment information sheet 2x A4 Waipuna Hospice
	Methadone pamphlet DLE Waipuna Hospice
	Patient Communication Book notebook Waipuna Hospice
	Planning for a Funeral pamphlet DLE Waipuna Hospice
	Understanding what is happening pamphlet DLE Waipuna Hospice
	Waipuna Hospice Services pamphlet DLE Waipuna Hospice

Appendix Three: Health literacy demands

Medicines

Knowledge
How each medicine works
How to take each medicine
How different medicines can be used to treat pain
Side effects and serious side effects of each medicine
What to do in the event of serious side effects
Contraindications for each medicine including food
Reliable sources for more information about medicine e.g. pharmacist, GP, internet
How to keep medicines safe
How to use devices that deliver medicines
Need to maintain a supply of medicine
Entitlements around medicines

Tasks
Read medicine labels and follow instructions
Read medicine cards or pill cards supplied by other health professionals
Use maths skills when giving medicines (number, dose, time)
Give medicines according to specific directions
Titrate medicines according to directions e.g. PRN medicines
Explain to patient and whānau about medicines
Ask questions of health professionals and pharmacists in relation to medicines
Research medicines using internet and other reliable sources

Read food labels to identify which foods to avoid
Develop and apply medicine safety plan
Discuss complementary medicines with patient whānau, health professionals and pharmacists
Operate devices e.g. syringe drivers in accordance with instructions
Discuss treatment of pain management with patient, whānau, health professionals and pharmacists
Keep records of medicines given including patient's physical, mental and spiritual wellbeing
Maintain patient's mana when giving medicines
Synthesise often conflicting data from multiple sources and make decisions e.g. seek more information, take action, seek specific directions or instructions

Providing care to patient

Knowledge
Understand disease/condition and physical and mental impacts and different methods for managing those
Understand progression of disease/condition and physical and mental changes
Understand importance of nutrition and how to provide adequate nutrition as required
Understand importance of hydration and different ways to maintain this
Understand palliative treatments offered and how they will improve quality of life for patient
Understand other matters that have to be attended to e.g. financial, legal, spiritual
Understand importance of personal care for patient's wellbeing
Understand importance of infection control when providing personal care, especially wound care
Understand importance of skin integrity and how to maintain this

Tasks
Read information about disease/condition and its progression
Discuss disease/condition and progression with patient, whānau and health professionals
Work in partnership with whānau and health professionals
Describe and discuss symptoms to health professionals as required
Request assistance from health professionals
Discuss nutrition and hydration needs with patient, whānau and health professionals
Read food labels to check nutritional analysis
Meet nutrition and hydration needs of patient
Provide personal care to patient including bathing, showering, toileting, changing dressings and so on
Manage infection control when providing personal care, especially wound care
Maintain mana of patient while providing personal care
Monitor patient's physical, mental and spiritual wellbeing
Maintain own physical, mental and spiritual wellbeing
Discuss care giving needs with patient, whānau and health professionals
Set up roster for whānau to provide care for patient
Maintain diary of patient's appointments
Arrange for patient to attend all appointments or make alternative arrangements
Research alternative treatment options for patient
Make and maintain contact with community organisations for assistance e.g. Cancer Society
Discuss with patient and whānau the need for ongoing social, mental and spiritual

support
Arrange social, mental and spiritual support for patient as required
Provide on a regular basis information for whānau about patient's physical, social, mental and spiritual wellbeing
Manage patient's and own time to ensure adequate rest and sleep
Advocate on behalf of patient as required with whānau, health professionals and community organisations in relation to treatment
Make decisions with other whānau members about when additional resources required or change in treatment required
Discuss new requirements with health professionals or community support organisations
Synthesise often conflicting data from multiple sources and make decisions e.g. seek more information, take action, seek specific directions or instructions
Receive training from health professionals about how to provide care, give medicine and use equipment

Navigating the palliative care system

Knowledge
Understand what palliative care is
Understand what palliative care services are available in your area
Understand range of palliative care service providers in your area
Understand how you access palliative care services
Understand what palliative care services are suitable for patient and whānau
Understand range of services provided by palliative care provider and how these can be accessed
Understand rights and entitlements of patient and whānau in relation to palliative care
Understand entitlements of whānau in relation to palliative care services

Understand concept of informed consent in relation to palliative care services
Understand patient's right to confidentiality

