

Patient and family perceptions of hospice services: 'I knew they weren't like hospitals'

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ABSTRACT

INTRODUCTION: The vision for palliative care service provision in New Zealand is for all people who are dying and their families to have timely access to culturally appropriate, quality palliative care services. An Auckland hospice's records show that the ethnically diverse population statistics were not reflected in the referrals for hospice services. The aim of this research was to gain a patient-and-their-family perspective on the hospice, including exploration of components of service care that could be improved for various cultural groups.

METHODS: Patients currently under the care of the hospice and family members were recruited from hospice records. Semi-structured interviews were conducted to explore the emerging issues. The study collected data from a purposive sample of 18 palliative care patients or carer family members, ranging in age from 39 to 81 years, who reflected the ethnic diversity of the population of the region. Interviewing was carried out by an experienced research assistant and continued until data saturation was reached.

FINDINGS: Four key themes emerged—hospice personnel's approach to patients, quality of service, cultural barriers, and strategies for future improvement. It was determined that the latter two were the most significant to address in this article.

CONCLUSION: The study revealed the need for information-giving and education, including public profiling of the hospice to strengthen community involvement. Strategies to reduce ethnic disparities include strengthening the awareness of, and access to, services by connecting with cultural groups through churches, community and specific cultural media.

KEYWORDS: Cultural competency; hospice care; palliative care; patient education; terminal care

Introduction

The vision for palliative care service provision in New Zealand (NZ) states that:

All people who are dying and their family/whanau who could benefit from palliative care services have timely access to quality palliative care services that are culturally appropriate and provided in a co-ordinated way.¹

The mission statement of Hospice NZ is that: 'Everyone who is dying and those that love them, [should] have access to the best possible care with the help of hospice'.² This vision is supported by

the New Zealand Palliative Care strategy,¹ one of the aims of which is to inform the public about palliative care services.

Patients and families facing a life-challenging or end-of-life illness seek support and assistance with physical, psychosocial and spiritual care to resolve issues, address their spirituality regardless of how they have lived their lives, and achieve as peaceful an end-of-life time as is possible. By accessing the care from hospice services, patients and families can face the challenges of their end-of-life journeys in a supported manner and environment. However, in general the New Zealand population have a low level of awareness about

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where their local hospice is located and what palliative care services are available.³

The number of deaths in New Zealand is projected to rise with population growth and ageing and these demographics will in turn result in a greater need for palliative care services. In addition, the ethnic diversity of the New Zealand population will rise exponentially from immigration, according to Statistics New Zealand.⁴ An implication of these statistics is an increased need for information-giving to the ethnically diverse population to heighten awareness of palliative care and hospice services available to them.

The hospice catchment area has a very diverse ethnic population within a total catchment population of 332 900. According to hospice records, 57% of patients referred for hospice services were New Zealand European, whereas this ethnic group comprise only 37% of the regional population, which is 25% Pacific, 19% Asian, and 14% Maori.⁵ At the time of the study in 2007/2008, 13% of the hospice patients were Maori, and Pacific and Asian populations were under-represented.

An educational approach is a crucial focus that has been explored internationally to address the challenge of removing barriers to palliative care access, providing quality palliative care whilst also providing community support to families in end-of-life care.⁶ Public lack of awareness and knowledge of available palliative care services will be a significant barrier to improving care access in the New Zealand context.

Previous New Zealand research has found that only a third of respondents were aware of their local palliative care organisation.³ Age and gender were significant factors that correlated with awareness levels of palliative care services, with those aged over 50 and women having greater awareness of hospice services.³ This research did not explore ethnic differences in public awareness and understanding of palliative care.

There is a need to identify the strengths and weaknesses of hospice services from a consumer perspective in order to formulate changes for the better.⁷ In New Zealand, strategic planning

WHAT GAP THIS FILLS

What we already know: The services of hospices generally are well utilised. While previous feedback from patients and families has been positive, statistics from the hospice in the study shows that patients from non-European ethnicities are only 43% of people referred for hospice services. This statistic does not reflect the ethnic composition of the local population.

