

American Journal of Hospice and Palliative Medicine®

<http://ajh.sagepub.com>

Needs and experiences of non-English-speaking hospice patients and families in an English-speaking country

Pam McGrath, May Vun and Lesley McLeod
Am J Hosp Palliat Care 2001; 18; 305
DOI: 10.1177/104990910101800505

The online version of this article can be found at:
<http://ajh.sagepub.com/cgi/content/abstract/18/5/305>

Published by:

 SAGE Publications

<http://www.sagepublications.com>

Additional services and information for *American Journal of Hospice and Palliative Medicine*® can be found at:

Email Alerts: <http://ajh.sagepub.com/cgi/alerts>

Subscriptions: <http://ajh.sagepub.com/subscriptions>

Reprints: <http://www.sagepub.com/journalsReprints.nav>

Permissions: <http://www.sagepub.com/journalsPermissions.nav>

Citations (this article cites 16 articles hosted on the
SAGE Journals Online and HighWire Press platforms):
<http://ajh.sagepub.com/cgi/content/refs/18/5/305>

Needs and experiences of non-English-speaking hospice patients and families in an English-speaking country

Pam McGrath, BSocWk, MA, PhD

May Vun, BA, PGradDip

Lesley McLeod, RN, GradDip, MPrimary Health Care

Abstract

There is increasing evidence that, in practice, hospice care is predominantly accessed by white, middle-class patients, who live in stable home environments with available caregivers and other supports. The present challenge for researchers, administrators, and clinicians is to identify populations of terminally ill patients most in need of hospice care and to direct services to these patients. As a contribution to the development of this area, this paper presents the findings from a recent Australian hospice study that examines the needs and experiences of families from non-English-speaking backgrounds. The findings

indicate that it is as important to focus on similarities as it is to highlight differences.

Keywords: diversity, ethnicity, hospice, multicultural, palliative care

Introduction

The hospice philosophy embraces a democratic commitment to the provision of sensitive, skilled, and compassionate terminal care to all members of our community. However, there is increasing evidence that, in practice, hospice care is predominantly accessed by the more privileged, middle-class, Anglo-Celtic patients, who live in stable home environments with available caregivers and other supports.¹⁻⁵ The indications are that those in greatest need may fall outside the referral network to mainstream care and differ significantly from the demographics of the typical hospice client.⁴ The present challenge for researchers, administrators, and clinicians is to identify populations of terminally ill patients most in need of hospice care and to direct services to these patients.³ This realization is

accompanied by a growing concern that the demographic reality of the ethnic and cultural diversity evident within Western societies must not be ignored, and thus attention to ethnic groups is essential in developing equity of access to service provision in palliative care.⁶⁻¹⁰

Australia's population is one of the most ethnically diverse in the world.¹¹ In recent times, at both governmental and service-delivery levels, there has been an acknowledgment of the inequities that exist in relation to access to health care provision for families of non-English-speaking background (NESB).¹²⁻¹⁴ However, there is only scant work published on NESB families in relation to hospice and palliative care, and the existing work usually deals with it tangential to broader issues.^{8,15} The assumption is made in the literature that the paucity of available research may be a result not only of limited work being carried out on the topic, but, more importantly, that the work completed is not being published.¹⁴ As a contribution to the development of this area, this paper presents the findings from a recent

Pam McGrath, BSocWk, MA, PhD, Research Director, Centre for Palliative Care Research and Education, Queensland University of Technology, Kelvin Grove, Red Hill, Queensland, Australia.

May Vun, BA, PGradDip, Multicultural Project Worker, Karuna Hospice Service, Windsor, Queensland, Australia.

Lesley McLeod, RN, GradDip, MPrimary Health Care, Director of Nursing, Karuna Hospice Service, Windsor, Queensland, Australia.

Australian hospice study that examines the needs and experiences of NESB families in relation to hospice care. The study was conducted by the Karuna Hospice Service (KHS), a community-based hospice organization that has a demonstrated commitment to fostering equity of access to palliative care through the medium of research.⁵

Multicultural community participation project

In August 1999, Karuna Hospice Service embarked on a project to develop culturally appropriate, home-based, palliative care service that would be inclusive of NESB families. The project was principally funded by KHS, although additional funds were obtained from the state government department of Multi-cultural Affairs, Queensland. The aim of the project was to identify the issues and needs of people from a non-English-speaking background and their families for home-based care during the terminal stage of illness. The expected outcome was an increase in access and participation of NESB families to KHS's free, 24-hour, at-home hospice service.

