

'Where do I go from here'? A cultural perspective on challenges to the use of hospice services

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What is known about this topic

- Within New Zealand there is rise in demand for palliative care and hospice services from an increasingly diverse patient population.
- Indigenous and minority populations are underserved by hospice services for a number of reasons, including language difficulties, beliefs about healthcare, lower referral rates, economic disadvantage and cultural and religious appropriateness.

What this paper adds

- The inclusion of multiple perspectives (patient, family/whānau, healthcare professional) provides a fuller understanding of the challenges to hospice service access for Māori, Asian and Pacific patients.
- The absence of shared cultural scripts between hospice services staff and the diverse cultural groups served can create barriers to accessing hospice services.
- A culturally sensitive model of hospice services for Māori, Pacific and Asian communities requires greater emphasis on family-centred decision-making.

Abstract

Do hospice services as shaped by a western perspective adequately fulfil the needs of persons from non-Western cultures? Based on a Western view of palliative care, the vision outlined in the New Zealand Palliative Care Strategy (2001) is to deliver palliative care services, including hospice services, to all patients and their families requiring them in the context of an increasingly pluralistic and multicultural society. It is predicted that over the next two decades the proportion of people identifying as Māori, Pacific and Asian will dramatically increase within New Zealand. Ministry of Health information provided through a GAP analysis identified hospices as facing access-to-care pressures for Māori, Pacific and Asian patients. It is therefore critical to identify the challenges to hospice service access for Māori, Asian and Pacific patients. This project involved qualitative interviews with 37 cancer patients (Māori, Pacific and Asian self-identified ethnicities), whānau/family and bereaved whānau/family, as well as 15 health professionals (e.g. referring GPs, oncologists, allied health professionals) within one District Health Board. Patients and their families included both those who utilised hospice services, as well as those non-users of hospice services identified by a health professional as having palliative care needs. Challenges to hospice service utilisation reported in the findings include a lack of awareness in the communities of available services, as well as continuing misconceptions concerning the nature of hospice services. Language barriers were particularly reported for Asian patients and their families. Issues concerning the ethnic representativeness of the hospice services staff were raised. The findings highlight the importance of patient and family knowledge of hospice care for utilisation of services. This information can be used for future planning to enable hospices to both provide high quality evidence based palliative care services for patients and families and provide consultative services to primary healthcare providers in the community.

Keywords: Asian, culture, end-of-life care, hospice services, Māori, Pacific, palliative care, terminal care

Introduction

New Zealand, in line with other developed countries, is increasingly required to deliver palliative care, including hospice services, to patients and their families within the context of a pluralistic and multicultural society. Indeed, while the majority of the New Zealand population identify as NZ European (67.6%), the proportion of the population identifying as non-European is set to increase dramatically over coming decades

(Statistics New Zealand 2006). Currently, the largest non-NZ European groups comprise the indigenous Māori population (14.6%), Asian peoples (9.2%) (Chinese, Indian, Korean, Filipino, Japanese, Sri Lankan, Cambodian, Thai, Vietnamese, Indonesian, other Asian), and Pacific peoples (6.9%) (Samoan, Cook Island Māori, Tongan, Niuean, Fijian, Tokelauan, other Pacific). Acknowledging this cultural diversity is important because, to provide holistic care, a central aim of palliative care, health and social care professionals need to 'be culturally aware, culturally sensitive, and culturally competent' (Orb & Wynaden 2001, p. 360). However, limited knowledge among health-care professionals about different cultures and lack of skills in cross-cultural communication are known to create barriers to effective healthcare delivery (Shapiro *et al.* 2002, Olson & Windish 2010), including within a palliative care context (McGrath *et al.* 2005).