What this study adds: This study reveals valuable insights that can be used strategically to improve hospice services. The outcomes can be utilised to increase the awareness of and access to services by strategies such as connecting with cultural groups through churches, community and specific cultural media.

is required to explore how to improve access to palliative care for increasingly culturally diverse communities.²

Utilisation of services also does not necessarily mean that the needs of patients and their families are being met. Dissatisfaction might relate to communication issues or interpersonal conflicts and misunderstandings, and patients and their families may be reluctant to complain.^{8,9} End-of-life illness is a time when patients and families draw on their cultural beliefs, practices and traditions to enhance spirituality. For example, for Maori patients and their families, special identification of areas for improvement in care may assist Maori patients to achieve the 'quality of dying' they seek. Improving service outcomes for Maori should also ensure an improvement of service for other ethnic groups who share the same values of extended family as carers, and a desire for holistic care based on the tenets of tinana, whanau, hinengaro and wairua (physical, family, psychological and spiritual health).¹⁰ Hospice is a philosophy of care that aims to incorporate the physical, emotional, social and spiritual needs of patients and those of their family.¹¹

The aim of this research was to gain the perspectives of patients and their families on the services provided by the hospice, including exploration of components of service care that could be improved for various cultural groups. The study focused on the adequacy of the dissemination of information about available services and their appropriate utilisation, the timeliness of service provision, the appropriateness of services, including cultural sensitivity of provided services, and

the integration of hospice care with other health care services in the primary health care sector.

Methods

This was a qualitative study designed to capture the experience of hospice patients and their family carers. The authors acknowledge that the perspective or position of the researcher shapes all research.¹² The lead author has a nursing background and a long career as a palliative care educator in both hospice and university settings, and was aware the multiple influences she has on research processes and on how research processes may affect her, in line with reflective research practices.¹³

This study used purposive sampling of patients under the care of the hospice and of family members of hospice patients who had died within the previous two years. Family member participants had been the main carer of the patient and were familiar with the care received from the hospice. Children and young adults under the age of 18 years and patients with cognitive impairment, due to illness progression or medication, were excluded from the study.

The eligible patient population was selected via the electronic medical records from all those who had accessed services from the hospice. Participants were chosen from this database for diversity of ethnicity, socioeconomic status, gender, age and religion.

Selected patients and families were sent a participation information sheet with a letter inviting their participation in the study. The information sheet contained a brief description regarding the aims of the study, and key components of care to be assessed were described. Consenting patients and/or family participants were approached by phone to arrange a meeting for the interview.

Semi-structured interviews completed were up to 30 minutes duration, audiotaped and transcribed with the participants' consent. These were conducted by an experienced research assistant employed by the hospice for the purpose of this project. The interviewer had had no prior interaction with participants in their previous association with the hospice. Figure 1 lists the questions asked during the interview. If the patient experienced tiredness or other symptoms that prevented the completion of the interview, a second appointment was sought that was convenient for the patient and family. Hospice counselors were available to support participants should the need have arisen for emotional support on grief issues. Interviews took place either at the hospice or in patients' homes in the community. Recruitment into the study continued until data saturation was reached.

A general inductive approach was used for analysis of the transcriptions for identification of emerging issues.¹⁴ The two researchers conducted independent coding of the data, with discrepancies addressed through adjudication.

Ethical approval for the study was granted by the Northern Y Regional Ethics Committee (Ref. NTY/07/06/060).