The project was based on a strong commitment to fostering collaboration with organizations representative of local ethnic communities and sought to involve ethnic communities in all phases of the project, including planning, development, implementation, and evaluation. Preliminary work was undertaken to establish relationships with key community leaders in a range of ethnic groups. A steering committee was established, which reflected this ethnic diversity, and planning was undertaken to run a series of focus groups on the topic of terminal care, involving representation from these ethnic groups.

Three focus groups were organized. These focus groups included

Indian, Filipino, Chinese, and Italian cultural groups, and carers that had experience with KHS were also invited. The topic for discussion was an exploration of different ethnic or cultural attitudes toward terminal care with a particular focus on the hospice experience. The first focus group had 12 participants, four Indian women, five Filipino women, two Australian women, and one Australian man. The second had nine participants, all of whom were Chinese with the exception of two Australian women. The participants in the third focus group were mostly Italian, including nine women and three men, with the exception of two Australian women. In all cases, the Australian representatives in the focus groups were individuals that had previously been involved with KHS and attended the group to provide an understanding to the other participants of the work of the hospice service.

The groups were conducted by a researcher with expertise in qualitative methodology in palliative care and experience in running focus groups. Participants were informed that their words were being recorded; they were informed of their rights to voluntary participation, confidentiality, withdrawal, and control of information offered; and all agreed to participate in the study. Individuals were asked to talk about their experience coping with a loved one that was seriously ill and to indicate their understanding of hospice care. Individuals that had previous experience with KHS were invited to provide their stories as a way of explaining the work of hospice. The discussions were audiotaped and transcribed verbatim. Where a participant spoke a language other than English, an interpreter from the appropriate ethnic group translated the words for the transcript. All of the transcripts were then entered into a qualitative computer program and analyzed thematically. All of the participants'

comments were coded, creating 55 free nodes. These free nodes were then organized under eight categories (actual experience with dying; attitudes and cultural beliefs about death and dying; sources of referrals; understanding of hospice; discussion on KHS; volunteers; other helpful organizations; and strategies for fostering NESB hospice services).

Findings

Actual experience with dying

There were some members of each focus group that already had actual experience in caring for a dying loved one. These participants were not those who were the invited clients of KHS, and so their stories did not include information about hospices. The main issues these participants raised were support, pressures, knowledge about hospice, and referrals.

Support. Participants from all groups spoke of the importance of the support they received from family members. Also, all groups talked about the great difficulties they faced when support was not available, such as when family members become ill, do not see it as their role to help, or the patient lives alone.

Pressures on family and carer. All of the groups spoke in great detail of the pressures on family members caring for a terminally ill patient. The problems described were as follows:

- The great demands imposed on the carers, causing "a lot of stress and strain to organize life around (the patient's) needs," to the extent that it "almost destroys your own life and your own family's life";
- The subsequent "loss of a social life";
- The lack of a break away from the situation;

- The problem of juggling work commitments and responsibility to other family members while caring for the patient;
- The interference with work and subsequent loss of income;
- The sheer physical hardship of caregiving, such as heavy lifting and lack of sleep;
- The emotional sequelae of stress, such as anger and a sense of “losing control”;
- Conflict in the family about the best way to approach the care of the patient;
- The “helpless feeling” of watching the loved one “gradually deteriorate” and “slowly go down hill”; and
- The sense of guilt about feeling negative and angry toward the patient because of the stress associated with the caregiving.

The emotional sequelae of this experience was said to “get to you and remain with you,” even after the loved one had died.

Knowledge about hospice. With the exception of KHS’s past clients and one person who had experience with hospice in another state, the participants in all focus groups indicated that they did not know about palliative care services and hospices. Lack of knowledge of hospice was indicated by such statements as: “we didn’t know about hospices...no doctor told us,” or “we didn’t know of any other [palliative care] services.”

Referrals to appropriate services. With the exception of those who had been asked to participate in the group as past clients of KHS, participants in all groups indicated that they had not been referred to palliative care

services. All groups indicated that they had no choice in how they wished to care for their loved one, as can be seen by the following quotes:

- “At the hospital there is no choice...if you bring the patient home, they don’t provide you anything” (Filipino);
- “If we had a choice, we wouldn’t send [loved one] to a nursing home” (Chinese);
- “You have no choice” (Italian).