The New Zealand Palliative Care Strategy (Ministry of Health 2001, p. 10) states that: 'all people who are dying and their family/whānau (extended family) who could benefit from palliative care [should] have timely access to quality palliative care services that are culturally appropriate and are provided in a co-ordinated way'. Māori, the indigenous people of New Zealand, have specific legal rights to equitable access to appropriate healthcare provision under the Treaty of Waitangi (Ministry of Health 2000). However, a recent study examining access of Māori to palliative care services in one region in New Zealand concluded that palliative care services nationally may not be adequately meeting the needs of Māori patients and their whānau (Penney *et al.* 2009). Bacal *et al.* (2006) go further, stating that many New Zealand European physicians are either ignorant of Māori cultural practices related to healthcare, or worse, hold inaccurate or inappropriate views about them. Previous research reports that both Māori and Pacific patients experience challenges to accessing specialist palliative care services including: a cultural preference for end-of-life care at home (Mann *et al.* 2004, Little 2009, Lawrenson *et al.* 2010); the difficulties of balancing the use of traditional medicines with Western health-care (Mann *et al.* 2004, Little 2009, Lawrenson *et al.* 2010); and communication issues relating to language barriers and a lack of information about palliative care (Ministry of Health 2003, Lawrenson *et al.* 2010). In addition, across all age groups, Pacific peoples, followed by Māori, live in areas of the highest socio-economic deprivation, meaning for some healthcare is unaffordable or not a priority (Counties Manukau District Health Board 2006).

Asian peoples represent the fastest growing population in New Zealand (Statistics New Zealand 2009)

and are likely to face specific challenges relating to unfamiliarity with the New Zealand healthcare system given that 90% of the current Asian populations were born overseas (Statistics New Zealand 2007). Little research regarding the use of hospice services and palliative care services within this group of New Zealanders has been conducted, although a qualitative exploratory study did identify that presenting to an acute hospital was a preferred means of accessing health-care by Chinese patients even in end-of-life situations (Gott *et al.* 2013).

There is growing recognition within New Zealand of the need to address cultural barriers to the use of hospice services and specialist palliative care services. For example, a recent report from the Ministry of Health identifies hospices as facing access to health-care pressures for Māori, Pacific and Asian patients. This report concurs with the consensus in the international literature that indigenous and minority populations are underserved by hospice services and specialist palliative care services (Phipps *et al.* 2000, Sullivan 2001, McGrath & Patton 2007, Carrion 2010, To & Boughey 2010). Given this background, it is critical to identify and understand the barriers to hospice services care faced by Māori, Pacific and Asian patients (Ministry of Health 2010).

Aim

The aim of the study is to identify challenges to the use of hospice services for Māori, Pacific and Asian patients within the context of one district health board. Based on this aim the objectives of the research were both to explore the attitudes of Māori, Pacific and Asian patients and their family/whānau towards hospice services care and to identify the reasons that eligible patients of Māori, Pacific or Asian origin did not utilise the hospice services under study.

Definitions

Within this study, a number of definitions have been adopted. In the first instance palliative care was defined as 'care for people of all ages with a life-limiting illness which aims to both 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 carers where needed, through the illness and after death' (New Zealand Nurses Organisation 2010, p. 5).

This study focused on barriers to access for non-Western cultural groups. Culture was defined as: 'A historically transmitted pattern of meanings

embodied in symbols' (Geertz 1973, p. 89). Culture, both at the level of the family and the societal level, was thus used to inform this work based on the notion that culture depends on 'shared meanings'.

The study also included participants from three ethnic groups represented in New Zealand. Participants self-identified their ethnicity as Māori, Pacific persons or Asian. Māori include all persons who identified Māori in response to the question of ethnicity (Statistics New Zealand 1999). Pacific peoples include New Zealand-born individuals and migrants from South Pacific nations who identified with one or more of the Pacific Islands because of ancestry or heritage (Ministry of Health 2009). Asian is defined based on the Statistics New Zealand (1999) as 'people who identify with an Asian ethnicity (e.g. Chinese, Indian, Korean) with or without other ethnicities with origins in the Asian continent using restricted geographical criteria. This definition includes people originating from Afghanistan to Japan (west to east) and from China to Indonesia (north to south)' (p. 21) (Statistics New Zealand 2006).