Findings

Eighteen interviews were conducted, 12 with patients and seven with caregivers, usually the spouse. In one instance, a patient and his wife

Figure 1. Questions asked during the semi-structured interview

1. **What did you like about hospice services you received? What worked well for you?**
 - How easy was it to find out what was available?
 - How timely were services provided?
 - Did services meet your needs?
 - Did you feel that your culture was respected/understood?
2. **What were the gaps? What did not work well for you?**
 - Were services too much too early, or too little too late?
 - Are there other services that could have been helpful for you?
 - How did hospice services fit in with care you received from your general practice and from the hospital?
 - Can you suggest ways that these different services might work better together?
3. **Many (e.g. Samoan or Asian) people in the area are not using hospice services.**
 - Any ideas why this is?
 - Any suggestions on how hospice can make their services more appropriate for them?
4. **Is there anything else important for hospice to know about your experience of the service?**

Table 1. Demographic characteristics of participants in the study

Interview number	Patient age in years	Patient gender	Patient ethnicity	Patient's country of birth	Study participant	Participant gender
1	39	M	Maori	NZ	Partner	F
2	81	F	NZ European	NZ	Patient	F
3	43	F	Maori	NZ	Patient	F
4	75	F	NZ European	NZ	Patient	F
5	68	M	NZ European	NZ	Patient and wife	M, F
6	70	F	Maori	NZ	Patient	F
7	75	F	NZ European	NZ	Patient	F
8	66	F	NZ European	NZ	Patient	F
9	40	M	Tongan	Tonga	Wife	F
10	69	F	Indian	Fiji	Daughter-in-law	F
11	80	F	Chinese	China	Husband	M
12	62	F	Korean	Korea	Husband	M
13	68	M	Cook Island	Cook Islands	Patient	M
14	60	M	Samoa	Samoa	Patient	M
15	75	F	German	Germany	Patient	F
16	42	M	Samoa	Samoa	Patient	M
17	44	F	Samoa	Samoa	Patient	F
18	71	M	English	England	Wife	F

M male; F female; NZ New Zealand

were interviewed jointly. Patients' ages ranged from 39 to 81 years, with ethnic diversity reflecting the population of the area (see Table 1).

Four key themes emerged. These were:

1. Hospice personnel's approach to patients
2. Quality of services
3. Cultural barriers
4. Strategies for future improvements.

These four themes are discussed in detail in the following sections, with examples of participants' responses.

Hospice personnel's approach to patients

Members of staff and volunteers were acknowledged for their friendly approach, readiness to converse with patients and families, and provision of professional care.

The friendliness of all the staff... I notice that they were always ready to have a word with, you know, with me. (#2)

Members of staff were also described as culturally aware in their practice.

Because we come from Fiji so maybe our culture is a bit different from the Indian one, but definitely I think the nurses are very understanding, yeah. (#10)

Quality of services

The quality of service was evaluated favourably. Appropriate equipment was also available and offered where needed. Visits from members of the clinical team were well received and described as being similar to a friendship.

And so, you know like we've found the regularity of the hospice people coming, to be fantastic. And it's like friendship. (#3)

Liaison with other care providers was described as good and as 'working in together'. This liaison also ensured that visits were alternated, so that the family were not overwhelmed with visits from too many people at the same time.

Once the hospice logged with the Cancer Society then they contact each other and make time so they won't come at the same day or all in one week, you know? (#9)

However, the study revealed patients' lack of knowledge about hospice and the possible services available.

But actually this interaction, I didn't know anything about it until they actually came in and started helping. (#10)

Cultural barriers

Cultural perceptions were significant as barriers to access and revealed insights that could inform culturally sensitive education about hospice services.

Well I think most Polynesians are just shy to use these sort of things. Too independent. (#3)

And also there's a lot of people that still don't like to, still haven't faced up to their mortality as far as their own, so hospice to them is basically also the step to the mortuary. (#16)

Cultural perceptions were significant as barriers to access and revealed insights that could inform culturally sensitive education about hospice services.

