Stocktake of Palliative Care Education and Support Needs for Māori Providers within Waikato DHB District

Final Report 2008

Executive Summary

This project commenced in November 2007 with the aim of completing a stocktake identifying the education and support requirements Waikato Māori providers have in relation to palliative care.

The aim of this project was to promote palliative care by working in partnership with Māori Health Providers to complete a stocktake identifying their education and support requirements. This would be done through achieving the following objectives:

1. Ensure Maori Health providers are aware of the palliative care approach with links to supporting essential[1] services and systems
2. Identify current Maori Health provider links with other Generalist and Specialist palliative care providers and vice versa
3. How do Māori Health Providers provide / or refer to palliative care support services for people?
4. How do Specialist Palliative Care providers link with Māori Health Providers?
5. To complete a stocktake of Waikato Māori Health Provider education and support needs in relation to palliative care
6. To complete a stocktake of Waikato palliative care services responsiveness to Māori[2]
7. Analysis of findings, with a final report provided to Waikato Palliative Care Operations Network and Waikato Māori Health Providers

From January-May 2008 Te Puna Oranga met with 11 Waikato Māori providers to discuss their education and support needs in relation to palliative care. The findings are broken down into the following categories:

- Provision of services by Waikato Māori providers regarding palliative care
- Awareness of the Waikato DHB Palliative Care Strategy
- Linking with Specialist Palliative Care Services
- Education and Support Needs
- Palliative Care Resources
- Funding
- Improving Palliative Care for Māori
- Current Palliative Care Services within the Waikato DHB Area

Recommendations from the stocktake are as follows:

1. To continue to promote palliative care by working in collaboration with Māori providers
2. The development of palliative care education and information resources for Waikato Māori providers, and Māori whānau moving through the palliative care system.
3. The establishment of a strengthening relationships network between Waikato specialist palliative care services and Waikato Māori providers

Future recommendations that may go beyond the 2008-2009 timeframe are as follows:

[1] Essential services include assessment, care co-ordination, clinical care, support care, education and advice

[2] This may include the development of Māori health plans, and Māori health policies that services use to enhance their services to Māori.

1. Development of a generalised palliative care support service encompassing the principles of Te Whare Tapa Wha to ensure holistic services are provided in collaboration with palliative care services
2. Development of a phased pilot project between Waikato specialised palliative care services and Waikato Māori providers to establish a Māori Palliative Care Nurse Co-ordinator, with the view of further developing this position to one of a Nurse Practitioner. This relates to both the stocktake undertaken and the *New Zealand Palliative Care Strategy* (2001).

Background

The Ministry of Health defines palliative care as
"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: to do this, a person's physical as well as psychosocial, spiritual and cultural needs are assessed and addressed.
2. Support the individual's family, whanau, and other caregivers where needed, through the illness and after death." (Ministry of Health, 2007)

The vision of the *New Zealand Palliative Care Strategy* is that all people who are dying and their family/whānau who could benefit from palliative care have timely access to quality palliative care services that are culturally appropriate and are provided in a co-ordinated way[3].

Palliative care should be provided by all health professionals (generalists), supported where necessary, by specialist palliative care services.

Generalist palliative care is palliative care provided by those affected by life-limiting illness as an integral part of standard clinical practice by any healthcare professional that is not part of a specialist palliative care team. It is provided in the community by general practice teams, Māori health providers, allied health teams, district nurses, and residential care staff. It is provided in hospitals by general adult and paediatric medical and surgical teams, as well as disease specific teams – for instance oncology, respiratory, renal and cardiac teams. Providers of generalist palliative care will have defined links with specialist palliative care teams.

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." [4]
Waikato specialist palliative care providers are:

- Hospice Waikato
- Palliative Care Unit (PCU), Health Waikato, Waikato DHB

The *Waikato DHB Palliative Care Strategy 2005-2010* goal is to ensure that all providers of palliative care in the Waikato work together with the community to ensure that all people with palliative care needs and their family / whanau have access to essential palliative care services, provided in a co-ordinated and culturally responsive way. The four key result areas of the local strategy are:

1. Integrated and collaborative care
2. Patient focus on improved access and equity to palliative care services based on identified needs and informed choices
3. Workforce development to ensure a skilled and competent workforce committed to the palliative care approach
4. Quality Systems

The Waikato spans a large geographical area and encompasses a diverse mix of rural, remote and urban areas. The *Waikato Palliative Care Strategy* identified the following key weaknesses:

- Lack of palliative care approach awareness within both public and private health care providers
- Fragmentation of providers and co-ordination of care and services

[3] Ministry of Health (2001)
[4] Ministry of Health, 2007

- Service gaps and access issues to essential palliative care services across the Waikato
- Workforce development.

