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Who are our clients? A profile of a community-based Buddhist hospice

Pam McGrath, PhD

Abstract

One of the ongoing challenges for those involved in the hospice movement is to find ways of effectively extending the provision of hospice services to all in need. Pragmatic, empirical research that provides information on the present and potential hospice population is essential to foster the development of services if this challenge is to be met. This discussion presents a descriptive profile of the clients of a community-based Buddhist hospice in Brisbane, Australia, known as the Karuna Hospice Service (KHS). This descriptive profile makes a contribution to the important task of establishing where we currently are, in the hope that this will begin to delineate where fresh energy needs to be directed in the future.

Background

The literature on the philosophy and practice of hospice care is now well established. The foundational writings of many significant authors have contributed to the development of a firm conceptual basis on which practitioners can build models of care and guidelines for service provision.

Pam McGrath, PhD, Research Fellow, Center for Public Health Research, Queensland University of Technology, Red Hill, Queensland, Australia.

Having achieved a clear understanding of the hospice vision, complemented by a sophisticated body of research on practice, one of the ongoing challenges for those involved in the hospice movement is to find ways of effectively extending the provision of hospice services to all of those in need. Pragmatic, empirical research that provides information on the present and potential hospice population is essential to the development of services to meet this challenge.

To date there has only been scant material published in peer-reviewed journals on the details of actual hospice services, programs, and clients in the Australian context.¹⁻⁵ Palliative Care Australia, the national body for palliative care in Australia, has taken the first step in building an overview of service provision through its 1998 census of palliative care services. The report from this study⁶ is an important initiative fostering the documentation of much needed information in the area of service provision. Information on hospice clients is also needed for effective service planning, not only for those who currently use hospices, but also to understand, by inference, the potential clients that are currently not being reached.⁷

This discussion presents a descriptive profile on the clients of a community-based, hospice service in Brisbane,

Australia, known as the Karuna Hospice Service (KHS). KHS is a Buddhist-based organization that has its origins entirely in the community.⁸ It is one of the 12 clinical providers of palliative care in the Brisbane, Queensland metropolitan area.⁶

Documenting descriptions of present hospice clients can help shed light on a wide range of important issues arising in the research literature. Descriptive profiles can provide information on the demographics of hospice patients and their families, details about their caregivers, their home situations, the referral sources of patients, their length of stay, cultural origins, spiritual orientation, and where they die. This information can enrich our understanding of a broad range of issues associated with extending the network to those in need of hospice service. I will first present the findings from a descriptive profile of one hospice, and demonstrate, in the discussion section, how such data are directly related to ongoing issues in service provision.

Karuna Hospice Service

Karuna Hospice Service (KHS) is a Brisbane, community-based, Buddhist organization which provides comprehensive home care services for people with a life-threatening illness and their

loved ones. This service provides full hospice-at-home services, with expert nursing, counseling and respite care. Nursing care is provided every day on a 24-hour basis, and consultations with palliative care medical specialists are available when required. Individual and family counseling is provided, as well as bereavement counseling and support, as well as pastoral care. The KHS team cares for adults and children who have a life expectancy of less than six months, who have a caregiver available and a general practitioner willing to be involved in home-based care. This service was established in 1991 by a group of visionaries in the community under the charismatic leadership of a Buddhist monk. It currently receives a significant part of its funding from the Regional Health Authority. Although it has only been established for eight years, this organization has already earned an excellent reputation in the local community for its innovative, committed and compassionate work with the dying. The name, *Karuna*, is from the Sanskrit word meaning "compassion."

Methodology

For this study, a totally inclusive sample of KHS's patients and their caregivers, from January 1997 to December 1998, was used. The data for this descriptive profile were obtained from the admission forms that were filled out when the patients first arrived at KHS. Although these forms were originally designed for administrative purposes, not research, they contained a great deal of relevant information for this project. Fortunately, the records had been fairly well maintained and hence provided extensive and in some areas fairly complete data. Sixty-one variables were developed from the categories on the admission sheet. The total number of cases entered during this time was

227. The data were entered into the SPSS statistical package and quantitatively analyzed with simple descriptive statistics.

Findings

Demographics

All clients were adults, ranging in age from 27 to 94. There was a fairly even gender distribution (male, $n = 120$, 52.9 percent; female, $n = 107$, 47.1 percent). Twenty of the families (8.8 percent) were experiencing the death of a parent where the ages of children ranged from as young as two months to 18 years. The number of children in these families ranged from one to four: (one, $n = 3$); (two, $n = 10$); (three ($n = 5$); and (four, $n = 2$).

