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Community-based palliative care for Bangladeshi patients in east London. Accounts of bereaved carers

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Abstract: The aim of this paper is to describe the palliative care experience of Bangladeshi patients and carers in the Tower Hamlets area in the east of London. Semi-structured interviews were carried out in Sylheti, the Bengali dialect of this community, with bereaved primary carers of 18 patients (10 male, eight female) referred to an east London community palliative care team between 1986 and 1993. It was found that patients were young, with a mean age of males of 55 years (range 34–65) and females of 40 years (range 28–57). Communication difficulties were common. The fluency in English of patients was low, with reliance on family members, especially children, for translation. The diagnosis was known by all patients, but only 56% of carers agreed with disclosure. Team dissatisfaction with communication was recorded in 16 cases. Fourteen patients died in London; however, 13 were buried in Bangladesh. Carers often reported symptoms as poorly controlled. Pain was said to be severe for 14 patients, and pain control said to be poor in 11. Family and friends provided most support during the illness and bereavement. Serious financial difficulties occurred in nine families. General practitioners were involved actively in six cases. In conclusion, there are ethno-specific needs in this particular community, many of which arise from socio-economic factors, recent migration and religious beliefs, and which are highlighted by terminal illness.

Key words: bereavement; ethnic groups; palliative care

Resumé: Cet article a pour but de rapporter notre expérience en soins palliatifs auprès de patients originaires du Bangladesh et résidant dans le quartier de Tower Hamlets dan l'est de Londres ainsi que de leurs soignant naturels. Les entretiens semi-structurés on été réalisés dans la dialecte Benglais de cette communauté, le Sylhet, auprès des soignants naturels en deuil de 18 malades (10 hommes et 8 femmes) qui avaient été confiés à une équipe de soins palliatifs en milieu communautaire de l'est de Londres entre 1986 et 1993. Les malades étaient jeunes avec un àge moyen de 55 ans pour les hommes (écart: 34–65) et de 40 ans pour les femmes (écart: 28–57). Les difficultés de communication étaient fréquentes. Les patients avaient peu de facilité en anglais et dépendaient de leur famille, surtout de leurs enfants pour la traduction. Tous les malades connaissaient leur diagnostic mais 56% seulement des soignants naturels étaient d'accord avec sa révélation. L'équipe était insatisfaite de la communication dans 16 cas. Sur 14 patients décédés à Londres, 13 ont été inhumés au Bangladesh. Les soignants naturels ont souvent dit que les symptômes étaient mal soulages. La douleur était dite sévère chez 14 malades etmal soulagée chez 11 d'entre eux. cx'est la famille et las amis qui apportaient le plus de soutien au cours de la maladie et du deuil. Dans 9 familles, il y avait eu de sérieuses difficultés financières. Un médecin généraliste était activement impliqué dans les soins de 6 malades. En conclusion, il existe des besoins

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éthiquement spécifiques de cette communauté, plusieurs résultant de facteurs socio-économiques, d'une immigration récente et de croyances religieuses; ces problèmes sont accentués par la maladie en phase terminale.

Mots clés: deuil; groupes ethniques; soins palliatifs

Introduction

In 1991, the Office of Population Censuses and Surveys of the UK included ethnicity in the census data for the first time.[1] This has facilitated a greater focus on the health issues of ethnic minority populations.[2–6] Within palliative care, attention has been given to issues of equity of access,[7–9] appropriate and culturally sensitive provision of services,[10,11] ethno-specific cancer demographics,[12] cultural and religious characteristics of various ethnic minorities,[13] and needs assessment.[7,9] There has been some recognition of the need for increased education about cultural characteristics and differences, and for increased recruitment of ethnic minority staff, at all levels, as a means of improving services.[14] However, while knowledge of cultural norms can provide useful baseline information, caution has been expressed about the danger of over-simplification and of adopting a 'checklist' approach to these issues. There is concern that such 'cultural summaries' encourage simplistic stereotypes, which fail to reveal the complexity of the life history of individuals and their communities, and the diversity of their human experience.[11]