Participants in the first two focus groups noted that they were referred to local domiciliary nursing (home care) that provided services such as bathing and showering the patient. Participants indicated that there were limits to these services, as can be seen by their comments, for example, “they just gave me a quick shower and it was, unfortunately, a very quick shower” or “it was basically to bath her...there was a kind of rapport...but maybe while bathing, talking and chit chat could occur rather than a piece of action.”

Participants indicated that “they didn’t know of any other services.” Although they were referred to the domiciliary nursing services from the hospital, no mention was made of hospices. The Cathay Club was mentioned by the Chinese participants as an organization that helped with referrals to appropriate services, for example, “they are the information center for a lot of things...we know they are there.” Nursing homes were used because families felt they had no other option.

All groups spoke about the important role of the local general practitioner (GP). The GP was involved in diagnosing the terminal condition, supporting the patient during the home-based care, and recommending the time for admission to hospital during the dying trajectory.

Cultural belief associated with dying

Participants spoke of the “different ways of communicating” about death and dying for people from different cultures.

Talking about dying. Participants from all of the cultural groups indicated that it was not comfortable for their ethnic group to talk about death or dying. Examples of such statements include:

- “I think this subject is taboo...we didn’t say you are dying” (Indian);
- “We don’t speak of death because we are superstitious and somehow feel if we speak it, we will evoke it” (Filipino);
- “They don’t want to talk about it [dying]...that is very Chinese in a sense, so we just have to respect it” (Chinese);
- “Oh, no, you are not going to talk about this [death]” (Italian).

This inability to talk comfortably about death was also noted to be generic for Anglo-Celtic Australians. For example, “I just want to say listening to you that I don’t think Europeans talk even more humbly about death and dying than you do.”

There was indication that to tell patients about the terminal nature of their disease was seen as the doctor’s role. The “Western way” of informing people directly was described as “too abrupt,” “terrifying,” and “blunt.” In other cultures, the notion that the person is dying is gently revealed over time. For example,

- “We didn’t tell him that he was dying...we couldn’t tell...it is part of our culture...I think he knew what was going on, but he didn’t say anything to us.” “We speak about death, but we don’t

...speak directly to the person who is dying...we talk everything and we will speak around, but we don't say it directly to the person" (Filipino);

- "We didn't say 'you are dying' ... but he knew it was there" (Indian);
- "Chinese people do not want to tell them straight away...the news has to be very gentle and a little bit at a time until the person accepts that they need to prepare...otherwise, we find it a little cruel and sometimes they just can't accept it and they will just shut you out altogether if you tell them" (Chinese);
- "You don't want [hospice workers] coming in and letting you realize that you are dying at home. I don't want to know I am dying. So, if only my family is there looking after me, I am not dying. I am still here" (Italian).

Dying in the home. As can be seen by the following quotes, all cultural groups represented in the three focus groups indicated that it "is quite a natural thing" to want to care for a seriously ill family member at home.

- "I think it is a cultural thing... you nursed your parents at home, it was your duty to do that and that is what we did...it is an Indian thing, I think" (Indian);
- "We have to see our relations in the home, so we know where they are and what they are like to the last moment of their lives. We want to be with them rather than put them in a nursing home or an old people home...we look after them at home" (Filipino);

- "Most Chinese would by choice if they could manage it...I think it is a cultural thing...like Chinese relationship is a bit closer...it is my responsibility to look after my parents...they look at it as their right" (Chinese);
- "We are tight-knit when things are to be done at home and they are to be done with the family...if there is a problem, it is family who copes, no one else is supposed to be involved" (Italian).

This position was contrasted with statements from an Anglo-Celtic Australian, who stated that "in our society, we are more selfish and family demands are different...it is not something that we have been expected to do, I guess...it is just not done."

All groups indicated that, given the choice, they would prefer to die at home rather than in the hospital. Quotations from each cultural group indicating this are as follows:

- "They want to be at home...it would be better to have a hospice at home than in the hospital because at home there is the feeling that in our culture you are surrounded with people you want" (Filipino);
- "The last thing they want is to be in hospital...I don't want to die in hospital. I want to die at home. I think it is a cultural thing" (Indian);
- "Most Chinese would by choice [choose to stay home], if they could manage it...Yes, most Chinese people would want to be cared for at home" (Chinese);
- "[Patient] didn't want to go to hospital...they would much rather die in their own beds" (Italian).