Methods

The study employed an instrumental case studies approach (Tellis 1997) to advance our understanding of the larger issue. The study was undertaken in regions located within one district health board. The hospice services under study is located in a district health board characterised by ethnic diversity having the highest number (250 000) and proportion (54%) of non-European cultural groups (Māori, Pacific and Asian) (Statistics New Zealand 2007). The study received ethical approval from the regional Health and Disability Ethics Committee NTX/11/EXP/130.

Sample

The study involved qualitative interviews with cancer patients, whānau/family, bereaved whānau/family and health professionals (e.g. referring GPs, oncologists, and allied health professionals). Cancer patients were selected as cancer deaths account for 29% of all deaths in New Zealand – representing the leading cause of death for both men and women (Ministry of Health 2008). In addition, the most common non-cancer diseases (e.g. heart disease, pulmonary disease, dementia, HIV, liver disease, renal disease, stroke coma and amyotrophic lateral sclerosis) (Gold Standards Framework Centre 2005) have both erratic and unpredictable courses, making prognostication more difficult (Brickner *et al.* 2004, Joshi *et al.* 2006). A total of 52 interviews were conducted (16 patients; 12

family members; 9 bereaved family members; 15 health professionals). Participants were purposively selected based on their demographic characteristics. Selection criteria included hospice services use or non-use, ethnic group (Māori, Pacific, and Asian) and role (physician, allied health professional, client, family member or bereaved family member). Hospice patients were identified by the hospice services senior clinical staff. Patients who did not use hospice services were selected based on the clinical judgement of a health professional (e.g. GP, community nurse) as being eligible for hospice services. These healthcare professionals were also responsible for distributing the recruitment information to eligible patients. The goal was to produce a balanced sample based on the above criteria. In particular, efforts were made to represent the diversity of experience within each ethnic group (e.g. Pacific participants included representatives from the Cook Island, Samoan, Tongan, Tokelauan, Niuean, Fijian communities and Asian participants included members of the Korean, Malaysian and Chinese communities).

Data collection

Semi-structured interviews were employed as the data collection method. With the prior written consent of the participants, interviews were audio-recorded and transcribed verbatim. The goal of the qualitative interviews was to provide an understanding of the point of view of the participants in a way that was not entirely predetermined or restricted. The interview schedule covered topics including: sources of support, perceptions of hospice services, perceived obstacles and facilitators to hospice services use. Interviews were conducted at a time and location convenient for the participant. Hospice patients, community patients who did not access hospice services, family members and bereaved family were interviewed either in their homes, the hospice services or in phone interviews. Healthcare professionals were interviewed either over the phone or at their office. An effort was made to match the cultural group of the participant with the researcher conducting the interview (e.g. Māori researcher with Māori participant, Korean interviewer with Korean participant etc.). This was considered the most culturally appropriate and culturally safe method of data collection (Wilson & Neville 2009).

Analysis

Analysis of the text generated from the interviews was accomplished utilising NVivo. The programme

was employed to carry out the administrative task of organising the large amount of text efficiently, coding and linking text and related codes through electronic memos to develop themes (Welsch 2002). The thematic analysis identified 'features of significance' (Love 1994) related to the study objectives. These features included the following: (i) repetition within and across interviews (ii) personal stories that explained present behaviour and (iii) responses that differed based on role (patient, family, health professional), culture and service use/non-use. Analyses were conducted by the research assistants (SB, LTH, DR, HL, ZW) (who provided cultural expertise), together with the study Project Manager (RF) who worked together to ensure data quality (e.g. using double-coding). Inclusion of researchers from each cultural group in the analyses provided a space where indigenous epistemologies and ontologies could be given voice (Cunningham 2000, Wilson 2008). Themes were developed based on an analysis of the transcripts and shaped in relation to the wider literature. Quotations selected were representative of both the most frequently occurring responses as well as the cultural diversity of the participants.

