

Practice paper

I never knew that! Why do people from Black and Asian Minority Ethnic groups in Leicester access hospice services less than other groups? A discussion with community groups

Sheila Markham SRN HVcert DipPSN BA(Hons) BSc

Project Lead, Broadening Horizons, LOROS, Hospice Care for Leicester, Leicestershire and Rutland Hospice, Leicester, UK

Zoebia Islam BA (Hons) MSc PhD

Senior Research Fellow, LOROS, Hospice Care for Leicester, Leicestershire and Rutland and Birmingham and Solihull Foundation Trust; Honorary Lecturer De Montfort University, Leicester, UK

Christina Faull BMedSci MBBS FRCP MD PGCertMedEd DipClinHyp

Consultant in Palliative Medicine, LOROS, Hospice Care for Leicester, Leicestershire and Rutland and the University Hospitals for Leicester; Honorary Professor DMU & LOROS Centre for Promotion of Excellence in Palliative Care, De Montfort University, Leicester, UK

ABSTRACT

In the UK, Black and Asian Minority Ethnic (BAME) patients are less likely to access palliative care services than their White counterparts. An increasingly diverse population makes this a cause for concern. This paper describes a project in Leicester to discover what members of the BAME communities knew about palliative care and the providers of hospice services; what they thought the barriers were to their use of these services; and how they would like to find out about them.

Informal discussion groups were used as the vehicle for information gathering; accessing communities to develop such groups posed specific problems. Two project workers made notes during and immediately after the discussion groups. These were thematically analysed.

Findings suggested that knowledge about palliative care was scant, though much valued when understood. Cultural and religious strictures on using palliative care services or a palliative care approach were not demonstrated, though others, including considerable concerns about food when an inpatient, were deemed of importance. The need to know what is locally available, and how to access those services, was uniformly agreed, and the information given warmly welcomed, even by those with reservations.

Keywords: Black and Minority Ethnic communities, end of life care, hospice, palliative care, South Asian

Introduction

Palliative care focuses on maximising the quality of life of those who have a life-limiting, progressive illness by providing pain and symptom relief, spiritual and psychosocial support to both patient and their families.

This care may be needed at diagnosis, at specific times during an illness, when death is anticipated and in bereavement (Department of Health, 2008). Specialist palliative care is provided by hospices and other

services such as Macmillan and Marie Curie nurses; hospices usually support those with a greater complexity of needs. The End of Life Care Strategy for England and Wales has highlighted the need for a greater focus on palliative care for everyone as they approach the last months of their lives in order to achieve key outcomes such as good symptom management and patient preference for place of care (Department of Health, 2008). There is growing evidence that there are considerable unmet needs and disparities in palliative and end of life care for Black, Asian and Minority Ethnic (BAME) groups (Calanzani *et al*, 2013).

In the past 20 years the UK has become more ethnically diverse and both the number and proportion of people from BAME communities have increased (Calanzani *et al*, 2013). Population projections suggest that this increase will continue, particularly among older age groups. In England and Wales, it is predicted that, by 2026, there will be over 1.3 million people from BAME groups aged over 65, compared to over half a million in 2001 (Calanzani *et al*, 2013).

Members of BAME communities are under-represented as users of specialist palliative care services (Koffman *et al*, 2007; Department of Health, 2008, 2012). Reasons for this include gatekeeping and low referral rates (Karim *et al*, 2000; Worth *et al*, 2009), differing patterns of disease, the restrictive referral criteria for hospices, communication issues (Richardson and Koffman, 2011), difficulty in accessing services, (Johnson, 2009) and poor satisfaction and mistrust of services (Frearson *et al*, 2013). Evidence suggests that actively involving BAME communities would help to raise awareness and increase access to services (Gunaratnum, 2006; Thacker and Faull, 2006). This paper describes a project in Leicester to engage with members of the BAME communities.

Leicester

Leicester has an unusual demographic: BAME people, mostly from South Asia, form 50% of the population, the highest proportion with Indian heritage in England and Wales. The Black population has doubled from 3% to 6% in the last 10 years with a growing Somali community (Leicester City Council, 2012). Gujarati is the second most spoken language in the city.

Leicester has a high prevalence of complex health needs, and amongst the widest health inequalities in England (Leicester City NHS, 2012). Leicester is a young city, with an average age of 35.5 years. Death rates in all communities are highest amongst the older sections of the population and almost a quarter of

residents aged over 60 belong to BAME communities (Phelps *et al*, 2011).