Thus, from the point of view of wanting to care for the family member at home and the family member by choice wanting to die at home, there was great similarity across all groups. As one participant summed up the situation, "so, in some way, if we get the message out, it may be an easier message for these cultural groups, as it is the way to go anyway...it is quite a natural thing."

All groups, however, also indicated that there was anxiety surrounding the last moments of life. There was a generic anxiety expressed about being capable of addressing the patient's medical needs. Participants talked about "feeling a bit scared" or "freaked out" at the thought of caring for the individual during the dying trajectory. As one participant stated, "I was thinking if we were to leave the hospital and I was the only one...I would get crazy along the way." This feeling state was also confirmed by Anglo-Celtic Australians in the group who indicated that "it became a pretty scary thing to consider...I thought I would never be able to do it." The concern was that without the correct knowledge, the carer could "do more harm," especially when "the thing starts to get complicated." As one participant stated, "Otherwise, you feel guilty that they are not being taken care of."

In both the Chinese and Italian focus groups, it was stated that "at the very last moment [families] would prefer [the patient] to go into hospital." On this issue, the Chinese participants made statements such as "most of them are not brave enough to let the person die at home...they don't want to dirty the house." Comments from Italian participants included "there is no way my children are going to see [the patient] die in the house" or "there is no way I would die in front of my children." It was considered that when "the time comes, it is better to go to the hospital, as it is better to look after them." The concern seems to be

about the "guilt" because the patient is "not being cared for properly."

In the Italian focus groups, there were many discussions ($n = 4$) on the difficulty (*i.e.*, the profound sadness or perhaps fear) of seeing a person die. Such statements included "when you have someone dying, it is not easy to watch them die"; "it is not a good thing to see the last breath"; or "I could never have done that at home and stayed in that house."

Decision-making. Participants in the Italian focus group noted that the family, rather than the patient, are to decide on if and when the patient would go to hospital. It was stated that "the daughters are the main ones who do the caring, but when the decision comes to go to hospital, the brothers decide."

Privacy was seen as a very important issue for both Chinese and Italian families. With regard to Chinese families, it was stated that "most of them try to keep it within themselves...if a family member is sick, you discuss it within the ethnic group." Chinese participants indicated that their families "don't use public services, but keep it [the care of the patient] within the family." Similarly, reference was made to the importance of "Italian pride," the community was described as "closed," others were seen as knowing a lot about "each other's business," and the judgments of others were considered important. These factors translate into a reluctance to allow others into the home because "Italian people are a little critical" and to have other families in the home during sickness, when "you cannot keep your house in the same way," may make one feel as if "someone may be coming in and criticizing." Consequently, "the older generations want to do it on their own." Traditional Italian families were described as "tight-knit" and "when things are to be done, they are to be done within the family." This factor would make the idea of using a

community-based hospice difficult. However, a suggestion was that it could be somewhat overcome by using non-Italian volunteers as assistants in the home. It was noted that the reluctance to allow others into the home "was breaking down now a little bit because people are realizing that...there are more older people" and "the newer generation [is] accepting it [someone coming into the home to help] more."

The members of the first focus group (Indian and Filipino) noted the reverse of the above situation, stating that they would "rather have someone they don't know, since it is more acceptable to us." The reason given for this is that "in our cultural context, if someone does something for you, then...you have to pay back the favor." By having the help provided by an outside group, such as a hospice, the family can be more assertive about what they want and will not feel indebted.

Language problems. Participants in all three focus groups spoke about the difficulties created by language barriers for NESB families. It was clearly stated that "language is a big problem," "the major issue is the language," and "the problem with communication." As one participant summed up the situation, "The first thing you need to know if you are doing multicultural work [is] you have to be careful of the language." Language was intricately linked with the notion of power in the health care setting. The inability to speak fluent English leaves families with a sense of disempowerment in asserting choices and expressing needs in mainstream health care. Because of the language barrier, NESB families are less likely to find out about or utilize mainstream services offered: "without the ability to communicate in English, they wouldn't know how to use it, even if they know about it"; "even if they know what to use, they don't know how to use it...even if you

come to their home, they can't tell you what they need." In the hospital situation, difficulty with English leaves patients "feeling lost," and the language barrier blocks important communication with nurses.