Tasks
Read palliative care services information pamphlets including consent form
Sign consent forms for palliative care services
Communicate with health professionals about services needed
Maintain rights of patient while navigating the system
Maintain confidentiality of patient's information
Discuss with patient about who should have access to information
Research other palliative care services available
Advocate on behalf of patient for additional palliative care services
Arrange for patient to attend palliative care programmes
Support patient while resident at hospice
Read and respond to any correspondence from palliative care services provider
Support patient by participating in palliative care service provider's activities e.g. social events, recording personal histories
Synthesise often conflicting data from multiple sources and make decisions e.g. seek more information, take action, seek specific directions or instructions

Appendix Four: Patient Whānau Information Letter, Consent Form & Interview Schedule



Peter Rothwell Academic Centre
Waikato Hospital
Pembroke St
Hamilton, New Zealand
Telephone 64 7 839 8750
Facsimile 64 7 839 8712
Email: j.kidd@auckland.ac.nz

The University of Auckland
Peter Rothwell Academic Centre
Waikato Hospital
Private Bag 3200
Hamilton
New Zealand

Kia ora

We are asking you to take part in a research project.

What is the project about? The project is about palliative care which is caring for people who have illnesses such as cancer or heart disease, and their whānau, when treatment doesn't work anymore. Part of the research project is finding out about Māori people's experience of palliative care. We also want to hear what Māori patients and whānau say about

- the information they needed to take care of themselves or their whānau member
- how health services and health workers communicated with patients and whānau
- and if patients and whānau have suggestions about how services and communication by health workers could be improved.

Who is doing the research? My name is Dr Jacquie Kidd (Ngāpuhi). The other members of the research team are Dr Peter Woolford (Pākehā), Ms Susan Reid (Te Rarawa), Mrs Nicola Collins (Pākehā), Ms Stella Black (Ngai Tūhoe), Rawiri Blundell (Ngāti Porou).

What do I need to do? We are asking you to take part in an interview. The interview will take about one hour. You can bring other whānau to the interview. You can choose where the interview will take place – your home or another place that you choose. You can also choose the day and time for the interview with you and your whānau. The interview will be undertaken by one or more of the following people:



Rawiri Blundell



Stella Black



Susan Reid

Will I be paid for taking part? A koha of a \$100 voucher will be made in recognition of the contribution you and your whānau have made to the project. You will not have to pay anything to take part in the project.

Why are you asking me to take part? We are asking you to take part because you and your whānau are involved with palliative care at the moment, or your whānau have been involved with palliative care in the past. Taking part in this project will help us to understand how Māori patients and whānau experience palliative care at the moment, and how palliative care can be improved for Māori patients and whānau.

The information from the project will be used by palliative care services and health workers, people involved in planning and funding palliative care services, and other researchers to improve palliative care services for Māori patients and whānau.

What will happen in the interview? I will talk with you about

- your experiences of palliative care
- the information you were given
- how health services and health workers communicated with patients and whānau
- and if you and your whānau have suggestions about how services and communication by health workers could be improved.

If you agree we would like to record the interview. You do not have to agree to the recording.

What will happen after the interview? If the interview is recorded we will send you typed notes of your interview so you can read them. We will invite you to a hui to talk about the results of the study. You do not have to read the notes or come to the hui if you do not want to.

Do I have to take part? You don't have to take part if you don't want to. If you choose not to take part this will not affect any future care or treatment. If you do take part you can stop the interview at any time and you don't have to explain why. Before the interview we will explain the project again and ask you if you agree to take part. We will ask you to sign a form if you agree to take part.

How long will the project take? The project will take about 7 months to complete (end of March 2013). A report for the whole research project will be written. You will not be identified in this report. If you would like to get a copy of the full report we will send you one. The full report will be available at the end of 2013.

How do you make sure my information is kept private? You will not be identified in the notes from the interview or in the report about the project. After the project is finished the consent form and interview notes will be stored in a locked filing cabinet or on a secure computer at the University of Auckland for ten years and then will be destroyed.

I (Dr Jacquie Kidd) will be the only person who can access the notes and computer files. The consent form with your name on will be stored in a different place from the notes.

What if I need more information about the project? If you have any questions you can get more information about the study from me. Please feel free to contact Stella Black, Research Assistant if you need any more information or have any questions about this research project.