As part of their work Hospice Waikato work collaboratively with rural District Nurses to ensure effective service delivery to rural Waikato.

Reducing Inequalities

Reducing inequalities for different population groups is a key principle of the *New Zealand Health Strategy*[5], as well as being a dual goal of the *New Zealand Cancer Control Strategy* and associated *Action Plan*[6]. Palliative care falls under both of these national strategies.

Within New Zealand Māori/non-Māori ethnicity is a strong measure of health need [7]. Māori experience poorer health outcomes than other New Zealanders, for example Māori are 9% more likely than non-Māori to be diagnosed with cancer and 77% more likely than non-Māori to die from their cancer[8]. This included the need for time, support for whānau, and flexible and responsive services[9]. Within the report *Access to Cancer Services for Māori*[10] one of the major gaps found was the lack of Māori cancer support services in New Zealand.

Within the Waikato DHB area there are 15 Māori providers. Of these 15 none are contracted to provide either generalist or specialist palliative care services. This is not to say that Waikato Māori providers do not provide some type of support to patients and their whānau with regard to palliative care. Waikato Māori providers are predominantly contracted to provide primary care services across chronic diseases such as diabetes, cardio-vascular and mental health. However, these diseases can develop to a point where the patient may require palliative care. It is therefore essential that a stocktake of Waikato Māori provider palliative care education and support needs is undertaken, with the view that any identified gaps will be overcome.

Objectives

In order to achieve the project statement of promoting palliative care by working in partnership with Māori Health Providers to complete a stocktake identifying education and support requirements, the following objectives were set for the project:

1. Ensure Maori Health providers are aware of the palliative care approach with links to supporting essential[11] services and systems
2. Identify current Maori Health provider links with other Generalist and Specialist palliative care providers and vice versa
3. How do Māori Health Providers provide / or refer to palliative care support services for people?
4. How do Specialist Palliative Care providers link with Māori Health Providers?

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[5] Ministry of Health 2000
[6] Ministry of Health 2003, 2005
[7] Minister of Health 2003
[8] Robson B, Harris R. (eds). *Hauora: Māori standards of health IV. A study of the years 2000-2005.* Wellington: Te Roopu Rangahau Hauora a Eru Pomare.
[9] Tamaki Healthcare PHO and Te Kupenga o Hoturoa PHO
[10] Cormack, D et al. (2005). *Access to cancer services for Māori: A report prepared for the Ministry of Health.* Wellington School of Medicine and Health Sciences.
[11] Essential services include assessment, care co-ordination, clinical care, support care, education and advice, end of life care

5. To complete a stocktake of Waikato Māori Health Provider education and support needs in relation to palliative care
6. To complete a stocktake of Waikato palliative care services responsiveness to Māori[12]
7. Analysis of findings, with a final report provided to Waikato Palliative Care Operations Network and Waikato Māori Health Providers.

Methods

The main method used to collect the information needed for this project were meetings held with Waikato Māori providers who indicated they were interested in participating. In total 10 Māori provider meetings were held and 11 Waikato Māori providers were involved. The meetings involved a range of Māori provider staff, including Chief Executives, Trustees, service managers, nurses and home care workers.

A semi structured questionnaire (see appendix one) was developed to use during the meetings with Waikato Māori providers. The questionnaire was used more as a guide during the meetings to ensure key information was being gathered.

A hui was held with a group of kaumātua to discuss their perspectives regarding palliative care. This was done at the request of one of the participating Māori providers. The group were asked what their experiences of palliative care were and how the pathway could be improved for Māori patients and whānau.

As well as this a questionnaire (see appendix two) was sent to the Co-ordinator for the Palliative Care Unit at Health Waikato. The most recent Health Share audit for Hospice Waikato was also reviewed for the purposes of this project. The audit answers questions specific to the palliative care of Māori accessing Hospice Waikato. Email contact was made with the Chief Executive of Hospice Waikato to ensure this would be sufficient.

Findings

The following findings have been developed from the meetings held with Waikato Māori providers since January 2008. They also include the review of the Hospice Waikato Health Share audit, and numbers extracted from the Waikato DHB Case Mix Service.