Interpreter services are not easily accessible: "even where the government provides some sort of interpreter service linked with centre link, this is difficult to access; it is not easy." There are legal problems with interpreters being used to interpret medical information, necessitating a patient to be in hospital or followed up by the hospital to qualify for the interpreter service. Although these services provide a number of free hours per month for voluntary services, they are usually well booked in advance and are not well suited to the emergency needs of hospices. One of the difficulties is the sheer number of different dialects within one language. For example, "when you are talking Chinese, you are talking about 20 or 30 more dialects that elderly people speak...if you aim for the Asian language, you will need a lot of volunteers to deal separately with all this diversity of language"; "I was from northern Italy and I could just speak a little bit [of his dialect]. However, where the patient speaks no English or does not have a close family member who speaks English, an interpreter service is essential.

Because dying raises sensitive emotional and spiritual issues, there are concerns that can best be expressed only in the ethnic language, "but when they want to express themselves... especially when the person is dying and things come out, it is really from the heart and heart talk is Italian, not in English...what comes from the heart comes in your own language." Similarly, the ethnic language is seen as more useful as a tool for communicating if there is a crisis or you need to motivate an individual. Reference was made to the fact that individuals pray in their own language.

Suggestions were made to ameliorate language difficulties, including: "an in-house [NESB] service and someone who could speak the language...would be a big help," or nurses who could speak the ethnic language would be able to build therapeutic relationships more effectively. "If you had a Chinese [nurse]...communication could be built that much faster and maybe while bathing a chat could occur rather than a piece of action"; "I think the Italian language would help because then they would be able to express themselves better to the person...when the nurses come." There was seen to be a need for a coordinator for NESB families. "These people need someone who can really talk the same language as the person, maybe a volunteer or the staff, someone who agrees to pick up the role [of advocate]." It was stated that using ethnic newspapers and radio stations to communicate the message in a language each culture would understand would be important.

The issue was raised that, whereas European Australians with a strong command of English can feel empowered in asserting their needs, for NESB families this is difficult because of the power imbalance. The "fear is there" because of the "different approaches to trying to explain." As one participant stated the case, "it is much harder for us...we haven't got that power...we would end up in the hospital [or doing what we were told] because we were so scared....I would think I would rather [do what was told, even if not agreeable] because I would be in trouble." Services such as KHS were seen as providing an important advocate for such individuals vulnerable to the power of the system.

Volunteers. Participants in all of the focus groups discussed the issue of the cultural factors underpinning the possible use of volunteers. Volunteers were seen as important, particularly when "nobody is there" to help,

because family members who work are not available to help, and it avoids the need to reciprocate for favors rendered. "We normally go and help each other...but then we have to help back, so, in a sense, we would rather have somebody we don't know, so it is more acceptable to us." The respite care that volunteers provided was seen as important. "If I could have someone release me for a day away from home without worrying and not having to rush back, that would be a great help." Volunteers were seen as being able to get family members to do things, such as eat, when a family member might not. For example, "[the patient] would not take anything I offered, but he would do everything for the volunteers."

Participants were asked if it was necessary for the volunteer to come from the same ethnic group. There was a mixed response on this issue, indicating that, for many, the ethnicity of the volunteer was not important. Rather, the quality (helpfulness) of the volunteer was more important than the ethnicity, and it was considered important that the volunteer was respectful of spiritual differences.

It was noted that to get volunteers from some communities may be hard because of the involvement of all family members in the workforce and the high commitments individuals have with activities in their spare time. It was stated that in the Chinese community this could be exacerbated because people would not want to be a volunteer with a hospice, as they would not want the bad luck associated with having contact with people dying. However, the qualities of volunteers were well respected, as can be seen by the following comment: "I admire the [volunteers'] courage...being able to choose and say I am going to do that. I admire your kindness."

Spiritual sensitivity. Mention was made of the need to respect the religious and spiritual philosophies of the

different cultural backgrounds. Participants noted that their experience with Buddhist practitioners was very positive in this regard, as "Buddhism is more encompassing of all religions"; "they don't come and push religion. They ask you what you want, then they are sure you get it." Buddhism, although seen as "foreign" to Westerners, was described as a "very appropriate" philosophy for hospice because practitioners are seen as "such gentle people" and thus would be most suited to caring for the dying. It was considered particularly attractive for the Chinese community.