Ms Stella Black Phone: 021 415 441

Email: stella.black@auckland.ac.nz

If you have any questions or concerns about your rights as a participant in this study, you may want to contact an independent health and disability advocate:

Free phone: 0800 555 050

Free fax: 0800 2 SUPPORT (0800 2787 7678)

Email: advocacy@hdc.org.nz

This study has received ethical approval from the Multi-region Ethics Committee, ethics reference number MEC/12/EXP/050, from 13 April 2012 until 31 March 2013.

Noho ora mai, ra
Dr. Jacquie Kidd, RN, PhD
Senior Lecturer
School Of Nursing
Faculty of Medical and Health Sciences

Peter Rothwell Academic Centre
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Hamilton, New Zealand
Telephone 64 7 839 8750
Facsimile 64 7 839 8712
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The University of Auckland
Peter Rothwell Academic Centre
Waikato Hospital
Private Bag 3200

Consent Form (patients and whānau)

Study: Palliative care, health literacy, Māori communities and health services

Request for interpreter

English	I wish to have an interpreter	Yes	No
Deaf	I wish to have a NZ sign language interpreter	Yes	No
Māori	E hiahia ana ahau ki tetahi kaiwhaka Māori/kaiwhaka pakeha korero	Ae	Kao
Cook Island Māori	Ka inangaro au i tetahi tangata uri reo	Ae	Kare
Fijian	Au gadreva me dua e vakadewa vosa vei au	Io	Sega
Niuean	Fia manako au ke fakaaoga e taha tagata fakahokohoko kupu	E	Nakai
Sāmoan	Ou te mana'o ia i ai se fa'amatala upu	Ioe	Leai
Tokelaun	Ko au e fofou ki he tino ke fakaliliu te gagana Peletania ki na gagana o na motu o te Pahefika	Ioe	Leai
Tongan	Oku ou fiema'u ha fakatonulea	Io	Ikai
	<i>Other languages to be added following consultation with relevant communities.</i>		

I have read and understood the information sheet dated 2nd July 2012 for volunteers taking part in the study designed to understand how Māori patients and whānau experience palliative care at the moment, and how palliative care can be improved for Māori patients and whānau.

I have had the opportunity to discuss this study. I am satisfied with the answers I have been given.

I have had the opportunity to use whānau support or a friend to help me ask questions and understand the study.

I understand that taking part in this study is voluntary (my choice), and that I may withdraw from the study at any time, and this will in no way affect my continuing health care.

I understand that my participation in this study is confidential and that no material that could identify me will be used in any reports on this study.

I have had time to consider whether to take part in the study.

I know who to contact if I have any questions about the study.

I consent to my interview being audiotaped	Yes	No
I would like my audiotape sent to me after the notes have been prepared	Yes	No
I wish to receive a copy of the results	Yes	No

This study has received ethical approval from the Multi-region Ethics Committee, ethics reference number MEC/12/EXP/050, from 13 April 2012 until 31 March 2013.

I _____ (*full name*) hereby consent to take part in this study.

Date:

Signature:

Full names of researchers:	Dr Jacquie Kidd Ms Susan Reid Mrs Nicola Collins Ms Stella Black
Contact phone number for researchers:	Dr Jacquie Kidd 07 839 8750 Ms Susan Reid 09 3613800 Mrs Nicola Collins 021 242 2530 Ms Stella Black 021 415 441
Project explained by:	
Project role:	
Signature:	
Date:	

Note: A copy of the consent form is to be retained by each participant and (in the case of patients) a copy is to be placed in the medical file

Interview schedule patient and whānau participants

a) Access to palliative care services

- i) how, when, and why whānau accessed PC services
- ii) where was PC obtained from
- iii) what was the whānau experience of the PC services
- iv) what were the strengths of involvement with PC services
- v) what could be improved/changed/added to improve your experience or the experience of other patients / whānau
- vi) what other services would have been helpful

b) current health literacy about palliative care

- i) what types of things did patient/whānau have to do when looking after themselves/ whānau member
 - ii) was this different from what patient/whānau member thought they might have to do before you were first involved with palliative care services
 - (1) if yes, how?
 - iii) Activities and strategies used by patient/whānau to get information (and provide information to health professionals)
- “How often do you need to have someone help you when you read instructions, pamphlets, or other written material from your doctor or pharmacist?”**
(1 = never, 5 = always)
- iv) did health services or health professionals give you any resources or tools to help you look after yourself/your whānau member
 - v) were these helpful? How could they be improved?