It is interesting to note that at this Buddhist-based hospice only six patients (2.6 percent) identified Buddhism as their religion with most patients recording either no religion or a denomination of Christianity (Table 1). Although the clients were predominantly Australian, there was wide variation in the nationalities recorded.

Nearly half the admission sheets ($n = 112$; 49.3 percent) were not formatted for information on welfare dependence. However, where data was available there was evidence that a large proportion ($n = 104$; 44.8 percent) of the clients were dependent on welfare, including: Department of Veteran Affairs pension ($n = 15$; 6.6 percent); aged pension ($n = 36$; 15.9 percent); caregiver pension ($n = 10$; 4.4 percent); domiciliary nursing care benefit (DNCB) ($n = 26$; 11.5 percent); invalid pension ($n = 1$; 0.4 percent); disability pension ($n = 15$, 6.6 percent); and employment benefits ($n = 1$; 0.4 percent).

As Table 2 details, the vast majority of patients (96.9 percent) cared for by KHS during this period were diagnosed with cancer. Most of the patients who did not have cancer died of

heart disease. The diagnostic groups are listed in Table 2 according to the primary cancer site.

Admissions

There were 105 (46.2 percent) clients admitted in 1997, and the number increased to 122 (53.8 percent) in the following year. Of the total number of clients admitted over the two-year period, the majority were first-time admissions (99.1 percent). Nearly half of these clients were referred from public hospitals (41 percent; $n = 93$). Other sources of referrals were specialists at private hospitals (13.2 percent; $n = 30$), general practitioner (15.9 percent; $n = 36$), informal networks (24.2 percent; $n = 55$), and undefined/other (4.4 percent; $n = 10$). There were admissions over the time of this study with seven to nine ($n = 3$) patients a month admitted on average, although some months there were as few as four admissions, and other months as many as 17.

Only a small proportion of clients (26.4 percent; $n = 60$) recorded reasons for being referred to KHS. Six of the reasons that were given included:

- the need for home care support (14.5 percent);
- the need for symptom management or support (2.6 percent); pain control (2.6 percent);
- a request for palliative care nursing (5.7 percent);
- a desire to return home from the hospital (0.4 percent); and
- a recommendation from a friend who had previously used KHS (0.4 percent).

Length of stay

As detailed in Table 3, the length of

Table 1. Demographics (n = 227)					
Age	Percent	Religion	Percent	Nationality	Percent
27 - 29	0.9%	No religion	42.7%	Australian	62.6%
30 - 39	4.9%	Roman Catholic	22.9%	UK	3.5%
40 - 49	8.9%	Anglican	10.6%	Italian	2.6%
50 - 59	21.3%	Church of England	7.5%	Scottish	1.8%
60 - 69	28.4%	Buddhist	2.6%	New Zealander	1.3%
70 - 79	25.8%	Uniting Church	2.2%	Spanish	0.9%
80 - 89	9.4%	Methodist	2.2%	Hungarian	0.9%
90 - 94	0.4%	Presbyterian	2.2%	Russian	0.9%
		Christian	2.2%	German	0.4%
		Assembly of God	0.9%	Dutch	0.4%
		Baptist	0.9%	Tongan	0.4%
		Quaker	0.4%	Japanese	0.4%
		Mormon	0.4%	Chinese	0.4%
		Jehovah's Witness	0.4%	Welsh	0.4%
		Salvation Army	0.4%	Cook Islander	0.4%
		Church of Christ	0.4%	Kenyan	0.4%
		Seventh Day Adventist	0.4%	Finnish	0.4%
		Greek Orthodox	0.4%	American	0.4%
				Aboriginal	0.4%
				Ukranian	0.4%
				Irish	0.4%
				South African	0.4%
				Greek	0.4%
				Thai	0.4%

time clients were cared for by KHS varied from one to 283 days. The majority of patients (56.4 percent) were cared for by KHS for fewer than 29 days. The majority of patients died in their own homes (53.3 percent; n = 121), others died in the hospital (33.5 percent; n = 76) or were discharged (13.2 percent; n = 30).

Caregivers

Only 4 percent (n = 9) of patients did not have a primary caregiver. For the majority (62.4 percent; n = 141), the spouse or partner was the principal caregiver; for many patients, daughters (17.2 percent; n = 39) and friends (4.4 percent; n = 10) provided the care. Others who were involved as caregivers included sons (4.0 percent; n = 9), sisters (3.1 percent; n = 7), daughters-in-law (1.8 percent; n = 4), mothers (1.3 percent; n = 3), brothers (0.9 percent; n = 2), and nieces or nephews (0.8 percent; n = 2). The majority of caregivers were female (63.3 percent; n = 144), although a small number of patients had both male and female caregivers (2.2 percent; n = 5).