Provision of information on KHS

Participants in all groups asked many questions about the service provided by Karuna Hospice Service. Representatives from KHS were asked to provide information on a wide range of topics and about how the service implements the hospice philosophy, including issues of autonomy, psychosocial care, pain and symptom management, information giving, 24-hour care, spirituality, the continuum of care, volunteers, and staffing.

Strategies and recommendations

As noted throughout all discussions, communicating the compassionate hospice message was difficult because it was associated with death and dying, a topic all cultures have difficulty handling. In short, the problem is "How is it possible to talk about death when no culture wants to hear about it?" However, suggestions for starting to address this problem included the following:

- Begin the process of talking about dying and hospice: "it is best to get it out there";
- It will be important to demonstrate leadership in communicating the

hospice message if this process is to be effective. This means that leaders of the ethnic communities need to take responsibility for communicating information about hospices and will need to take steps to introduce KHS to their communities;

- For leadership to happen, it will be necessary for KHS to continue to work with and convey the hospice message to the “gatekeepers” of ethnic communities;
- There will be a need to reach the target audience of people that are in the position of actually having to cope with a loved one who is dying;
- Hospital doctors and local general practitioners will need to be targeted and convinced of the importance of their providing appropriate information and referrals to NESB families;
- Use ethnic media, newspapers and radio, to communicate the hospice message in the appropriate language. Some participants noted that they learned about the services of KHS through newspaper articles or the radio. It was noted that KHS should pass proofs of their media releases on to the appropriate ethnic group’s leaders before releasing them to make sure the stories are culturally sensitive;
- Put out a request for volunteers on ethnic radio, saying that there is the need for the volunteers and describing the service;
- Link with other volunteer or ethnic community organizations to access volunteers with a variety of ethnic language skills;

- To a large degree, people need actual experience with hospices, or at least with caring for the dying, to understand the message, and so it will require networking with people that have actually had experience in this area to communicate the message to a broader audience. As one participant stated, “we need people actually going to KHS for a while...it is very hard to convince people...you have to have [contact] with what KHS is about and its spirit”;
- It is considered important to “win the confidence” of families in ethnic communities; and
- Communicate with the younger generation, where the traditional attitudes that act against communication of the hospice message are breaking down.

Discussion

The findings from this survey were a surprise, as they were contrary to the original expectations. It was anticipated that individuals from ethnic groups would emphasize the difference between people rather than their similarities. With the exception of the important issue of language, most of the participants’ statements indicated a shared reality with regard to the dying trajectory. In summary, the common experience included stories of hardship in caring for loved ones that were dying when hospice was not available, the lack of referrals to appropriate services, the difficulties of talking about issues of death and dying, and the fear of the responsibility of caring for a loved one at home. Also, there were shared stories of the common desire to die at home, the appropriateness of caring for family members, and the appreciation for hospice care when it was available.

However, the crucial issue in reaching NESB families, as it is for mainstream Anglo-Celtic families, is that because hospice is associated with dying it is a difficult message to communicate. The participants were forthcoming with important suggestions about strategies to assist the process, based on networking and building relationships within communities to convey the hospice message through culturally sensitive community networks and the ethnic media. Such a process needs leadership and the possibility of direct contact with those that have had hospice experience.

Hospice is not a concept restricted to Western Anglo-Celtic countries and there is evidence in the literature of recent hospice initiatives in all of the cultures included in the present study.¹⁶⁻²¹ Hospice is a philosophy with a generic appeal across culture and ethnicity. The findings from the present study affirm Gunaratnam’s²² critique of multiculturalism in palliative care that there is a danger inherent in too exclusively focusing on ethnic difference. Indeed, the present findings indicate, as Gunaratnam²² predicts, that an emphasis on difference may cover or disguise the essential similarities in the dying experience across cultural groups. The similarities, it is argued, are as important as the differences in informing our understanding of strategies to bring hospice care to the majority of people within our societies.

Conclusion

The findings from this research can be summarized concisely in two statements by participants: first, “I don’t think we are really too much different, we are putting too much emphasis on our ethnic group”; and, secondly, “the word that help is there is important.”