This study aimed to describe the palliative care experience of people of one ethnic minority community in the UK, the Bangladeshi community of Tower Hamlets, a borough of East London and City Health Authority (ELCHA). The Bangladeshi community accounts for more than 23% of the borough's total population of 160 000[1] and is the largest expatriate community of Bangladeshi in the world. It has been described by Laugharne (personal communication), as the 'most deprived and disadvantaged among all the ethnic minorities in the UK'. There are high levels of unemployment, overcrowding and poor housing. Islam is the exclusive religion. More than 50% of the population are less than 14 years old and only 3% older than 60 years. The majority (63%) were born in Bangladesh,[15] and 64% speak little or no English.[16]

Cardiovascular disease is the leading cause of death in this ethnic minority group; cancer incidence is not known. Cancer mortality registration includes only cancer deaths which are registered in the UK, and does not detect those who travel to Bangladesh to die. According to Garlick (personal communication), there were 136 cancer deaths of Bangladeshis registered in ELCHA between 1986–1992, 104 males and 32 females. Ninety died in hospital, 30 at home and 16 in non-National Health Service (NHS) hospitals or elsewhere.

A community palliative care team (CPCT) in the ELCHA, consisting of medical, nursing and social work personnel, provides shared care with the general practitioners and district nurses. During the study period, all members of the team were from the majority population. From 1991 to 1995, ethnic minority referrals to this team accounted for between 10–16% of the total referrals of around 450 patients per year and, of these, 15–20% were Bangladeshi. All referrals to the CPCT during this time period had a diagnosis of advanced cancer.

Bangladeshi referrals appeared to cause a disproportionate amount of team conflict and concern about the appropriate ways to respond to their needs. Clarke *et al*.[17] have stated that 'When [the palliative care team's] ideal standards cannot be attained because they do not correspond with the wishes of the patients and family, respecting the patient's autonomy puts a greater emotional stress on all members of the team'. This community team experienced this: communication difficulties were common, and conflicts with patients and carers frequently arose in relation to the administration of analgesia. There were difficulties assessing symptoms, explaining medications, supporting carers and addressing the many social needs which have an impact on community-based efforts of care. This ethnographic study aimed to increase the understanding of the experiences of this community and to help the palliative care providers to tailor their services appropriately.

Study design

The carers of all Bangladeshi patients under the community team between 1986 and 1993, who lived in the borough of Tower Hamlets, were eligible for entry into the study. Patients were identified by review of all admissions to the team during this period. Case notes were reviewed for demographic data, evidence of communication difficulties, intensity of input of care and any special areas of concern. An introductory letter written in Bengali and English was sent to all carers traced. A local translating service produced the Bengali translation which was evaluated by Bangladeshi members of a local health promotion group. A male Bangladeshi interviewer was recruited and he telephoned the carers to explain the study in Sylheti, their dialect, and to arrange an interview. More than one carer could volunteer to be interviewed. A consent form was signed by those interviewed.

The interviews were conducted in Sylheti, using a semi-structured questionnaire designed for the study. Topics covered are listed in the Appendix. The interviewer had had previous experience with health surveys in the locality. For this study, he was trained in conducting less structured interviews and eliciting more free expression of experiences by carers.

A pilot interview was carried out in which the interview was taped and subsequently transcribed. This proved too time-intensive for this study. Interviews were therefore manually recorded at the time of the interview.

The interviewer met frequently with the researcher for discussion of each interview, at which time additional information was appended. Carers were given means of further contact if they wished to have follow-up after the interviews. The local Research Ethics Committee approved the study.

Results

Interviews

A total of 35 patients were identified from the notes: Table 1 gives the demographic details of the 18 patients whose carers were interviewed and Table 2 the reasons for not interviewing the carers of the remaining 17 patients identified. All interviews but one were in Sylheti and took place in the carer's home. One interview was in English, at the carer's request, and held at the local hospice. Most interviews lasted approximately one hour with one shortened by disagreement between two carers over the facts of the case. The mean time interval from death to interview was 53 (range 16–96) months.

