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The role and potential of community based cancer care for Māori in Aotearoa/New Zealand

A thesis presented in partial fulfilment of the requirements for the degree of

Doctor of Philosophy in

Public Health

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New Zealand

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2016
Abstract

There are unacceptable ethnic differences in cancer survival in Aotearoa/New Zealand and quality of life differs between Māori and non-Māori at all stages of the cancer journey. Overseas studies have recognised that all the priorities for cancer services are affected by actions in primary care – reducing the risk of cancer, early detection and faster access to specialist treatment, improved support for patients living with cancer, and reducing inequalities. Additionally, the importance of strategic policy to direct practical and effective community-based cancer care has also been identified. Māori health provider organisations have been using a ‘Whānau Ora’ approach to provide primary health care services for over twenty years; however their contributions to cancer care have been largely invisible. This qualitative study explores the role and potential of community based cancer care for Māori as a means to addressing three study questions:

- What helps patients and whānau to access and receive cancer services?
- What is the role of primary care, which includes Māori health providers and mainstream providers, in facilitating access into and through cancer care services?
- Does current cancer control policy adequately address Māori needs?

Using a case study approach, participants from four areas of cancer care were recruited within a Māori-centred, ethic of care framework, to explore the experiences of those who plan, manage and administer, deliver, and receive cancer care. The main source of data was in-depth semi-structured interviews. The key themes identified from this research are that: whānau hold critical and multiple roles across cancer care; there are gaps in supportive cancer care and information that is appropriate for Māori; ongoing relationships with a primary
health care provider assist whānau to navigate their cancer journeys, with Māori health providers in particular, delivering wide ranging cancer care services, and linking patients with mainstream services; engaging successfully with the cancer care system currently requires an individual rather than collective approach; cultural safety education should extend across all cancer care services; communication between cancer care providers is improving and; cancer control policy in Aotearoa has a universal focus which does not adequately address Māori needs.

The role of primary care is pivotal in Māori cancer care access, from prevention through to survival, and must be at the forefront of cancer policy. Acknowledgement of the different support and quality of life needs of Māori, including recognition of the interdependence of whānau as a strength, is required. Māori health providers have the potential to play a much greater role in cancer care and support, but sustainable funding models are required if Māori health providers are to continue, and expand on, the wide range of work that they undertake within their communities. The newly implemented Whānau Ora Initiatives may provide a vehicle for provision of sustainable community cancer care services.
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Glossary

Aotearoa  Land of the long white cloud.  New Zealand

awhi  embrace, support

hapū  sub tribe

hīmene  hymn

hinengaro  mental state

hui  meeting
<table>
<thead>
<tr>
<th>Maori Word</th>
<th>English Translation</th>
</tr>
</thead>
<tbody>
<tr>
<td>iwi</td>
<td>tribe</td>
</tr>
<tr>
<td>kai</td>
<td>food</td>
</tr>
<tr>
<td>kaimahi</td>
<td>worker</td>
</tr>
<tr>
<td>kanohi</td>
<td>face</td>
</tr>
<tr>
<td>kanohi ki te kanohi</td>
<td>face to face</td>
</tr>
<tr>
<td>karakia</td>
<td>prayer</td>
</tr>
<tr>
<td>kaumātua</td>
<td>elder</td>
</tr>
<tr>
<td>kaupapa</td>
<td>topic, idea, foundation</td>
</tr>
<tr>
<td>Kaupapa Māori</td>
<td>Māori foundation</td>
</tr>
<tr>
<td>Kite</td>
<td>basket</td>
</tr>
<tr>
<td>Kohanga reo</td>
<td>Māori language nests</td>
</tr>
<tr>
<td>Ko wai au</td>
<td>What do I bring to this?</td>
</tr>
<tr>
<td>korero</td>
<td>talk, to speak</td>
</tr>
<tr>
<td>Māori</td>
<td>normal (also the name of the Indigenous people of Aotearoa)</td>
</tr>
<tr>
<td>Māoridom</td>
<td>the Māori world</td>
</tr>
<tr>
<td>marae</td>
<td>meeting ground</td>
</tr>
<tr>
<td>manuhiri</td>
<td>visitors, or proper behaviour with new people</td>
</tr>
<tr>
<td>matua</td>
<td>father</td>
</tr>
<tr>
<td>mihi</td>
<td>greet</td>
</tr>
<tr>
<td>mirimiri</td>
<td>massage</td>
</tr>
<tr>
<td>mokopuna</td>
<td>grandchildren</td>
</tr>
<tr>
<td>(or moko)</td>
<td></td>
</tr>
<tr>
<td>noho whakaiti</td>
<td>appropriately quiet and watchful</td>
</tr>
<tr>
<td>ora</td>
<td>wellness</td>
</tr>
<tr>
<td>Pākehā</td>
<td>descendants of colonial settlers from England, Ireland, Scotland and Wales</td>
</tr>
<tr>
<td>Pounamu</td>
<td>greenstone</td>
</tr>
<tr>
<td>rongoā</td>
<td>medicine</td>
</tr>
<tr>
<td>tane/tāne</td>
<td>man/men</td>
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</tbody>
</table>
tamariki/tāmariki  child/children

tangata whenua  people of the land

tapu  sacred, forbidden

Te Ao Māori  the Māori world

Te Reo Māori  the Māori language

Te wanatanga katoa  complete governance

tikanga Māori  Māori values and beliefs

tinana  physical body

tūpuna  ancestor

wahine/wāhine  woman/women

waiata  song

wairua  spirit

whakairo  carving

whakamā  shy

whakapapa  genealogical table, cultural identity

whānau  people connected by whakapapa or kaupapa

whānau ora  healthy families

whenua  land

whakapapa  lineage, genealogical table, cultural identity

whanaungatanga  relationship, kinship

whare  house

wairua  spirit, attitude
# Abbreviations

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Full Form</th>
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<tbody>
<tr>
<td>CEO</td>
<td>Chief Executive Officer</td>
</tr>
<tr>
<td>CCDHB</td>
<td>Capital and Coast District Health Board</td>
</tr>
<tr>
<td>CCNZ</td>
<td>Cancer Control New Zealand</td>
</tr>
<tr>
<td>DHB</td>
<td>District Health Board</td>
</tr>
<tr>
<td>DNA</td>
<td>Did Not Attend</td>
</tr>
<tr>
<td>GP</td>
<td>General Practitioner</td>
</tr>
<tr>
<td>HRC</td>
<td>Health Research Council</td>
</tr>
<tr>
<td>IPA</td>
<td>Independent Practitioner Association</td>
</tr>
<tr>
<td>ISP</td>
<td>Independent Service Provider</td>
</tr>
<tr>
<td>KOETI</td>
<td>Kia Ora e Te Iwi</td>
</tr>
<tr>
<td>MWWL</td>
<td>Māori Women’s Welfare League</td>
</tr>
<tr>
<td>NSU</td>
<td>National Screening Unit</td>
</tr>
<tr>
<td>NZ</td>
<td>New Zealand</td>
</tr>
<tr>
<td>PHO</td>
<td>Primary Health Organisation</td>
</tr>
<tr>
<td>UN</td>
<td>United Nations</td>
</tr>
<tr>
<td>WHO</td>
<td>World Health Organisation</td>
</tr>
<tr>
<td>WINZ</td>
<td>Work and Income New Zealand</td>
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