For all individuals, no matter what their background, the holistic and individualized care offered by hospices for

both the patients and their families can be of immense value. There are indications of real hardship for those who have to cope with the demands of caring for loved ones during the dying trajectory, when such services are not available. Thus, it is of the utmost importance that we bring the hospice message to as many as possible. The findings presented in this paper indicate that in our attempts to communicate the hospice message in a culturally diverse society it is as important to remember our shared humanity as well as our difference.

References

1. Brenner P: Issues of access in a diverse society. *Hospice J.* 1997; 12(2): 9-16.
2. Higginson I, Astin P, Dolan S: Where do cancer patients die? Ten-year trends in the place of death of cancer patients in England. *Palliative Medicine.* 1998; 12: 353-363.
3. Hunt R, McCaul K: Coverage of cancer patients by hospice services, South Australia, 1990 to 1993. *ANZ J Public Health.* 1998; 22(1): 45-48.
4. Johnson C: Hospice: What gets in the way of appropriate and timely access. *Holistic Nursing Practice.* 1998; 13(1): 8-21.
5. McGrath P: Who are our clients? A descriptive profile of a community-based Buddhist hospice. *American J Hospice & Palliative Care.* 2000; 17(3): 178-184.
6. Gaffin J: Opening doors. *European J Palliative Care.* 1995; 2: 6-7.
7. Haroon-Iqbal H, Field D, Parker H, Iqbal Z: Palliative care services for ethnic groups in Leicester. *Int J Palliative Nursing.* 1995; 1: 114-116.
8. McNamara B, Waddell C, Yuen K: Palliative care in a multicultural society: Perceptions of health care professionals. *Palliative Medicine.* 1997; 11: 359-367.
9. O'Neill J: Ethnic minorities—neglected by palliative care providers? *J Can Care.* 1994; 3: 215-220.
10. Sheldon F: Will the doors open? Multicultural issues in palliative care. *Palliative Medicine.* 1995; 9: 89-90.
11. Young C: Australia's heterogeneous immigrant population: A review of demographic and socioeconomic characteristics. In Donavan J, d'Espaignet E, Merton C, van Ommeron M (eds.): *Immigrants in Australia: A Health Profile.* Australian Institute of Health and Welfare: Ethnic Health Series, No 1. Canberra: Australian Government Publishing Service, 1992: 11-33.
12. Australian Bureau of Statistics, Queensland: *The Social Characteristics of Immigrants in Australia.* Canberra: Australian Government Publishing Service, 1994.
13. Manderson L, Reid J: What's culture got to do with it? In Waddell C, Petersen A (eds.): *Just Health: Inequality in Illness, Care and Prevention.* Melbourne: Churchill Livingstone, 1994.
14. Waddell C: *Ethnic Diversity in Dying, Death and Bereavement and the Delivery of Culturally Appropriate Palliative Care.* Unpublished doctoral dissertation. Department of Anthropology, University of Western Australia, 1998.
15. Health Department of Western Australia and the Western Australia Hospice Palliative Care Association (HDWA): *Palliative Care in Western Australia to the Year 2001.* Perth, Western Australia, 1995.
16. Ajithakumari K, Sureshkumar K, Rajogopal M: Palliative home care—the Calicut experience. *Palliative Medicine.* 1997; 11(6): 451-454.
17. Chaturvedik S, Chandra P: Palliative Care in India. *Sup Care Can.* 1998; 6(2): 81-84.
18. Low J, Pang W, Lee A, Shaw R: A descriptive study of the demography, symptomatology, management and outcome of the first 3,000 patients admitted to an independent hospice in Singapore. *Ann Acad Med, Singapore.* 1998; 27(6): 824-829.
19. Peruselli C, DiGiulio P, Toscani F, et al.: Home palliative care for terminal cancer patients: A survey of the final weeks of life. *Palliative Medicine.* 1999; 13(3): 233-241.
20. Sbanotto A, Burnhill R: Palliative care in Italy: The current situation. *Sup Care Can.* 1998; 6(5): 426-429.
21. Sze F, Chung T, Wong E, et al.: Pain in Chinese cancer patients under palliative care. *Palliative Medicine.* 1998; 12(4): 271-277.
22. Gunaratnam Y: Culture is not enough: A critique of multi-culturalism in palliative care. In Field D, Hockey J, Small N (eds.): *Death, Gender and Ethnicity.* London: Routledge, 1997.