Rural general practitioner perspectives of the needs of Māori patients requiring palliative care

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Abstract

Aim We aimed to identify rural general practitioners perspectives of the needs of Māori patients receiving palliative care and to discover what actions the general practitioners had undertaken to meet these needs.

Methods This was a cross sectional postal survey of rural general practitioners. A questionnaire was developed which included a number of questions relevant to cultural needs when providing palliative care to Māori.

Results 186/440 rural general practitioners responded to the survey. 52% said that they had no Māori with palliative care needs in the last 12 months, 23% had one patient and 25% had looked after 2 or more. An estimated 126/204 (62%) Māori patients had died at home. The greatest need identified by rural general practitioners when dealing with Māori patients requiring palliative care appears to be for good communication which they saw as especially important when a large family/whānau are likely to be involved. Other notable concerns were the apparent gaps in some areas for home care and the demand for more Māori nurses to be available in rural areas.

Conclusions It appeared that there was great variation in the demand for palliative care services for Māori. Some rural general practitioners rarely encounter Māori patients whilst for others caring for Māori who are in need of palliative care is an important part of their practice. There is some demand from general practice for cultural competency training and support from Māori providers and Māori services in District Health Boards. Further research in this area would be valuable.

Although the New Zealand Palliative Care Strategy (2001) (NZPCS) aims to ensure equitable provision of services—at the time of its publication there were concerns expressed about access to care for rural patients and for Māori.1

The international literature suggests there maybe disparities in the care provided for those suffering from non cancer causes of terminal illness, for the socially deprived, the elderly and those from ethnic minorities.2,3

In many clinical areas such as diabetes, heart disease and some cancers there are good studies to show the disparities in outcomes for Māori.4 However there are few measures of disparity for palliative care and consequently little objective evidence of need. Cormack et al noted anecdotal reports of differential utilisation of palliative care services by Māori—and a belief that late referral of Māori to palliative care resulted in reduced access to equipment and support services.5

Research from Australia has demonstrated the needs of their indigenous population.6,7

In particular there has been concern that there is a lack of domiciliary support and so
many Aborigines die in hospitals in a culturally unfamiliar environment. The need for culturally appropriate services for indigenous people has been cited in a number of papers and this is likely to be relevant for Māori.

The provision of more culturally appropriate services for Māori has been improved through a growth in the number of Māori providers of health care services, although an internal study showed few Māori providers in the Waikato District Health Board offer palliative care services. There have also been moves to improve the cultural competency of non-Māori health services staff. The RNZCGP quality assurance program for general practice—the Cornerstone Accreditation—includes a section on cultural competency—and the Medical Council has introduced cultural competency as a requirement for all New Zealand registered medical practitioners.

Access to specialist palliative care services is seen as a key issue in rural areas where distance from a relatively scarce resource means that rural patients are more dependent on their local general practices and district nursing services for palliative care provision. Given that many Māori live in rural areas, or return to their ancestral/tribal home when terminally ill, means that they are disadvantaged in their access to specialist services. There may also be cost issues when transferring care from one District Health Board to another.

As part of a survey of the needs for palliative care services in rural areas we aimed to identify the opinions of rural general practitioners about the needs of Māori patients receiving palliative care and to discover what actions they had undertaken to meet these needs.

**Methodology**

This was a cross sectional survey of rural general practitioners. We report here the findings from specific questions about cultural aspects of palliative care that we asked as part of a larger study. The participants were all general practitioners identified by the New Zealand Institute of Rural Health in a recent workforce survey. A questionnaire was developed partly based on a questionnaire that had been used in Australia. A number of questions relevant to provision of palliative care for Māori were added after discussion with Te Puna Oranga, the Māori Health Unit of the Waikato District Health Board.

The New Zealand Rural General Practice Network were consulted and also advised on the questionnaire. Key questions that were asked included: How many Māori ‘palliative care’ patients have you managed in the last 12 months? Where have your Māori patients died? Are there specific needs that you have identified for your Māori patients? Are there allied health professionals with experience in Palliative Care and on whose expertise you may draw? (including Māori providers). What do you see are the main gaps in the provision of palliative care for Māori? Have you done anything in your practice to ensure you provide culturally appropriate services for Māori palliative care patients?