Findings

Demographic characteristics

Fifteen healthcare professionals (eight physicians, five nurses and two allied healthcare professionals) and 37 (nine hospice services patients, seven non-hospice services patients, 12 family and nine bereaved family) interviews were conducted. Healthcare professionals, most often reported 'a little' (6/15) of their workload was related to palliative care delivery. A majority of the clinicians wanted additional palliative care training (10/15) (Table 1). Patient and family participants self-identified as Māori (6), Pacific (20) and Asian (9). Two family members reported NZ European ethnicity. GP's were most frequently reported by patients and families (21/37) as the healthcare professional integral to their (or their family members') care (Table 2).

A matter of culture

Challenges to the use of hospice services were underpinned by the cultural differences between the communities served and the suppliers of health services. To illuminate some of the impacts of culture on hospice service utilisation, topics which emerged in the interviews, were organised in terms of predominant themes. Although the nature of the rela-

Table 1 Healthcare professional characteristics by gender

Gender	Frequency			Per cent	
	Male	Female	Total	Male	Female
Age	7	8	15	46.7	53.3
25–34	0	2	2		13.3
35–54	3	3	6		40.0
55+	3	3	6		40.0
Unknown	1	0	0		6.7
Ethnicity					
New Zealand European	3	0	3		20.0
Māori	2	5	7		46.7
Samoan	1	1	2		13.3
Chinese	0	2	2		13.3
British	1	0	1		6.7
Position					
Physician	6	2	8		53.3
Nurse	0	5	5		33.3
Allied health	1	1	2		13.3
Length of time at this practice					
1–4 years	2	5	7		46.7
5–10 years	3	3	6		40.0
11 years or more	2	0	2		13.3
Would you like additional palliative care training?					
Yes	4	6	10		66.7
No	3	1	4		26.7
Don't know	1	0	1		6.7
Workload devoted to treatment of patients with palliative care needs					
None	1	2	3		20.0
A little	4	2	6		40.0
A moderate amount	0	2	2		13.3
A lot	2	0	2		13.3
All	0	2	2		13.3

tionships is complex, for the purposes of clarity, themes identified in the interview texts were organised by category and subcategories and included the following:

Awareness of hospice services

Patients and families often reported a lack of familiarity with the role of hospice services or the services available. There was a lack of awareness that 'care and support' could be found in a range of services which were easily accessible and 'user friendly'. For example, they were unaware that they could use it for a couple of days respite rather than a week at a time. A Korean patient who did not use hospice services stated the following:

I have never heard about palliative care... Hospice information was given by specialist without any explanation. (Mrs X – patient non-hospice services)

Family/whānau of former patients also did not understand how they could utilise the hospice services. For example they were unaware that they could use

Table 2 Patient and family characteristics by gender

Gender	Frequency			Per cent	
	Male	Female	Total	Male	Female
Age	10	27	37	27	73
18–24 years	1	1	2		5.4
25–34 years	0	2	2		5.4
35–54 years	2	14	16		43.2
55+	7	10	17		45.9
Ethnicity					
New Zealand European	0	2	2		5.4
Māori	0	6	6		16.2
Samoan	3	3	6		16.2
Cook Island Māori	1	2	3		8.1
Tongan	2	1	3		8.1
Niuean	0	1	1		2.7
Fijian	1	2	3		8.1
Fijian Indian	0	1	1		2.7
Tokelaun	0	3	3		8.1
Korean	0	5	5		13.5
Chinese	2	1	3		8.1
Malaysian	0	1	1		2.7
Role					
Patient hospice services	5	4	9		24.3
Patient community	1	6	7		18.9
Family member/carer	3	9	12		32.4
Bereaved family	0	9	9		24.3
Most important health professional					
GP	5	16	21		56.8
Specialist physician	3	7	10		27.0
Nurse	0	4	4		10.8
Hospice physicians and nurses	1	0	1		2.7
Unknown	0	1	1		2.7

hospice services for a couple of days respite rather than a week at a time. One whānau member went further to state:

The whānau needs to know, to have a clear explanation of what hospice services...not provides but wraps the family in ... They need to know, to ensure that the whānau fully understand, not just give them this verbatim stuff and it goes over the top of the whānau head and then they have to try and remember 'oh what did they say'? (Bereaved 2 – Māori bereaved family member)

A Cook Island patient who utilised hospice services day stay services complained that the terminology used was not easy to understand:

I think a lot of it comes down to the big words ... You talk about the word 'palliative.' I mean, if we were to say that to our own families, if I said that to my own family, they're probably thinking [that] I'm swearing at them. (Ms. C – hospice services patient)

One Samoan patient voiced the opinion that many Pacific Islanders do not understand the flexibility that is allowed in hospice services care with regard to following cultural and spiritual practices.

Your last stage before you pass away ... I don't think they understand that they can do it their way; their family can die the way, [as] if they were in Samoa, this is the way they die and you can do that here. (CO – hospice services patient)

Access to information

Barriers to information access were responsible in part for the lack of understanding concerning both the meaning as well as the range of services available. These barriers were created through issues with language as well as a by the cultural presumptions held by some healthcare providers.

Language challenges identified by participants included both translation (rendering written material accurately into a target language – e.g. Māori, Samoan, Cantonese etc.) and interpretation (transposing spoken messages from one language to another). In particular, the presence of an interpreter to facilitate communication was challenged. A Korean patient who did not use hospice services stated this as:

Brochure was written in English and I had to asked husband to interpret it.... It may be difficult for me to access [services] if it exists in New Zealand due to [the] language barrier. (Mrs. X non-hospice services patient)

The daughter of a Cantonese speaking hospice services patient stated that access to 'multi-lingual' interpreters was difficult:

A lot of people who come to New Zealand now are Mandarin-speaking... but Cantonese is very hard, you can't find anyone that speaks multi-languages. I think that is the main obstacle that we've actually encountered. (Ms. C – hospice services patient)

The relative of a Tongan hospice services patient spoke of the reluctance of Pacific persons to utilise professional interpreters:

Tongans ... don't feel comfortable with an interpreter in front of them. They just want to talk straight to the person, you know...We can bring someone to translate for us, but I found in a lot of my people, they don't feel comfortable with telling their problem to someone in front of another person. (Mr. V – family member)

There was also evidence that some physicians still made cultural presumptions concerning preferences in hospice services utilisation. The 'gatekeeper' role played by these physicians limited access to information about hospice services based on the attitude that 'they' won't

use it anyway. This takes on added significance given that the majority of patients and family members (21/37) saw the GP as playing the most important role in care (Table 2):

I think if you had an extended Māori family they'd be probably much keener to be at home with the whānau, and possibly with some of the Pacific people as well.

Interviewer: because of that sort of cultural preference?

The culture of the home and the family and the Marae [tribal] forum for social life ... but I can't see that as a specific barrier. I think it's a more attractive alternative. It's not a barrier it's just that actually that's what they want. (Physician K – GP)

Misinformation

A lack of good information was often replaced with misinformation or misunderstandings about the nature of palliative care and hospice services. This misinformation concerned the nature of hospice services, the quality of services available as well as the inclusiveness of the services. A general mistrust of the health system and the potential financial impact of use based on misinformation were also apparent. These themes are outlined below:

Hospice was perceived as a place rather than a philosophy of care. Specifically there was a belief that hospice services is a place for people to 'come and die'. A conflict therefore existed between the struggle for survival and the need for friendship care and support. A Cook Island hospice services patient reflected this as:

When I first heard about hospice services I thought... I'm going over there to die. That was my first thought about hospice services, not knowing that they provided all these services. (Ms. C – hospice services patient)

There was also a misconception concerning the quality of the services available. A family member of a Korean non-hospice services patient viewed hospice services as a stark institutional structure:

I do not want to leave my husband at hospice services where it could be cold and bed is not wide enough. (Mrs H – Family member)

Participants shared their fears of discrimination based on both their as well as others' experiences within the health system. These made them wary of any treatment provided by health professionals. A kaumātua (Māori elder) spoke of the discrimination he had encountered highlighting the differences in perceptions between the predominantly European healthcare system and Māori in terms what treat-

ments are deemed 'appropriate' as well as the availability of services to Māori:

I have dealt with issues concerning discrimination ... It's through the whole system, what is available, what we are made to understand...what is right for us or what is right for them is not necessarily what we think is right for us. (Kaumātua – Māori elder)

Contrary to the reality of the situation of free services for all (Hospice New Zealand 2012) there was a perception that hospice services are only available for persons with an inability to pay. They equated the service with being on unemployment benefit, which was viewed with a sense of shame. The family member of a Tongan patient who utilised hospice services day services reflected this as:

I always thought hospice services was like government-funded body that looks after the disabled, elderly, the sick. [It is] for families who are not financially capable of looking after that person so they do need assistance. (Mr. V – family member)

A Korean participant described the stigma attached to hospice services use:

I [would] rather work hard myself as much as possible rather than [use] a free service. My family are not very keen on [the] benefit and would like to work hard to earn income to cover my care expenses. (Mrs. H – non-hospice services patient)

Cultural obligations intertwined with financial worries were reported as potential barriers to both hospice services utilisation and healthcare access in general. A whānau member of one Cook Island Māori patient stated this as:

He was still ... limping and in pain to go to work because of the mentality that we have on ourselves to where work is more important than our health because of our worries about what the outcome is if we don't have work. (T – family member)

Cultural understandings

Cultural norms and values impacted on the willingness to seek healthcare assistance. Misunderstandings about the nature of a disease sometimes created a barrier. The misperceptions concerning male potency and prostate cancer were highlighted by a Cook Island Māori patient:

I think some men think prostate mean sex problem or something like that. (B – non-hospice services patient)

Issues surrounding the appropriateness of what to discuss and with whom, created challenges to access to health-care in general and hospices services in par-

ticular. A 'shyness' driven by cultural norms impacted on the willingness of some participants to ask for help. This was particularly evident in dealing with health issues related to sexuality. A Korean participant stated this as:

A lot of Korean woman do not disclose medical conditions about women's illness because it is not very comfortable culturally to talk with [a] foreign doctor about it and attend physical examination of breast and vaginal exam. (Mrs X – non-hospice services patient)

Participant age may have been a contributor to 'shyness' (17/37 over 55 years) potentially reflecting a cohort effect in the retention of traditional values (Table 2).

Reluctance to speak to healthcare professionals from a different cultural background extended to hospice services staff whose background was also predominantly NZ European. The absence of shared cultural scripts, perceptions of health and illness and an understanding of preferred methods of communication served to discourage hospice services use. The consequences for service access were highlighted by one Māori healthcare professional:

There's a barrier why these kinds of people don't come into our establishment. Do you think it could be because we don't have any coloured faces to match them, to relate to them? (Nurse W – hospice services nurse)

Discussion

The findings indicate the importance of knowledge of hospices for utilization of services. Lack of knowledge of hospice services programmes among socially disadvantaged groups has been a common theme emerging from research both internationally (Gelfand *et al.* 2004, Rhodes *et al.* 2006) and within New Zealand (Bellamy & Gott 2012). This lack of knowledge stems from a number of sources.