They probably don't avail themselves too much in the initial stages of our Western medicines because they've got their own way of doing it through the herbal side, through the mushrooms which they use from the hills to cure their tumours and reduce the tumours which have been effective in themselves. (#12)

Pacific Islanders, it's like rest homes, you know? Rest homes are a concept that just doesn't seem to gel with the Pacific Island psyche because normally it's the reason why you have big families. It's because when parents are older, then the family looks after them. They don't realise that it's more a support system rather than you take care of them because I can't take care of them sort of thing. (#17)

I knew they weren't like hospitals and I think perhaps other cultures that haven't come across them don't quite understand what they're there for. (#18)

Strategies for future improvements

Participants were asked how services could be improved and what measures could be taken to 'close the gaps' discussed. These strategies included having education and information made culturally accessible via churches and community groups, and having information provided in other languages (for example, in local Korean newspapers). Information about the hospice should be provided earlier in the care pathway, with early reassurance for families that support is available, and with exploration of the possibility of providing home help and support for spouses struggling with care as well as household chores.

Yeah, so maybe they're not aware or maybe they don't have the, what shall I say, the confidence to actually come to ask. So maybe they don't know what hospice does so they just say if you don't know just stay away from it. (#10)

One strategy identified was to have staff members and volunteers from other ethnicities available to make contact with patients and families, to assist in information giving and support that can enhance the services and care.

And perhaps if they had people of their own ethnicity representing them from the hospice. That might break through that communication thing. (#2)

One point suggested was with regard to families with children visiting in-patients causing intrusive noise and disturbance. It is recognised that Maori and Polynesian patients need the support of extended family and require a place to be with their large group of family members. This includes children and requires space and restrictions to prevent intrusion on other patients and families.

And then whanau [family] came in and I'm being part-Maori myself, and you'd have 30-odd people running around making absolute riot and the other patients were compromised. And at one stage we had to get the nurses to tell the kids to stop stomping on the balconies and to keep their voices down. (#1)

Discussion

Key findings

While the qualitative nature of the study prevents generalisations, it appeared that Pacific and Asian patients were much less likely to take advantage of hospice services, such as home visiting, day-stay and rest-home facilities. These findings may be transferable to other hospices in other settings where there is a similar context of ethnic diversity, especially a high proportion of Pacific people.

The study revealed gaps in knowledge and understanding about the hospice service and reflected the lack of profile building and public relations by the hospice in the public arena. There was a general lack of awareness of what services are provided, the philosophy of care and what hospice stands for, and indeed, the perception that when hospice gets involved, death is sure and imminent. This latter misperception has long been a barrier to access and requires address in education.

The cultural perceptions revealed in this area were important insights for the service. The reasons described for Pacific peoples' hesitance in accessing care included a genuine lack of awareness of what is available, that accessing services for their dying family member is simply 'not their way', or that they are too shy to access a service that is predominantly European in concept. A further reason given was that at this stage of illness, Western forms of medicine are not seen as conducive to the traditional ethnic forms of medicines they favour.

Comparison with other literature

There is a growing body of evidence of diverse attitudes towards palliative care across and within ethnic minority groups. In Australia, a study exploring whether hospices were adequately serving patients of non-English-speaking backgrounds, found that these patients 'were likely to retain values related to death from their original culture, in preference to the dominant culture of Western society'.¹⁵ The authors recommended a number of strategies to provide a more culturally sensitive service, such as training of staff

in diverse cultural needs, use of the telephone interpreter service and welcome signs in key community languages.¹⁵

A study of Korean Americans identified cultural and structural barriers to advance care planning and hospice use in Florida, US.¹⁶ However, it has also been reported that family members' views towards advanced care planning may not always be congruent with the patient's.¹⁷ Another US study found that African Americans were less likely than whites to have advance directives and had less favourable beliefs about hospice care.¹⁸