In addition to the primary caregiver, there was also a wide range of individuals available as contact persons for the patient. Daughters (64.7 percent), sons (51.1 percent), and spouses/partners (33 percent) were by far the most frequently listed contacts. However, mothers (10.1 percent), fathers (4.4 percent), stepchildren (2.6 percent), sisters (11.5 percent), grandchildren (9.7 percent), sons-in-law (8.8 percent), daughters-in-law (8.4 percent), friends (11 percent), brothers (6.1 percent) and nieces/nephews (.8 percent) were also available.

Perhaps reflecting the older age demographic of the group, one tenth (10.6 percent; n = 24) of the patients lived alone. The majority lived with their spouse/partner (64.8 percent; n = 147). Others resided with daughters

	Percent & frequency
Malignant	
gastro/intestinal	27.6%
lung	20.7%
urogenital	8.2%
melanomas	7%
breast	5.3%
brain	5.2%
unknown primary	4.7%
gynecological	4.3%
biliary tract	3.9%
lymphomas/Hodgkins	2.7%
ear/nose/throat	2.5%
bone	1.8%
blood	1.7%
other	1.4%
<i>Subtotal</i>	97%
Nonmalignant	
cardiac failure (including MI)	1.8%
COAD	0.4%
endstage renal failure	0.4%
motor neurone disease	0.4%
<i>Subtotal</i>	3%
Total	N = 227; 100%

(27.3 percent), daughters-in-law (2.2 percent), sons (18.1 percent), sons-in-law (5.7 percent, stepchildren (0.9 percent), mothers and mothers-in-law (3.1 percent), sisters (3.1 percent), fathers and fathers-in-law (0.9 percent), brothers (0.4 percent), grandchildren (4.8 percent), or friends (3.4 percent).

Discussion

To situate the findings within the hospice literature, it is important to identify KHS's organizational structure in terms of the writings of models or types of services. As a community-based hospice, without inpatient facilities, that looks after patients in their

Number of days	Percentage
1 - 9	24.2%
10 - 19	19%
20 - 29	13.2%
30 - 39	9.7%
40 - 49	5.3%
50 - 59	4.8%
60 - 69	5.3%
70 - 99	7%
100 - 149	6.2%
150 - 199	3.5%
200 - 283	1.8%

own homes, the KHS model would be labeled as “home care or a hospice without walls” on the hospice service continuum.⁹

According to Clark,¹⁰ there is a separation between hospices caring for adults and specialist services that have been developed specifically for children. KHS’s profile reflected this pattern, as there were no children being cared for by this hospice. This was in spite of the fact that when data were being collected for this study, there was no hospice for children available in the geographical region. As KHS is able and willing to be involved in pediatric palliative care, this pattern would reflect present referral factors operating at pediatric treatment centers.

Although inpatient hospices predominantly care for the elderly, with two-thirds of patients who die in hospices over 70 years of age, there is evidence that patients who die in their own homes are from all age groups.¹⁰ With the exception of children, KHS reflected this pattern, with a considerable number of young to middle-aged patients cared for by the service. This

data provides an indication of the devastating impact of cancer throughout all age groups within the community. Of particular note is the number of very vulnerable families that experience the extreme hardship of losing a parent while the children are still young.

Effective and compassionate hospice care is based on a sensitive appreciation of, and respect for, the individual differences, needs and circumstances of patients. Respecting the spiritual and cultural background of hospice patients is now acknowledged to be an important aspect of providing effective and compassionate care.^{3,11-13} Previous research published on KHS explored the notion of spirituality in relation to their work.^{3,8,14-17} Although inspired by Buddhist notions of compassion and wisdom, KHS was described as incorporating a generic spirituality with a theological/metaphysical openness. Tolerance and a respect for a multiplicity of perspectives were recorded as important aspects of the philosophy of service of this hospice. The present descriptive profile affirms the previous research, with its evidence that this service cares for individuals from a wide range of spiritual and cultural backgrounds. As stated previously, only a very small percentage of the clients were nominally Buddhist.