The questionnaire was piloted with a small number of semi-rural doctors who were not to be included in the main study and minor changes were made – overall the questionnaire seemed acceptable to the pilot doctors. Questionnaires were then posted to each rural general practitioner with a stamped addressed envelope. Questionnaires had a unique identifier. If after 4 weeks there was no response then a repeat posted questionnaire was sent or if the first questionnaire was returned indicating that the doctor had left then attempts were made to identify the replacement doctor. Ethical approval was received from the Northern Y Regional Ethics Committee.

**Analysis**

The general practitioner responses were grouped and tabulated with percentage response rates. Open questions were assessed by grouping key themes.
carried out independently by two researchers and then the key points compared and discussed.

Results

186/440 rural general practitioners responded to the survey—42% of those sent a questionnaire. The age of the respondents were recorded in categories—50% were aged 35–49 years and 49% were aged 50 plus. Only two respondents were aged less than 35 years. Thirty-two percent were female.

Ten general practitioners did not answer the question “How many Māori patients have you looked after in the last 12 months”? Of the 176 that did 91 (52%) said that they had no Māori patients, 40 (23%) had 1 patient and 45 (25%) had looked after 2 or more. If the responses were categorised depending on which Island the practice was located then we find 51/69 (73.9%) of South Island practices responded they had no Māori palliative care patients whilst only 40/107 (37.3%) of North Island practices said they had no Māori.

There were an estimated total of 204 patients who had been looked after in the last 12 months by the 176 general practitioners who responded. An estimated 126/204 (62%) of these patients had died at home compared to an overall estimate of 46.5% for all palliative care patients (16). 59/176 (33%) of respondents said they had used Māori Health providers for support of their palliative care patients.

56/139 (40%) answered “Yes” to the question “Are there specific needs that you have identified for your Māori patients?” 83 answered “No”. Where doctors had answered “Yes” and elaborated as to their perception of need the strongest theme coming through was the need to involve whānau/family in the management. This included comments about the space needed to accommodate whānau when someone was dying.

There were comments about the need to follow tikanga/Māori principles/protocols when caring for Māori, in particular noting the sensitivity when dealing with particular parts of the body or the requirements for a tangi (Māori funeral). There were comments on the need for more time/interaction/communication when involved with Māori patients and to identify the key people with in the family.

Other comments included a perception that Māori preferred to be cared for and die at home or some general practitioners noted the converse—that many Māori did not want to go to or die in hospital. There was also a feeling that there was a reluctance to attend clinics or have blood tests. One respondent mentioned poverty as an issue. Of those who said “No” to Māori having specific needs – most commented they had very few Māori patients. One general practitioner commented “All our patients are treated the same”.

In response to the question “What do you see are the main gaps in the provision of palliative care for Māori?” 86/186 (46%) did not respond to this question whilst 31/186 (17%) stated that there were no particular gaps or they had no experience with Māori. In those that noted gaps, key themes that appeared were the need for better communication, the need for more Māori nurses, or Māori palliative care nurses and some mentioned the need for more home care services or services out of hours.
Several respondents commented that the lack of knowledge about hospice/palliative care services by some Māori patients was a gap that needed attention. Other points made were the problems of access for patients who were living in isolated or very rural areas, the issue of costs/lack of resources/lack of heating, and the problem of rising demand at a time when rural general practitioners were becoming scarcer. One respondent mentioned that Māori often request an alternative medicine approach.

78/186 (42%) responded “Yes” to the question “Have you done anything in your practice to ensure you provide culturally appropriate services for Māori palliative care patients?” On the other hand, 43 general practitioners did not respond to this question and 65 said “No”.

There was a strong sense that general practitioners were asking patients and family about their wants and needs and responding to their request. One respondent commented:

“I am aware of a large band of strong capable women who know what to do—will consult/tell me what they want and I do as I am told”. Working with whānau was seen as important, whilst others talked of seeking guidance from local Marae and local kaumatua. Some recorded that they had attended tangi.

One general practitioner stated: ‘I have been in New Zealand for 5 years and I am still learning’. Some 15 practices seemed to have initiated involvement with local Māori Health providers or with the Māori Health services of their local DHB. Finally, nine general practitioners noted that they had attended or arranged cultural competency training and one doctor specifically mentioned the Cornerstone programme.