Regardless of ethnicity, there are some universal needs of dying people and their families: being acknowledged, cared for; the importance of a safe, aesthetic and spiritual environment; and the holistic approach encapsulated by the palliative care philosophy.¹⁹ An Australian study of non-English-speaking hospice patients found that, regardless of their background, 'the holistic and individualised care offered by hospices for both the patients and their families can be of immense value', and that what is most important is ensuring that people are made aware that these services are available.²⁰

Other research into Asian American perspectives on palliative care found that education and awareness could improve outcomes and active dialogue among health care professionals, patients and families. This could be beneficial, with clinicians more culturally sensitive in accepting family-centred decision-making along with the autonomy model.²¹ Ethnic differences in palliative care access between Pacific peoples, Asians and other ethnicities reduced to non-significance once intensive palliative care consultations for end-of-life care were introduced in Hawaii.²²

The indication is for information to be provided in a multi-layered and appropriate manner for specific community groups. With respect to our study, the Pacific cultural opinion that it is 'not their way' to access care from a provider for their dying member of family may be difficult to uphold in the New Zealand context. Possible consequences of urban life for Pacific peoples is fragmentation of family infrastructure, geographical separation between family members, and the

need to earn wages, leaving no-one available at home to care for the dying person. It is important that Pacific people in New Zealand receive the message that hospice and other palliative care services are available and that they can be of value for all people, regardless of ethnicity.

New Zealand research has indicated that, despite the rhetoric in the New Zealand Health Strategy,²³ provision of palliative care is not always translated into health care delivery and individual clinical practice, with integration of primary, secondary and tertiary services often lacking.²⁴ There is a role for both hospital specialists and general practitioners to suggest hospice care as an option for all dying patients in their care. The position of palliative care coordinator at the Mary Potter Hospice in Wellington is described as arranging specialised palliative care for people living at home and helping to bridge the communication gap between health care providers.²⁵

Strengths and limitations

The strengths of this study are the revelations around information giving, the lack of public profiling of the hospice, and the need for culturally appropriate education. The study also revealed areas that require more exploration in research and continued monitoring in the way of audit. A limitation of the study is that the 'culture of niceness' associated with hospices is sometimes a barrier to identifying the gaps in the system. Although the interviewer was independent to the hospice (a researcher not previously associated with the hospice), the study was commissioned and conducted by the hospice, with the purpose of identifying service gaps and barriers and participants may have been loath to criticise the service. As this study was specific to the ethnically diverse hospice in a particular locality, the findings cannot be generalised nationally. Furthermore, the ethical approval required initial contact by letter, whereas an approach via phone or face-to-face may have been more culturally appropriate in some cases and may have influenced participation.

Implications

Public information giving and education can accompany public profiling of a hospice to

strengthen community involvement and create a relationship that could be of mutual benefit to both as partners. A relationship that encourages the involvement of groups in activities with hospice can enhance the work relations of both sides, profile hospice in the community and assist with education and fundraising opportunities.

The outcomes of this project are important to the direction and focus of strategy for a future plan that will target access issues and improve services for the consumer public in the local region. This strategy includes cultural appropriateness in health care practice for all patients and families with life-challenging and life-limiting illness, a time when spirituality, values and cultural practices take on a new significance to them. Spiritual care is an important component of palliative care, particularly for those of ethnic minorities.²⁶ Egan et al.'s²⁷ study in New Zealand hospices concluded that spirituality may include a search for one's meaning and purpose in life, ultimate values, a sense of connectedness, identity and awareness, as well as religious beliefs for some.

This project informs future planning to enable the hospice to improve their palliative care for all patients and families in their region and to work closely with the community to provide consultative services to their primary health care providers. Multi-layered education in the community must reflect the cultural diversity of the specific catchment area in content and advertising. Hospices can strengthen the working relationship, awareness of and access to services, by making contact with cultural groups through churches, community and cultural media specific to some ethnic groups.

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COMPETING INTERESTS

Yvonne Bray was employed as an educator at the hospice at the time this study was conducted. The authors have no other conflicts of interest to declare.