Table 1 Demographics of patients and carers interviewed

Study initial	Age (yr)	Sex	Primary malignancy	Main carer(s)	Age of main carer (yr) at time of death	No. of children	Family age range	Death to interview (months)
B	33	F	Stomach	Husband	43	4	6–16 years	90
C	28	F	Glioblastoma multiforme	Husband	57	7	3 months–18 years	60
D	57	F	Breast	Son (daughter-in-law)	26	3	Not known	89
E	58	M	Lung	Wife	35	10	18 months–26 years	94
F	65	M	Lung	Wife (son)	34	7	Adult	56
G	58	M	Lung	Wife	57	5	12–26 years	96
H	28	F	Pancreas	Husband	29	5	2 months–6 years	72
I	53	F	Breast	Husband	52	7	Young adults	51
J	54	M	Pancreas	Wife	31	6	1–14 years	72
K	57	M	Oesophagus	Nephew	35	4	4–15 years	16
L	40	M	Unknown primary	Wife	33	4	7–18 years	16
M	44	F	Stomach	Son (daughter-in-law)	25	5	16–25 years	16
N	59	M	Lung	Wife	56	5	Adult	43
O	34	M	Cholangiocarcinoma	Wife	25	1	4 years	43
P	47	F	Cervix	Son (daughter-in-law)	29	8	4–26 years	50
Q	56	M	Lung	Wife	36	7	14 months–19 years	23
R	52	F	Uterus	Husband	60	2	Adult	16
S	56	M	Larynx	Wife	45	5	3–25 years	50

Table 2 Reasons carers of remaining 17 patients were not interviewed

No.	Reason
2	Lived outside Tower Hamlets
5	Unable to trace – inaccurate recording of name of spouse in records
2	Failed interview appointments
2	Refused participation in study
1	Included in pilot study
1	Still alive
4	Carer not available for interviews – no longer in area

Communication

Language. Few patients were fluent in spoken English and fewer were literate in English. (See Figure 1.) The one female patient and one female carer who were literate in English were both less than 30 years old.

Use of professional interpreters. Table 3 shows the reliance on family members, and particularly on children, to interpret for health professionals. A doctor fluent in Bengali who worked on the CPCT for a period during the study helped to interpret for three patients. Two of the three carers who had a professional interpreter felt that it had been helpful. One felt it was difficult to explain the patient's full medical history, and the second found that interpreting had placed onerous demands on family members requiring them to be available at all times to interpret. This carer also felt that questions were too personal for the children to have to ask their mother. However, only two carers who did not have a professional interpreter expressed regret about this. One cited concern that a son or the neighbour's daughter had to stay back from work/school when the team visited, and the second that the personal nature of the questions made this role too difficult. Ten other carers felt a professional interpreter was not necessary as they were satisfied with family or friends interpreting. Four did not comment on this question. It was common for men to act as interpreters for their wives, whether the men were carers or patients.

Table 3 Translating for the CPCT

No.	Main translator
5	Patient
8	Children
2	Spouse
3	Other relatives
4	Professional interpreter