c) Communication and palliative care

- i) what information did they receive from services;
- ii) how was this information communicated to them;
- iii) were any resources used to support communication
- iv) what was their experience of the communication and associated resources;
- v) what were the strengths of the communications/resources they received;
- vi) what could be improved

Appendix Five: Health Professional Information Letter, Consent Form & Focus Group Interview Schedule, Key Informant Interview Schedule



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The University of Auckland
Peter Rothwell Academic Centre
Waikato Hospital

Private Bag 3200
Hamilton
New Zealand

Tena koe

My name is Dr Jacquie Kidd. I am the leader of a research team funded by the Health Research Council and Ministry of Health that is undertaking a research project called 'Palliative care, health literacy, Māori communities and health services'. Other members of the research team are Mrs Nicola Collins, Ms Susan Reid and Ms Stella Black.

One part of the project involves interviews with health professionals who provide palliative care services. We are interested in their perspectives and understandings about Māori access to palliative care services. We are also interested in health professionals' perspectives on health literacy and palliative care for Māori patients and whānau, what the health literacy demands of palliative care are, and how services and health professionals take into account patient/whānau health literacy skills and service health literacy demands when they are working with Māori patients and whānau. We are also interested in the tools and resources that health services and professionals use to help them communicate with Māori patients and whānau.

We are talking with health professionals working in palliative care services in Auckland and the Bay of Plenty. We would like to have a focus group with staff, and are inviting you to participate in this focus group.

Your participation in the study will contribute to understanding Māori access to palliative care services, the health literacy demands placed on Māori patients/whānau by health services and health professionals, and whether and how these needs and demands are met. This information will be useful for palliative care health workers, palliative care services, people involved in planning and funding services, and for other researchers.

Your participation is entirely voluntary. If you do agree to take part in the study, you are free to withdraw from the study at any time, without having to give a reason. Before the focus group we will explain the study again and ask you if you consent to take part. We will ask you to sign a consent form.

There will be one focus group that will take about one hour. The focus groups will be held at your workplace. During the focus group you do not have to join in all of the discussion, and you may leave the focus group if you wish without having to give a reason. We will also record the focus group using a digital recorder.

Taking part in the study will not cost you anything and you will not be paid for taking part in the study.

The information from your interview will not include any detail that identifies you or your organisation.

The research will be completed at the end of March 2013. A report for the whole research project will be written. Neither you nor your organisation will be identified in this report. If you would like to get a copy of the full report we will send you one. The full report will be available about the middle of 2013.

After the study is finished the notes, transcripts and recording files from the focus group will be stored in a locked filing cabinet or secure electronic files at the University of Auckland for ten years and then will be destroyed. The consent forms will be stored in a different place to the transcripts, notes and recording files for ten years and then destroyed.

You can get more information about the study from Nicola Collins. Please feel free to contact her if you need any more information or have any questions about this research project.

Mrs Nicola Collins, Research Manager Phone: 021 242 2530

Email: nicola.collins@auckland.ac.nz

If you have any questions or concerns about your rights as a participant in this study, you may want to contact an independent health and disability advocate:

Free phone: 0800 555 050 Free fax: 0800 2 SUPPORT (0800 2787 7678)

Email: advocacy@hdc.org.nz

This study has received ethical approval from the Multi-region Ethics Committee, ethics reference number MEC/12/EXP/050, from 13 April 2012 until 31 March 2013.

Noho ora mai, ra

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School Of Nursing
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Hamilton
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Consent Form (health care professionals)

Study: Palliative care, health literacy, Māori communities and health services

Request for interpreter:

English	I wish to have an interpreter	Yes	No
Deaf	I wish to have a NZ sign language interpreter	Yes	No
Māori	E hiahia ana ahau ki tetahi kaiwhaka Māori/kaiwhaka pakeha korero	Ae	Kao
Cook Island Māori	Ka inangaro au i tetai tangata uri reo	Ae	Kare
Fijian	Au gadreva me dua e vakadewa vosa vei au	Io	Sega
Niuean	Fia manako au ke fakaaoga e taha tagata fakahokohoko kupu	E	Nakai
Sāmoan	Ou te mana'o ia i ai se fa'amatala upu	Ioe	Leai
Tokelaun	Ko au e fofou ki he tino ke fakaliliu te gagana Peletania ki na gagana o na motu o te Pahefika	Ioe	Leai
Tongan	Oku ou fiema'u ha fakatonulea	Io	Ikai
	<i>Other languages to be added following consultation with relevant communities.</i>		

I have read and I understand the information sheet dated 19th September 2012 for volunteers taking part in the study designed to understand health professional's knowledge about health literacy, the health literacy demands associated with palliative care, and how these demands are managed for Māori patients and whānau involved with palliative care services.