Lost in translation

Consistent with the international literature (e.g. Cunningham 2000, Ma & Du 2000, Twinn & Cheng 2000, Wieringen *et al.* 2002) linguistic barriers may preclude adequate communication between patients and providers. In particular, many Chinese and Korean older adults in New Zealand are immigrants who lack English language skills and rely on their families to access health services (Garrett *et al.* 2008). These patients and their families experience challenges to gaining knowledge about hospice services in the absence of easily accessible information in their

primary language. In addition many Asian as well as Pacific participants, driven by concerns about privacy and shared cultural understanding, are reluctant to use an English-speaking interpreter (Toafa *et al.* 1999, Ngo-Metzger *et al.* 2003a,b, Wong-Kim *et al.* 2003).

Culture

Beliefs about individualism and collectivity, communication and decision-making styles are all influenced by culture (Lenninger 1977). These beliefs result in a diversity of expression by various cultures, and lack of awareness of these various means of expression creates much 'miscommunication' among persons of different cultures (Wright *et al.* 1997). Of importance to Māori patients and whānau interviewed was the recognition that the patient is not the only one who takes this journey. As articulated by the kaumātua (Māori elder) the whānau 'walks together'. Appropriately accommodating whānau may mean ensuring health professionals are communicating with the correct whānau members early in any care planning. Whānau dynamics vary and engaging with a family/whānau at the beginning, during and at the end is important. Family/whānau meetings may provide an efficient method of communication and information sharing. Prior experiences of perceived discrimination or poor service by health professionals or health services may add to Māori patients and whānau distrust and over protection when engaging with hospice services (Harris *et al.* 2005). In such cases, a soft approach and time to 'whakawhānaungatanga' or build relationships and trust is advisable (Walker *et al.* 2008). Kearns & Dyck (1996) highlighted the lesser value attached to the knowledge of 'others' in comparison to the value attached to Western medicine within New Zealand. This power differential continues to create a barrier to hospice service access for Māori, Pacific and Asian peoples. According to Kearns & Dyck (1996, p. 374) the solution to this barrier requires healthcare professionals to 'speak less about and more with'.

With respect to the Pacific and Asian communities *shyness* which is related to the preservation of personal dignity, in some instances outweighed concerns for health (Tang *et al.* 2000). 'Death by cultural respect' was highlighted (McLaughlin & Braun 1998). This was illustrated in the example of a grandfather who refused needed care. Pride and cultural position became a boundary which carers/family members were unable to cross. Concerns about the preservation of personal dignity can lead to a refusal to accept treatment or referral to hospice services.

Although Asian societies differ in many ways Confucian-based cultures including China and Korea value modesty. This is particularly evident for women when dealing with gynaecological issues (Tang *et al.* 2000). Furthermore, older Asian women, based on a stronger adherence to traditional values, may be less likely to seek treatment for sexuality-related health issues (Vu 1996). Within Asian communities consensus among family members has also been identified as a key factor in decision-making (Bowman & Singer 2001). Although the participants in this study indicated that information and decisions were collectively discussed, there was selectivity about who was included. One participant noted that information should not be disclosed to children because they are perceived to be more fragile.

The 'big picture'

One factor that looms large is the additional financial exposure incurred in Māori and Pacific communities in New Zealand (Counties Manukau District Health Board 2006). The socioeconomic disadvantage experienced by these groups is a key contributor to their health status inequality (Salmond & Crampton 2000). This burden is worsened by high levels of cultural obligation to serve as carers (even to extended family members) (Garrett *et al.* 2008). There was a general lack of awareness demonstrated amongst Māori and Pacific participants that 'care and support' could be found in a range easily accessible and 'user friendly' services. Misconceptions about hospice service eligibility prevented access for some participants. Protestant work ethic (Weber 1930) beliefs such as asceticism, hard work, thrift, frugality, postponement of gratification etc. find their equivalent in the tenets of many Asian religions (Furnham 1990). In the case of the Chinese and Korean participants, cultural notions of welfare may underlie the resistance to explore the use of hospice services (Ka 2001).