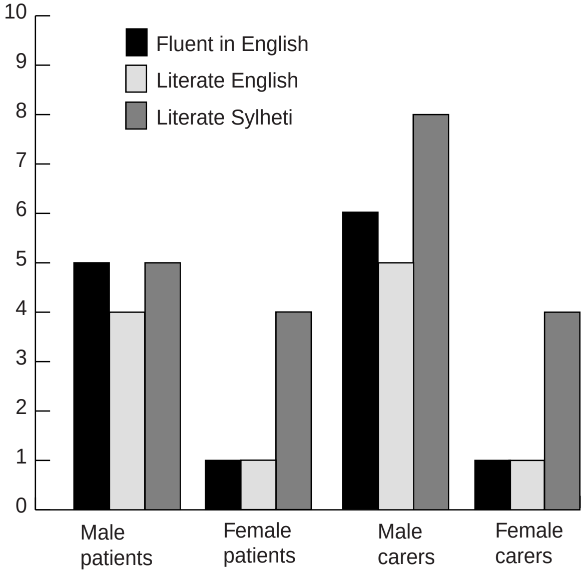

Figure 1 Language abilities of patients and carers

Quality of communication. Ten carers reported satisfaction with their level of understanding and the ease of communication with the CPCT. Thirteen felt able to contact the team between scheduled visits if necessary. In contrast to this, the team's records reported poor communication as a problem in 16 cases. In 11, the team's perception of the inadequacy of communication was in contrast to that of carers who expressed satisfaction.

Carer of patient L. 'Although I was the main carer, I was kept in the dark and not involved in any decision-making until my husband died.'

Carer of patient E. 'He [patient] was fluent in English. The team advised about physical care but they talked to my son.' *CPCT comments.* 'English is poor. There is a language barrier; the 17-year-old son interprets but is said not to know the diagnosis.'

Carer of patient N. 'I have two sons, their wives, eight nephews and a neighbour's daughter who interpreted for me on many occasions. Now I can realise that on many occasions, whatever the palliative care team said, it was not translated to me at all.'

CPCT comments. 'Poor communication, the neighbour's daughter (age 15 years) stays home from school to interpret, also the son and daughter-in-law interpret.'

Talking about the diagnosis. All patients were said to know the diagnosis, however only six carers felt it was right for them to be told. Reasons given were: the patient has a right to the truth, truth in itself is important to uphold, the patient could prepare for death, and openness about the diagnosis brought them closer together. The eight carers who opposed full disclosure of the diagnosis felt it was weakening for the patient to know and might hasten death, and that it would destroy hope and make the patient more anxious and depressed. One patient, a doctor, diagnosed his own cancer so the issue of disclosure did not apply. Three carers said that they did not know whether the patient should have been told or not. One of these valued the discussions he was able to have with his wife when she knew. The second said that her husband tried to shield her from knowing too much and she still felt confused about it all, and the third said that he was pleased that he had been able to take his wife to Mecca as she requested after she was told. Two carers said that they did not care whether they were told or not.

Symptom control

The six most common symptoms are shown in Figure 2, with pain as the most commonly reported symptom. It was said to be severe in 14 patients and poorly controlled in 11.

Communication during the last days of life

Many carers reported that the patients had expressed a particular desire in terms of a 'last wish' (Table 4).

Six patients were said to have talked openly about dying and their wishes for the care of children after their death. Spiritual issues were often spoken of, and requests for forgiveness and for prayers were common.