I have had the opportunity to discuss this study. I am satisfied with the answers I have been given.

I have had the opportunity to use whānau support or a friend to help me ask questions and understand the study.

I understand that taking part in this study is voluntary (my choice), and that I may withdraw from the study at any time, and this will in no way affect my employment.

I understand that my participation in this study is confidential and that no material that could identify me will be used in any reports on this study.

I have had time to consider whether to take part in the study.

I know who to contact if I have any questions about the study.

I wish to receive a copy of the results	Yes	No
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This study has received ethical approval from the Multi-region Ethics Committee, ethics reference number MEC/12/EXP/050, from 13 April 2012 until 31 March 2013.

I _____ (*full name*) hereby consent to take part in this study.

Date:

Signature:

Full names of researchers:	Dr Jacquie Kidd Ms Susan Reid Mrs Nicola Collins Ms Stella Black
Contact phone number for researchers:	Dr Jacquie Kidd 07 839 8750 Ms Susan Reid 09 3613800 Mrs Nicola Collins 021 242 2530 Ms Stella Black 021415441
Project explained by:	
Project role:	
Signature:	
Date:	

Note:

A copy of the consent form is to be retained by each participant and (in the case of patients) a copy is to be placed in the medical file.

Interview schedule health professionals

1) Māori access to palliative care services

- a) Health professionals (HP) experience of Māori access to palliative care services (under / over access, quality)
- b) Do you think that Māori access differs between generalist (e.g. GP based) or specialist PC services?
 - i) If so, why?

2) Health literacy for Māori in palliative care

- a) HPs understanding of the term HL
- b) What health literacy demands does palliative care/the service make on patients / families HL?
- c) Does the service take these HL demands into account in provision of services and resources?
 - i) if so, how?
 - ii) How does HP know this?
 - iii) Can HP give examples?
- d) Generally speaking, do patients/whānau level of HL differ between Māori and non-Māori patients/whānau?
 - i) If so, how?
 - ii) How does HP know this?
 - iii) Can HP give examples?
- e) Does the service use any strategies to help address the different HL levels seen with Māori patients/whānau?
 - i) If yes, what are the strategies?
 - ii) How were they developed?
 - iii) How effective are these strategies?
 - iv) Could they be improved?
 - v) If so, how?

3) Communication with patients and whānau

- a) In general, how does HP communicate with patients/whānau initially?
 - i) And over time?
- b) Are different communication strategies / techniques / approaches / resources used with Māori patients/whānau?
 - i) If so, can you describe these
 - ii) How were they developed?
 - iii) What are the strengths of these approaches?
 - iv) How do you know these are strengths?
- c) What are the barriers to effective communication with Māori patients and whānau?
 - i) What is currently being done to address these barriers?
 - ii) What else could be done?

Key informant interview schedule

Health literacy (HL) demands are the reading, writing, speaking, listening, and numeracy (maths) patients and whānau have to do to engage with your services.

1. Could you please tell me what the process is when a patient and whānau first comes into contact with your organisation?

ii) Who do they first have contact with?

iii) What do patients and whānau have to do at that first contact? What information do you collect from them and how

(a) Oral interaction only

(b) Fill in forms

(c) Read documents

(d) Sign documents

1. As the process progresses, who else do the patient and whānau have contact with?

2. What other things do patients and whānau have to read, write, calculate, speak about, listen to?

3. What do you notice patients and whānau doing – taking notes, asking you to explain more, checking things on the computer or other information sources

4. What do you ask patients and whānau to do about decision making? How do you involve patients and whānau in decision making?

5. (where relevant) About equipment – how do you instruct patients and whānau how to use this?

6. (where relevant) About giving and using medications – how do you instruct patients and whānau how to use this? What do you ask patients and whānau to do about this (e.g. keep notes, ring GP, ring pharmacist)

7. (where relevant) About symptom management such as level of pain, level of discomfort, how the patient's symptoms have been, new symptoms, - what do you ask patients and whānau to do about these things?