Provision of services by Waikato Māori providers regarding palliative care:
All of the providers were clear that they were not contracted to provide palliative care to clients on their data base. However, almost all (with the exception of one) stated that caring for patients and whānau who are receiving palliative care inadvertently occurred within the work they do. Services provided included:

- Advocacy for the patient/ whānau
- Caregiver services
- Organisation of resources required by the patient and their whānau (when in the home)
- Developing pathways for the patient/whānau into palliative care services
- Provision of transportation to and from health services required
- Wraparound[13] services for patients with palliative care

[12] This may include the development of Māori health plans, and Māori health policies that services use to enhance their services to Māori.
[13] Wraparound services include looking at the disease state as well as other social and health factors impacting on a person's wellbeing. It may involve ensuring transport is available, housing is adequate and certain resources are available to the patient.

- Provision of karakia, rongoa clinics, mirimiri, and korero[14]
- Provision of a 'space' specifically for kaumātua to socialise

One Māori provider owns an elderly persons rest home and will accept palliative care patients in desperation.

The majority of these services are not funded specifically for palliative care patients; however Waikato Māori providers will provide these services to ensure their whānau do not go without.

Awareness of the Waikato DHB Palliative Care Strategy
Of the 11 Waikato Māori providers only one had heard or received a copy of the Waikato DHB Palliative Care Strategy.

Linking with Specialist Palliative Care Services
Waikato Māori providers will refer to both the Palliative Care Unit and Hospice Waikato when a request is made by a patient. Contact is kept with District Nurses when and if required. Generally telephone referrals are made to specialist palliative care services, at times this will be done via the District Nurse.

Raukawa Hauora indicated that they had made more formal links with the Palliative Care Unit and were working on building this relationship further.

A key issue to note at this point is that further knowledge on the services provided by specialist palliative care services in Waikato would be an asset to Māori providers.

Education and Support Needs
Education and support needs are broken down into two categories: those for Māori provider workers and those for whānau receiving palliative care. These are outlined below.

Support/Education Needs of Māori providers
A vast amount of information was gathered in relation to Māori provider palliative care support and education needs. These have been summarised in the following points:

- Developing pathways of networking and connecting with generalist and specialist palliative care service providers in the Waikato
- Updated knowledge on the availability of resources and services for patients requiring palliative care. Special consideration needs to be given for those living in rural areas
- Training regarding what palliative care encompasses
- Training regarding the roles and responsibilities of District Nurses, Hospice Waikato, Palliative Care Unit and how Waikato Māori providers may be able to compliment these services
- Training regarding Not for Resuscitation Orders
- Training regarding the process of discharge from the hospital to the community
- Training regarding palliative care for staff working in rural older persons rest homes
- Clinical training of Māori provider nurses in the area of palliative care to ensure they have an accurate level of understanding. This training may not lead to the

[14] Karakia (prayers), rongoa (alternative health; Māori health methods), mirimiri (massage), korero (conversation

delivery of services, but may be a means of enabling nurses to answer questions posed by whānau receiving palliative care
- Knowledge of where to access out of hours palliative care support services
- The development of a case study on Māori whanau receiving palliative care to identify where interventions may have assisted
- Support of and for District Nurses providing palliative care services in rural areas to ensure they have adequate resources for whānau
- An education pack/programme for patients/whānau/community providers that outlines the transition from the Palliative Care Unit to the community. Similar to the training carried out for OPRS
- Improved communication across agencies (for example Work and Income New Zealand, General Practitioner services, Primary Health Organisations, Hospitals) to ensure easier pathway of care for those receiving palliative care.

Providers would like the opportunity to further develop their knowledge and skills in palliative care but would also like to be financially recognised for this. It is essential to recognise the financial and human resource limitations placed on Māori providers and ensure these are accommodated for when training packages are developed.

Support/Education Needs of Whānau[15]

- Provision of clear, concise and easily understood information regarding resources, services and entitlements available for patients receiving palliative care. This information needs to be readily available for any whānau who will be supporting the patient if/when they return home. There is a need to have this information reinforced to patients and their whānau, i.e. a single delivery of this information may not be adequate. Follow up may be required.
- Provision of practical, disease specific training for whānau supporting palliative care patients. This is to ensure supporting whānau members are confident in the care they will be providing to the palliative care patient, and also to ensure the patient is as comfortable as possible.
- Defining palliative care and long term illness.
- Education regarding the definition of Not For Resuscitation Orders. Some whānau and patients may respond in anger when asked, however this may come from a lack of understanding.
- Provision of support to the supporting whānau. This may include grief support, education regarding what to expect during palliative care stages, entitlements for supporting whānau, support after death has occurred.
- Provision of information to supporting whānau regarding any resources and entitlements they may be permitted to receive.
- Ensuring a patient does have adequate support available if they do return home at end stage.
- Ensuring the patient and supporting whānau are aware of the discharge process from the hospital to the community, and are aware of who to contact when support is needed in the home. This also relates to greater communication between the hospital, the patient and the whānau.
- Greater information for patients regarding the services of Hospice Waikato. The majority of Māori providers identified Hospice Waikato as an excellent service for Māori palliative care patients once these patients were aware of the services available.
- Education for supporting whānau regarding the administration of medication, and what to do with any surplus medication after a patient's death.