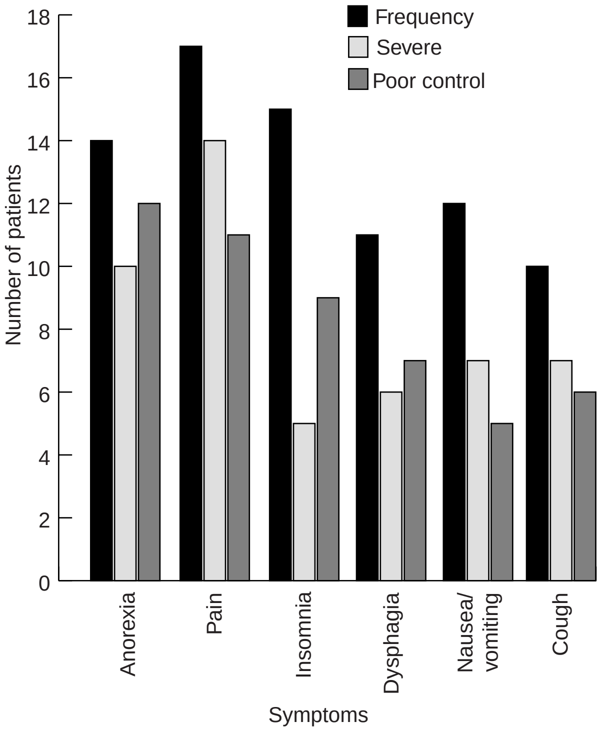

Figure 2 Six most common symptoms

Table 4 The last wish

No. of patients	Wish
3	Related to child's future, for example, marriage
8	To make pilgrimage to Mecca
1	Burial in Bangladesh
4	See family in Bangladesh or bringing family to the UK

Carer of patient H. 'She reassured the family, telling us "Don't worry too much, maintain a normal life"; she asked me to look after the children, and gave advice about the care of the children, about remarriage for me and spoke about dying. It was right to tell her, as she expressed her last wish and many things that were important.'

Carer of patient P. 'She asked forgiveness for any past hurts. "I don't have much time left; I am going to die soon. Please forgive me if I hurt you" – she wanted to die in Bangladesh and a plane ticket was arranged but she died before she could travel.'

Carer of patient J. 'He told us not to send his body to Bangladesh and to bury him as soon as possible. He also said to tell the hospital staff not to push morphine injections onto him.'

Preparation for death

Seven carers felt well prepared for the death, seven did not and four were unsure.

Carer of patient L. 'Although we were told, we did not want to believe it – I did not believe he was going to die. Although doctor told us that he wouldn't have enough time left, I was not prepared for death but in the back of my mind, I had the thinking that it could happen any minute.'

Death and burial

Four patients died in Bangladesh (Table 5). Of the 14 who died in London, 10 died at home, two in hospital and two in a hospice. Although most deaths occurred in London, there was a preference among carers for Bangladesh as the place of death and the majority of those who died in London were transferred after death to Bangladesh for burial. The reasons for these preferences are shown in Table 6. All patients were buried, in accordance with the Islamic faith.

Table 5 Place of death and burial

	Place of death	Preferred place of death	Place of burial
London	14	4	5
Bangladesh	4	11	13
Not important		3	

Spiritual care

Religious practices. Religious duties and practices were very important throughout the illness and bereavement period. Ritual prayers were said by family and friends, such as reading from the Koran and reciting the Kalima, especially as death approached. Religious representatives (the mullah or Imam) visited most patients during the illness. Expressed acceptance of the illness as 'God's will' was common, although carers also expressed a continued hope for cure until the time of death, and difficulty in understanding why the illness had occurred.

Carer of patient Q. 'The illness was devastating. I asked God, why did you give such a disease to my husband?'

Carer of patient O. 'I questioned whether I had done something wrong to Allah. Why is He punishing me like this? I felt sorry, not angry, with Allah. We have to be patient. Good things come in the future with His help. He loves me and is helping me. I feel closer to Allah. No one else can give me peace.'

Carer of patient C. 'I was prepared for her death but I had faith in God who could save or spare her life for the children. It is God's wishes and I am pleased in his decision.'

Conflicts with non-Muslim carers. It was commonly stated that health providers were 'also human beings' and were 'doing their duty'. How-

Table 6 Reasons for preference for Bangladesh as place of death

No.	Preference
5	Presence of extended family
8	Carry out religious and cultural practices
1	Patient's expressed wish
3	Desire to return to native 'homeland'

ever, there was also close supervision of the care to ensure it was in keeping with their Muslim beliefs. Conflicts arose in three cases, two in the hospice and one in hospital, in relation to religious practices. Conflicts also arose in relation to treatment. On the other hand, carers expressed satisfaction when professionals respected their beliefs.

Carer of patient O. 'There was a cross on the wall. My relatives said to tell the staff to take it off but I said to leave it and I prayed in another room where there was no statue or cross.'