The Leicester, Leicestershire and Rutland Hospice (Leicestershire Organisation for the Relief of Suffering, LOROS) provides palliative care services: inpatient care, day care, outpatient clinics, specialist community nurses, counselling and lymphoedema services. Clinical activity figures from LOROS from 2009–10 show rates of 11.5 referrals per 10 000 BAME populations and 29.5 referrals per 10 000 White British population in the city. In a city projected to have a non-White majority population sometime after 2011, this referral rate seems disproportionate although demographic factors may influence this. Activity data suggested that BAME patients may be accessing services late in their illness. This prompted LOROS to undertake an exploration of the awareness and understanding of specialist palliative care services among BAME communities in Leicester City.

Aims

To understand why the local BAME communities were not using the hospice (LOROS) services and identify appropriate ways to improve access to specialist palliative care services by exploring:

- care towards the end of life
- palliative care as a concept
- perceived barriers to accessing hospice services
- what they would like hospice and palliative care services to offer
- ways they would like information about hospice and palliative care services.

This project was classed as an evaluation of current services and did not require ethical review. Verbal assent was obtained from discussion group members. Confidentiality was assured; all extracts from the discussion groups were anonymised. The project was funded by the Health and Social Care Volunteering Fund.

Methodology

A steering group supported, guided, advised and monitored the project. This group included hospice managers, a public health statistician from the local authority, representatives from the community health trust, a local GP, workers from the Race Equality Centre and Age UK. More than half the members were from BAME communities. The group enabled access to communities by identifying organisations

and leaders and through personal introductions to local networks.

Informal discussion groups with members of the BAME public with their 'intimate understanding of local conditions' were considered the most valuable and feasible sources of information to capture the views of people with a spectrum of illness experience, and not just focus on those who were already 'patients' or the family of patients (Lai Fong, 2003). Focus groups, requiring recording and transcribing of the meetings, were not thought feasible as obtaining consent for recording and transcribing can be an intimidating factor in some cultures (Lund and Denicolo, 2012).

Mapping local voluntary and community organisations facilitated contact with community groups – Indian, Somali, African-Caribbean, Pakistani and Bangladeshi – and religious organisations – the Muslim Burial Council of Leicester (MBCOL), Hindu Association of Leicester, Sikh community leaders. Organisations which crossed religious, ethnic and cultural divides were also approached (Sanctuary Housing, Savera Resource Centre users group, Age Concern Asian Elders Forum for Leicester City). Meetings with organisations and community leaders were achieved with some effort. These resulted in enthusiastic appreciation and a stated willingness to facilitate discussion groups; securing firm dates for these events proved elusive in many cases. This reflects recent experience in Luton (Herodotu, 2012). Some discussion groups were achieved by contact with managers, others resulted from networking with community development workers. Most were enabled by less formal networking on the part of the project workers. In practice the discussion group usually followed a planned meeting of a group, so was not the main purpose of the gathering.

SM and AV designed the project and collected data. SM collated the data, undertook analysis and drafted this paper, CF and ZI assisted with analysis and finalised this paper.

Discussion groups

Two project workers (SM and AV) developed a topic guide to explore knowledge of palliative care services, delivery, access, barriers and concerns, what they would like and ways of locating information. Gujarati speakers frequently required the translation skills of one of the project workers (AV). Following introductions, an explanation of the purpose of meeting with the group, with emphasis on wanting to listen to their views, was given in English and Gujarati. The reasons for note-taking were also explained and assurances given that all comments would remain confidential

and anonymised if used in the report or any future publications. The topic guide was used flexibly to promote discussion. Afterwards attendees received information about palliative care services. The project workers each formulated detailed accounts of each discussion immediately, adding comments about their own observations and impressions. They then discussed their accounts and produced a single amalgamated record.

Analysis

The data were examined by the project lead (SM) using inductive thematic analysis to identify key themes (Boyatzis, 1998). This is a method for identifying, analysing and reporting patterns arising from within data. During the first reading major issues were noted; the texts were then re-read line by line with open coding. Codes were then collapsed into categories of similar topics; categories were then clustered to allow key proto-themes to emerge. The data were then re-examined to assess how information was assigned to each proto-theme, to identify relevant incidents of each proto-theme and to ensure data had not been selectively used.

Findings

Ten discussion groups were held with a total of 134 participants (Table 1). Groups reflected a diversity of ages (14 to 80 plus years), gender, ethnic, religious and cultural backgrounds.

THEME 1: WHAT WOULD YOU WANT AT THE END OF LIFE FOR YOURSELF, OR THOSE THAT MATTER TO YOU?

Participants described the goal of this last part of life as 'dying with a comfortable heart', a term generated in one group and supported in others which may reflect the support needed for patients to feel life's work has been achieved, to acquire acceptance and spiritual peace. Fulfilling the person's last wishes, seeing old friends and family, viewing videos, and treating the patient normally were considered to be important aspects of end of life care. Practical help, with bills, the funeral and equipment, and being cared for at home with the family were all spoken of. Only a few mentioned dignity, pain management or quality of life.