'A way forward'

The results of this study revealed the need for increasing the public presence of hospices within the communities they serve. As recommended in the literature (Williamson 1996, Cort 2004) these efforts should include educational programmes designed to reflect the cultural diversity of the communities.

In cultures characterised by an emphasis on trust and personal relationships, one-to-one discussions about hospice services care via community organisations may be the most effective approach to altering

beliefs (Bray & Goodyear-Smith 2007). Volunteers recruited from community organisations could improve understanding due to the trust accorded these organisation members. Volunteers could also assist with the development and dissemination of culturally appropriate educational materials. Engagement with Pacific churches would also increase awareness. Since the 1700s, Christianity and the church have played a central role in Pacific culture and life, acting as both a meeting place and an organising force for community projects (Medical Council of New Zealand 2010).

Wide variations in the GPs' (who are the primary referral source for hospice services) understanding and views about when and how to refer patients to hospice services was demonstrated. The evidence suggests that the cultural presumptions of some physicians may hinder referrals of Pacific, Asian or Māori patients to hospice services. In particular, Asian stereotypes of the 'model minority' in terms of health status hide the real disparities that exist in terms of access to palliative care (Chen & Hawks 1995). These misconceptions are compounded by the fact that Korean and Chinese patients and families would not proactively ask their GP to make a hospice services referral (e.g. Uba 1992, Chui 2002). Improving hospice services access requires health professionals to be more conscious of their own cultural views and attitudes and more open minded to those of others (Kearns & Dyck 1996). These goals of culturally safe practice can be advanced through greater incorporation into Continuing Medical Education programmes (CME's). Collaboration with Asian health practitioners in the delivery of information is also recommended. Research indicates a preference among Asian patients for healthcare providers with whom they share a common language and cultural understanding (Kwok & Sullivan 2007). Continued engagement with Māori health providers including the development of palliative care education resources for both Māori health providers as well as whānau is also advisable.

Recruitment of staff reflective of ethnic makeup of the community is also vital. Studies have indicated that cultural diversity among hospice services staff may influence diversity among hospice services patients (Harper 1995, Krakauer *et al.* 2002, Reese *et al.* 2004). The uniqueness of Māori, Pacific and Asian cultural styles of delivery are found in more than just in the use of ethnic-specific languages, it also lies in a 'way of doing and thinking', in a particular belief or value system. Increasing the diversity of clients may best be accomplished by members of the same cultural group.

This study like any other is not without limitations. In utilising the contributions of a small number of participants, the study suffers from disadvantages in terms of generalisability to all members of each cultural group. Furthermore, the interviews dealt specifically with cancer patients and their whānau/families. It is unclear to what extent these views can be applied to other diagnostic groups. Future research is required to explore the views of patients with other life-limiting illnesses.

Nevertheless, the results offer an important addition to the literature providing the views of *both* hospice services staff and non-European patients and their families regarding challenges to the access of hospice services. Previous studies within New Zealand have either focussed solely on the views of care staff (Bellamy & Gott 2012) or on the views of one specific cultural group (Bray & Goodyear-Smith 2007, Moeke-Maxwell *et al.* 2010). The inclusion of multiple perspectives provides a more complete understanding of the challenges to service access. One family member summed it up best:

Knowledge is the key to understanding different cultures... without knowing the people that they're [hospice services] dealing with... especially if they're dealing with people who are sick. How do you make it better for them? (Ms. P – Family member)

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Conflict of interest

None declared.

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Authorship

All authors (Rosemary Frey, Merryn Gott, Deborah Raphael, Stella Black, Linda Teleo-Hope, Hyeonjoo Lee, Zonghua Wang) were involved in the concep-

tion, design and implementation, data analysis and interpretation and drafting of the paper. All authors were involved in the review and approval of the final article for publication.

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