Carer of patient S. 'I had a bad experience in the hospital. I stayed with my husband there and I wanted to do religious duties in the hospital but, because of the doctors and nurses, I was not able to do the necessary things I had to do. It made my husband angry. Once he came home from the hospital. I wanted to do ablution but nurse said I couldn't. I wanted to stay with my husband but they said I couldn't.'

Carer of patient N. 'I practice my religion as a Muslim. I don't believe in injections, which was injected in my husband's body just before he died. It is forbidden as a Muslim.'

Carer of patient Q. 'I can trust them. The nurse came to my home, I went to pray and she was happy to wait for me until I finished my prayer.'

Carer of patient R. 'My wife was in the hospital. The nurse used to come to my wife and tell her now is your prayer time. They facilitated everything for her and I am very happy with them and I can trust them.'

Impact on carers

Children. Children were actively involved in the care of patients and prominent in interactions with health providers. They acted as interpreters in eight families. This appeared to have a negative impact on some children. The 16-year-old son of patient S interpreted for his parents. The CPCT noted that 'the son interpreted, his English is not good. He is taking the weight of his father's illness on his shoulders' (and later) 'Son seems "burnt out" and is less often there to interpret.' At interview, 50 months after the death of the father, his mother stated that he had fainted at the funeral and that she was unhappy about his current behaviour. 'My son is disturbed and sometimes violent towards me. My husband is on my mind all the time.' In a further three families, other young relatives (nephews) or friends (neighbour's daughter) interpreted for the team. Five teenage children gave up their school studies in order to be available for interpreting and to help care for the patient. Three young adult sons in one family, whose father was in Bangladesh, gave up their work to care for their mother.

Other carers. In nine families, members had given up work in order to care for the patient. In seven, family members were brought from overseas to help; in four, carers became sick themselves while caring for the patient.

Bereavement period

Seventeen carers found their main support in the bereavement period came from their family. Less frequently mentioned supports were friends, other relatives, the mosque community, health professionals and neighbours. Only four found the CPCT had been helpful at this time. Nine families experienced significant financial difficulties after the death which included trying to meet the costs of transporting the body back to Bangladesh (Table 7). At the time of death or at the funeral, seven children fainted and were said to have been very distressed. Seven carers did not feel that all in the

Table 7 Carers comments on financial difficulties encountered

Carer	Comment
C	I had used up savings, needed help from family and DHSS
H	I was in debt and got help from social fund
J	I borrowed from relatives
K	We had to spend over £1000
M	We are three brothers, all of us gave up work; we borrowed from relatives for funeral expenses
N	I borrowed from relatives and am paying back slowly
P	I was out of work for six months; I borrowed from relatives and have repaid the loan
R	I was on sickness benefit long before my wife died, and had not worked for a long time. I had no savings and borrowed from relatives. I am paying back out of my income support
S	My savings were not enough to travel to Bangladesh so I borrowed from relatives

family had fully recovered after the death. The average interval since death in these seven families was 43 months (16–94 months). Ten carers still found life difficult or very difficult since the death (mean interval since death was 63 months).

Other services provided by the CPCT

Practical help. Commodes and Spenco (pressure-relieving) mattresses were provided in eight and seven cases, respectively. Other aids such as wheelchairs and syringe drivers were not often utilized. However, carers felt that they had received the equipment they needed.

Other services. Services such as home help, 'night sitters' and transport assistance were seldom utilized. The district nursing service was consistently actively involved in the care of the patients but general practitioners were significantly involved in only six cases.

Social work assistance. Six families received financial help such as one-off money grants (for four families), grants towards funeral expenses (for two) and application for welfare benefits. Rehousing applications were also made for three families. Two carers stated they had been unaware of possible financial assistance and three carers had refused financial grants. In addition, there was assistance with immigration applications for relatives to come to care for the patient and also in travel arrangements for the body and/or family to travel to Bangladesh.