[15] In this instance whānau relates to a person who is receiving palliative care and the people supporting that person during this stage

Palliative Care Resources
Discussions with Māori providers highlighted some issues regarding the availability of resources for palliative care patients. In some rural areas it has been difficult for palliative care patients to access resources. In some cases the resources that have been provided to the patient have been inappropriate and not received in a timely manner.

At other times a patient may have moved from receiving funded care of a certain type (for instance under DSL) and due to their terminal illness have now moved into palliative care. There appears to be some gaps regarding the transfer of care from one state into palliative care in terms of funding and resources available to the patient now in palliative care.

Following on from this some providers have identified a gap between moving from DSL funded care into funded palliative care. There appears to be a lack of information regarding what funding is available once a patient has moved into palliative care. Providers asked if there was a possibility of maintaining the level of resources and services available once a patient has moved into palliative care.

At times the shortage of Community Occupational Therapists has meant an increased wait in time for home assessments to be completed. Providers asked whether there was another avenue that could be used for the completion of small assessments in the home (for instance the installation of a hand rail) when workforce shortages are an issue.

Funding
It was clear from the outset of this project that Waikato Māori providers do not receive funding to provide any type of palliative care. However throughout each of the meetings it became obvious that some type of support is provided to palliative care patients and their whānau if they come in contact with a Māori provider, regardless of whether the provider is funded to provide this service or not. Discussions with providers highlighted the need to financially recognise the type of support work Māori providers deliver with regard to palliative care.

In some cases Māori providers do receive referrals to provide care and support for palliative care patients, however the funding does not follow the patient and it makes it difficult to provide the services required by the patient. Providers highlighted the need to contract palliative care services on an individual basis.

There also appears to be a lot of confusion regarding funding received through DSL once a patient in diagnosed as palliative care.

Improving Palliative Care for Māori
Questions regarding improving the palliative care pathway for Māori were asked during the meetings held with Māori providers. The following points highlight (in summary) the feedback provided:

- Establishing one clear pathway for palliative care patients to ensure streamlined services
- Increased knowledge of how to move through the health system
- Access to information regarding the various local societies and support groups and the resources offered through these. This is to ensure patients and their whānau can be fully informed of the resources and services available to them.

- The development of an information pack that outlines resources and services available local to the patient and the supporting whānau. This should be provided upon palliative care diagnosis.
- Being fully informed at each step of the pathway and ensuring key information is provided clearly to both the patient and the supporting whānau. This includes being fully informed of every diagnosis
- Eliminating unrealistic expectations placed on the patient. For instance, if blood tests are required is there a way to have these done after hours or at a location closer to the patient?
- Further building collaborative relationships between patients/whānau/community providers and specialist palliative care services
- An increased frequency of palliative care nurses in the community
- Supporting the wellbeing of the patient so as to ease their journey. This may mean looking beyond the treatment of the primary disease.
- To ease the journey in a culturally safe environment with adequate resources, enabling the patient to live well and to die with dignity, respect and aroha.
- Establishing a co-ordinator to work across agencies for the betterment of the patient
- Further health education targeted at younger population groups to decrease the prevalence of chronic diseases.

Māori specific palliative care services
Most providers discussed the development of Māori specific palliative care services. One such avenue talked about was the establishment of a Māori Palliative Care Nurse Co-ordinator, with the view of further developing this position to one of a Nurse Practitioner. This position would be based in the community with one of the local Māori providers. There should be a view to develop further positions of this type in the Māori community. Some providers indicated they would be interested in services of this kind, but without additional funding were not able to provide these services in the immediate future.

It should be noted at this point that Taumarunui Community Kokiri Trust owns and manages an older persons home in Taumarunui, and in times of desperation will provide beds for palliative care. As well as this the Trust has a vacant three bedroom facility that could possibly be used for palliative care beds. There may be an opportunity in this instance to develop a joint venture between this Māori provider and specialist palliative care services for future palliative care services in Taumarunui.