Discussion

This survey seems to show that there is variable involvement of rural general practitioners with Māori patients who require palliative care services. Those practicing in the South Island were more likely (74%) to have no involvement with Māori palliative care patients. Only 25% of rural general practitioners looked after 2 or more Māori palliative care patients in a 12-month period.

Whilst it is known that there are variations in recording of ethnicity in general practice and on the National Health Index we do not know whether there is systematic under recording of Māori ethnicity in rural general practice. However, it is possible that our data under records the need.

Sixty-two percent of rural Māori patients died at home. We know from the NZPCS that in general Māori patients requiring palliative care are more likely to die at home than non-Māori—53.2% compared with 30.8% but our data suggests that rural Māori maybe more likely to die at home than urban Māori patients. This maybe due to reduced access to resthome or hospice beds or more family support for rural patients. The need to be with family at this time reflects similar findings from Australia.

For those general practitioners who are involved in looking after Māori patients who are dying—it was the role of the family/whānau that marked the main difference to managing care for non-Māori patients. This is known as Te Whakawhanaungatanga—the gathering of family and friends to provide spiritual and practical support. This involves issues of space when accommodating large numbers, whether in hospital or
at home, the need for good communication and the need to acknowledge traditional practices. A study from the West Coast of New Zealand reported that when whānau provided palliative care they were not eligible for financial support which was seen as inequitable. The above findings are similar to those noted in other publications on the needs of indigenous people from Australia or North America.

We found that 111/186 (59%) of the rural general practitioners in this survey rated their current level of Palliative Medicine knowledge as good or very good. However the majority also indicated they would like more training. In regards to their knowledge of cultural factors it appeared to us that some practitioners have made an effort to improve their understanding of the cultural needs of their patients either through some formal cultural competency training, or by seeking advice from local kaumatua, Māori providers or the Māori Health advisors from their local District Health Board.

On the other hand there were many that believed there were no gaps or special needs for Māori. This would suggest that there is a need for more research to explore the differences between Māori and non-Māori patients requiring palliative care so the needs for any cultural competency training could be better informed.

The strengths of this paper is that it is one of the first that we could find that has looked specifically at the needs of Māori patients requiring palliative care—all be it from the perspective of the general practitioner. There is an important paper on the palliative care needs for prisoners within New Zealand which notes that those dying in prison are usually Māori, given the over representation of Māori in the prison population and mention is made of the needs of Māori in a paper on the introduction of a Palliative Care Partnership as well as a section in the report ‘Access to cancer services for Māori.’

A potential weakness of the study was the response rate—only 42% of rural general practitioners responded to the survey. It maybe that the views of non-responders would be different from those who did complete the questionnaires. However we believe our findings are of interest. As stated above this survey was from the viewpoint of rural general practitioners.

We acknowledge that relying on general practitioners recall may also introduce a bias but we believe that it is useful to try and quantify their workloads. It may well be that the views of patients and their families, or nurses and other health professionals may have given a different perspective. Again there appears to be a need for further research in this area. We believe it is also important to look at the needs of Māori patients living in urban as opposed to rural settings.

One theme that did not emerge with respect to rural Māori with palliative care need was any need for specialist input. Only one respondent mentioned this as a particular need for Māori patients. This may have been because most doctors had good telephone access to specialist advice or they did not see this as being a particular issue for Māori when compared to non-Māori rural patients.

In summary it appears that there is great variation in the requirement for palliative care services for Māori from rural general practitioners. Some rarely encounter Māori patients whilst for other rural general practitioners caring for Māori who are in need of palliative care is an important part of their professional practice.
The greatest need appears to be for good communication which respondents saw as especially important when a large family/whānau are involved. It maybe that more in depth research is required into the involvement of whānau in the management of dying patients.

Other notable concerns are the apparent gaps in some areas for home care and the demand for more Māori nurses to be available in rural areas – something that Primary Health Organisations and District Health Boards could consider. Finally it was apparent that there is some demand for cultural competency training and the continuing support of Māori providers and Māori services in District Health Boards to support the provision of Māori palliative patients in the community.

Competing interests: None

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