Carers' impression of the CPCT

Most carers perceived the role of the team as one of offering both practical (for example, provision of medication, physical care and observation) and emotional support (for example, providing comfort, caring and 'looking after' the patient). Most carers (89%) rated the team as helpful or very helpful, but two rated the help as very poor. Socio-economic reasons were cited for dissatisfaction (such as failure to be rehoused) rather than physical reasons. It was clear that some carers were overwhelmed with needs at this time.

Carer of patient J. 'I have six children including twins who were then one year old. I had to leave my children at home to visit my husband in the hospital and the hospice. My relatives do not live in London; they are in North England. I begged the authority for help but I did not receive any. Once there was a fire in the kitchen. In the end, I received help but it was too late for me.'

Discussion

This study provides a snapshot of the interface between palliative care providers and the Bangladeshi community at this time. The design was limited by resource constraints. Ideally, interviews would have been taped and transcribed to ensure completeness of documentation. Also, it would have been preferable to have two interviewers, one male and one female, in order to offer a choice to carers. The male interviewer recruited was a member of the local community, which may have influenced the interviews in some cases. Several female carers were interviewed with other members of their family, such as their sons or daughters. If the interviewer had been female, they may have interviewed alone and been more frank in their replies.

The demographics of this study population, with the young age of patients and carers, overcrowding, poor housing, low socio-economic status, low level of fluency and literacy in English, and low literacy in Sylheti are all consistent with the demographics of the Bangladeshi population in Tower Hamlets. The impact of these demographics on the provision of effective community-based palliative care has not been specifically addressed by the palliative care services. In particular, at the time of the study, there was little use of professional interpreters with a heavy reliance on family members to interpret, especially children and young adults. While this was often seen as being acceptable to the carers interviewed, it was recorded as being less satisfactory to the CPCT, and a source of conflict and concern for the team members. While the lack of English fluency of this population is potentially compensated for by the majority of Bangladeshi's having a general practitioner who speaks Sylheti,[18] in this study only six carers reported that the general practitioner was significantly involved in the patient's final illness and care. This points to a need to target this group of practitioners for palliative medicine education.

The use of children to act as interpreters has been described as 'unprofessional, unethical, uncivilized and totally unacceptable'[19] and as a practice which 'decreases the ability of a practitioner to act in this patient's best interests on issues in which there is conflict or misunderstanding'.[20] The account of carer S indicated that this role had a detrimental effect on her son in his adjustment to his father's illness and death. There was also evidence of selective interpreting, in which women carers in particular seemed to be excluded from discussions. Bangladeshi women had the lowest level of English fluency of all ethnic minority groups in the ELCHA.[18] This, in combination with their traditional role in this community, resulted in a profound lack of voice and representation as both patients and carers. Palliative care teams need to be aware of such social dynamics and strive to ensure standards of care and communication in keeping with palliative care principles, while respecting the traditions and values of individuals within different cultures.

At the time of this study, there was no organizational commitment to addressing such issues and the pre-existing model of palliative care was applied to all, regardless of ethnic background. A simple example of this was the inaccuracies encountered in the recording of carers' names, using the English naming system, which made it impossible to trace many carers of Bangladeshi patients. Another example was the lack of appropriate bereavement follow-up for Bangladeshi carers. Despite the limitation however, most carers were very satisfied with the team; it is possible that the two who rated the help as very poor may have represented recording errors at the time of interview. Low expectations of the service resulting from a low level of prior knowledge of palliative care might have influenced levels of satisfaction.

Programmes are challenged to develop what Roberts calls 'cultural competence'[21] defined as 'to honour and respect those beliefs, interpersonal styles, attitudes and behaviours, both of families who are clients and the multicultural staff who are providing services'. This requires a commitment at all levels of the organization if it is to develop.