The providers discussed the need to recognise cultural differences with regard to palliative care and dying. There is a need to practically incorporate Māori values into the delivery of palliative care, and at times the best avenue to do this may be through a Māori provider. It was acknowledged that mainstream palliative care services definitely have a role to play in the care of Māori palliative care patients, however there was also a need to recognise the role Māori providers have to play in ensuring cultural (as well as clinical) needs are adhered to.

Current Palliative Care Services within the Waikato DHB Area
Within the Waikato DHB region specialist palliative care services are provided by two main providers:

- Hospice Waikato
- Palliative Care Unit (PCU), Health Waikato, Waikato DHB

These services are centrally located in Hamilton, although services are provided to outer lying areas.

Within the rural communities palliative care services are mainly provided by District Nurses, either within the home of the patient or in residential care (for instance funding has been provided for palliative care beds in rest homes within some of the rural communities), and in some cases G.P's will provide some type of palliative care. Tokoroa Community Hospice Trust is a small community organisation that provides a support service for palliative care patients and assists in the provision of palliative care equipment.

A review of the recent Health Share Audit[16] for Hospice Waikato shows that this provider has fully achieved against all contractual agreements in relation to Māori health and the provision of culturally appropriate service delivery to Māori entering their services. A discussion with the CE of Hospice Waikato has also highlighted an increase from 7% to 14% of Māori entering the adult service over the past fiscal year (2006-2007). For the same year 36% of all children seen at Rainbow Place identified as Māori.

Numbers from Waikato DHB Case Mix show that from 2006-May 2008 a total of 163 discharged patients from the Health Waikato Palliative and Terminal Care Medical Services identified as Māori. These numbers (along with the increase in Māori entering Hospice Waikato) highlight the need to continue to provide culturally appropriate palliative care services.

Hospice Waikato has developed, and continues to improve, a Māori health plan. They also have ongoing input from a Kaumātua to ensure their services are appropriate to Māori. The Health Waikato Palliative Care Unit are able to access resources such as the *Waikato DHB Tikanga Recommended Best Practice Guidelines*, and are also obligated to follow Waikato DHB policies and procedures (including the Māori Health Policy).

Recommendations

Recommendations from the stocktake are as follows:

1. To continue to promote palliative care by working in collaboration with Māori providers
2. The development of palliative care education and information resources for Waikato Māori providers, and Māori whānau moving through the palliative care system.
3. The establishment of a strengthening relationships network between Waikato specialist palliative care services and Waikato Māori providers

Future recommendations that may go beyond the 2008-2009 timeframe are as follows:

1. Development of a generalised palliative care support service encompassing the principles of Te Whare Tapa Wha to ensure holistic services are provided in collaboration with palliative care services
2. Development of a phased pilot project between Waikato specialised palliative care services and Waikato Māori providers to establish a Māori Palliative Care Nurse Co-ordinator, with the view of further developing this position to one of a Nurse Practitioner. This relates to both the stocktake undertaken and the *New Zealand Palliative Care Strategy* (2001)

[16] HealthShare Final Audit Report: Waikato Community Hospice 2007

Appendix One

Questionnaire for Māori Providers:

1. Are you aware of the WDHB Palliative Care Strategy and Action Plan?

2. What geographical area do you cover?

3. Is palliative care an area that you, as a worker or a provider, work in?

4. If yes, how do you provide palliative care services, or how do you refer to palliative care support services for people? (What types of palliative care do you provide?)

5. How do you link with other generalist and specialist palliative care providers? And how do they link with you when needed? What links do you have with other palliative care providers?

6. What, if anything, are your needs with regards to education and support in relation to palliative care? (What would help you?)

7. How do you think palliative care services for Māori could be improved?

Appendix Two

Questions for Palliative Care Unit:

1. How do you ensure culturally effective service delivery to Māori? For instance are the recommended Tikanga Best Practice Guidelines utilised in your unit?

2. Are you aware of the Māori health strategies for the Waikato DHB? (If not we are able to supply these for you)

3. What training/education opportunities do PCU staff have in terms of culturally effective service delivery? (For instance Te Ara Tika Tuatahi and Te Ara Tika Tuarua)

4. How are Māori involved in the development of your services?

5. How do you link with Māori providers in the Waikato DHB region?

6. How do you think palliative care services for Māori could be improved?