There is conclusive evidence that KHS is reaching a diversity of spiritual and cultural groups, but it is not yet possible to make any firm statements about the socioeconomic status of this hospice’s clients. Alterations in the admission form will make the data available for further studies. If hospice services are to reach all those in need in our community, it is imperative to access information on the socioeconomic demographic of clients. The present study strongly suggests that KHS is reaching patients restricted in their lifestyle since they are subsisting on pensions. However, further

information is needed on this important topic if hospices are to address the important issues associated with social inequalities in health care.¹⁸⁻²²

KHS’s percentages on diagnostic groups agree with the literature that indicates that hospices are predominantly caring for patients with malignancies.¹⁰ The high number of patients with cancer is a holdover from the referral processes from mainstream institutions, since KHS has an open admission policy that is supportive of nonmalignant referrals. Members of KHS are cognizant of recent concern about including nonmalignant groups under the umbrella of hospice care.²³ Although hospice is now associated predominantly with oncology, there is evidence that some hospices do care for patients with noncancer diagnoses. For example, Farnon and Hofmann’s work²⁴ indicates that 39 percent of the patients in the hospice they surveyed in the US did not have a diagnosis of cancer.

New directions in hospice care necessitate a sensitive understanding of the process of referring patients.²⁵ Although hospice services are now well established, there is still evidence in the literature that a “conspiracy of silence” exists among patients, professionals, and families that blocks referrals to appropriate palliative care services.²⁶⁻²⁷ Hospices are now acutely aware of the importance of working successfully with networks to their services.²⁸ This is an important issue at the present stage of hospice development, where radically new forms of service provision and the promotion of community care cuts across the strongly held belief that hospice care must be inpatient.²⁹

As shown in the data, the main sources of KHS’s referrals are the major public and private hospitals. It is obvious from such data that appropriate and timely referrals to hospices are still dependent on the attitudes and understandings of the health professionals

working in these institutions. The degree to which hospices manage to effectively reach those in need of their services still depends to a large degree on educating mainstream health professionals about managing the transition from curative to palliative care.^{30,31} Although it is now widely acknowledged that timely referrals to hospice care are essential for effective provision of care, evidence suggests that hospices are still underutilized.³²

Concern is expressed in the literature that patients are not referred to hospice until they are very close to death.^{33,34} Research by Farnon and Hofmann²⁴ indicates that the average length of stay in the hospice they surveyed in the US was 34 days, with over half of the patients (51 percent) dying within 14 days. More than a third (35 percent) died within seven days of admission. The figures in this study affirm the literature that indicates that the majority of stays are quite short in length.

It is interesting to note that short stays may not be as problematic as it was first thought. It has been hypothesized that the greater the predeath length of stay in hospice, the better the primary caregiver's bereavement adjustment would be post-death. Research by Speer and associates³⁵ indicates that there are no statistically significant differences in bereavement adjustment between caregivers with varying predeath lengths of stay. Research by Greipp³⁶ also challenges the notion that longer stays are preferable; it showed that, of the 36 patients interviewed about their decision to enter hospice, 94 percent indicated that the timing of their referral was appropriate, and that they did not think they should have been referred earlier. Consequently, firm conclusions cannot be reached on the implications of KHS's data on length of stay.

The majority of patients in this study died in their own homes. As Clark¹⁰ documented, for most hospice

patients the opportunity to die in your own home depends on family relationships and the supportive attitude of the main unpaid caregivers. The data in this study not only shows that for KHS's patients there were innumerable family supports but also that recording this information is a high priority for staff, whose work is directly dependent on working effectively within the family network.

Although only small in number, there was group of patients who did not have a caregiver. There is evidence in the recent literature that hospices are able to care for individuals living at home without primary care persons.^{8,37} Indeed, research on the Wissahickon Hospice Live Alone Program in Philadelphia, Pennsylvania indicates that not only was this hospice able to maintain patients alone at home, they could provide safe care and enable home death for this group of patients. However, patients living alone tended to require more supportive services than regular patients and to incur higher patient care costs.³⁷

For those who had someone to look after them, the majority of caregivers were female. This resonates with the literature on caregivers that indicates that women are still taking most of the responsibility for caring for the sick and elderly in our society.

Conclusion

By situating the findings from this descriptive profile within the hospice literature, it is obvious that KHS's client base shares a similarity with hospices elsewhere concerning referral sources, length of stay, age range, diagnostic groups, family involvement, and caregiver gender. As a Buddhist-based hospice, KHS is somewhat distinguished by its philosophical orientation. Nevertheless, the data suggests that this orientation is not exclusive but reaches a great spiritual and cultural diversity.

The challenge for hospice in the 21st century is to broaden the client base to extend the opportunity of hospice care to all in need. A taking stock of "who our clients are" is a first step toward understanding the new direction we need to take. This descriptive profile of KHS contributes to the important task of establishing where we presently are, with the hope that this knowledge will begin to delineate where fresh energy needs to be directed in the future.

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