Increasingly, the role of health advocates in bridging the territory between ethnic groups is being recognized and developed in the ELCHA. An evaluation study of bilingual health care schemes in east London commissioned by the East London Consortium in 1994 found that the existing diverse schemes met approximately 35–40% of existing needs.[16] The incorporation of bilingual health advocates into the regular service practices of palliative care, either by creation of advocacy positions within teams or by contracting with advocacy services, would significantly improve the ability to meet specific needs. Other measures such as staff education in multicultural health and the recruitment of bilingual and ethnic minority staff, and identifying ethnic minority group representatives with whom to liaise regularly, would help services to keep abreast of each comunity's changing needs. Pamphlets and videos are time-consuming and expensive to prepare and the information often dates very quickly. Pamphlets also do not reach the needs of the illiterate.

Another area of importance revealed by this study was the strong preference of patients and carers for the death and burial of patients to occur in Bangladesh. It is not limited to this ethnic group[22] and suggests that palliative care practitioners working with ethnic minorities of recent migration should be aware of such strong links with the homeland and should initiate discussions about returning home while the patient is still well enough to travel. This is less costly for families and, as in the four patients in this study who died in Bangladesh, may lead to a more peaceful ending of life despite the lack of medical resources. Palliative care teams may need to raise this with other medical practitioners involved, in order to prevent unnecessary medical treatments from preventing the patient from travelling.

Of note, most patients who died in the UK died at home, in contrast to the findings of Higginson *et al.*[23] who linked low socio-economic status with an increased likelihood of hospital deaths. Their analysis did not include ethnicity and it is likely that differing ethnic groups will strongly favour home deaths because of isolation in hospitals from poor communication, the differing food requirements and the desire to observe religious duties. Family members may also see it as a sacred duty to look after the patient themselves.

The lack of bereavement support revealed by this study was a further important finding. The usual follow-up procedures were inadequate. Travel to the homeland or to be with relatives elsewhere in the UK, incorrect recording of names, communication difficulties and different cultural norms for bereavement all made bereavement follow-up difficult. There were indications of considerable unresolved grief among the carers interviewed. In particular, the large numbers of bereaved children (90 for these 18 patients), the majority of whom were under 20 years old, raises important social issues for this community. There were often tensions between generations, precluding adequate support for these children. Specific bereavement supportive measures are urgently needed. It has been suggested that bereaved children in ethnic minority communities are at particular risk of pathological grief and later maladjustment, given that grief is often compounded by other losses and lack of traditional supports, in a community estranged from its own culture.[25]

The socio-economic difficulties were often heightened, with 50% of families going into significant debt, taking years to clear. There is a need for practical financial support, addressing both ethno-specific needs and pre-existing socio-economic need. Few of the carers in this study approached the palliative care service for financial help. For some, the illness served as a vehicle for them to highlight pre-existing socio-economic problems, in particular poor housing conditions.

As expressed by Helman,[24] 'the ethnographic approach to the study of societies and cultures involves the study of small-scale societies, of relatively small groups of people, in order to understand how they view the world and organize their daily lives'. He also points out that 'culture is only one component of a complex mix of influences on what people believe and how they live their lives' and that 'it must always be seen in its particular context.' There is a need for further studies in other communities and countries in order to avoid simplistic and inaccurate stereotypes of ethnic minority and cultures. It is hoped that such studies will increase the compassion and understanding of those working within this field who come in intimate contact with such diverse belief systems. Palliative care is developing internationally and there is the opportunity to learn from practitioners working in the countries of origin of many of these ethnic minority communities. Facilitating discussion and the exchange of information and experiences will enhance the development of models of palliative care, which are culturally appropriate and sensitive and give this area of medicine a more truly universal face.

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Appendix

Topics covered by the questionnaire

- Communication
  - – language, fluency, literacy – Sylheti, English
  - – comprehension and explanation
  - – use of professional interpreting services
  - – disclosure of diagnosis and of prognosis
  - – final wishes of the patient.
- The remembered death.
- Spiritual care.
- Bereavement
  - – burial
  - – coping of individual family members
  - – adjustment
  - – CPCT follow-up
  - – impact of the illness and death on the family.
- Symptom review.
- Practical help.
- Services provided by CPCT.
- Previous knowledge of the service.
- Other services provided and utilized.