Many people of all ages and backgrounds wanted someone, volunteers, nurses or family, to sit and be

Table 1 Composition of the 10 Discussion Groups

Group	Female	Male	*Age	**Ethnicity/religion (where known)
1	10	2	50+ years	African-Caribbean
2	4	3	30+ years	White, Mixed Race, South Asian, African-Caribbean
3	6	0	30+ years	South Asian Hindu
4	4	9	14–16 years	South Asian, White, Mixed-Race
5	4	0	30 +years	South Asian
6	17	5	60 +years	South Asian Hindu
7	10	4	20+ years	South Asian Hindu and Muslim
8	25	4	40–80 years	Indian, Caribbean Hindu, Christian, Sikh, Muslim
9	7	12	60+ years	Indian Sikh
10	2	6	14 -30 years	South Asian Hindu
Total	89	45		

* We asked youth groups for their age range. Over 60s groups were self-explanatory. In some cases ages were estimated by the researchers.

** South Asian refers to people of Indian, Pakistani and Bangladeshi origin.

with the dying person. Younger respondents voiced the need for support and counselling for the family and those who had young children. However, openness to services was not a universal feature:

‘Some cultures don’t like to disclose illness and want to stay at home and look after the patient at home. Don’t open up and ask for help – keep it to themselves.’

There were descriptions of envisioned interactions between patients, families and care staff. The term *tender care* was one that resonated with many older participants. The need for compassionate holistic care was expressed in terms of the desired behaviours of staff:

‘Someone to hold your hand, give you a cuddle, understand your pain.’

Several participants stated that professionals should smile and show an interest in the patient and family.

All groups wanted cultural and religious understanding, recognising the need to support the diversity

of faiths and cultures in the city. Institutional settings for care should provide ‘a good atmosphere, with music, religious support’. Involvement of religious leaders was mostly seen as positive, though concern was expressed that they should be sensitive to the needs of the patient and family.

The issue of multiple visitors, an expectation in many cultures, was discussed, with a number of elderly group members being quite vociferous in their condemnation of this tradition. Escaping this was seen as a real benefit of being an inpatient in a hospice or hospital. It also avoided potential breaches of confidentiality, as visitors often coincided with nurse or doctor attendance and remained during the consultation. However, many also expressed the benefits of seeing family and friends, and felt it to be supportive and even uplifting for patients.

Whilst acceptance of death was spoken of frequently, one African-Caribbean participant made clear that death should not be spoken of in front of the patient, that hope should always be stressed, right

up to the end. Two people introduced the topic of voluntary euthanasia, both viewing it in a positive light. One participant had previously experienced poor care for a dying relative, and was very clear about wanting explanations given with courtesy, privacy and dignity for the patient, and the opportunity of choice about when to die.

THEME 2: WHAT IS PALLIATIVE CARE TO YOU?

The majority of participants did not know about palliative care. It seemed a difficult idea for many people, even when broken down into a simple explanation; once explained, it met with general approval. Both the concept of ‘palliative’ and the concept of ‘care’ held potential for misunderstanding. The most common initial response was head-shaking. One Somali respondent had asked, within her community, for their understanding, and said that the 30 people she had consulted had no idea. When she explained palliative care, it was generally approved of and those delivering such care ‘must be of very good heart.’

Comments such as ‘it is when no medicine is working’ and ‘domestic care for the very ill’ and ‘keeps you comfortable at home’ demonstrated that a small number of people had some knowledge, usually from personal family or friend experience. Two different groups mentioned being sent to a nursing home.

In contrast to the majority, the two youth groups showed real understanding of the nature of palliative care, with some individuals stating that they had received teaching about end of life issues in religious education lessons, and that they were aware that differing religions may have diverse views on this topic.

THEME 3: WHAT WAS KNOWN ABOUT SERVICES THAT PROVIDE PALLIATIVE CARE IN LEICESTER

In general the level of awareness about services was very low. Most knew about LOROS hospice – that it is a charity, cares for cancer sufferers, has many shops and runs a lottery – although very few had been there. ‘LOROS means death and dying’ was a comment from a Bangladeshi man. A small number knew about Macmillan as a charity that cared and comforted the dying; the majority did not recognise the name. Very few had heard of the hospice-at-home service; those who did had personal experience. Even when reminded about the annual sale of daffodil lapel pins, there was little evidence of recognition of the Marie Curie service. Some respondents had read about this service in a magazine article, or been told of it by relatives in London.

THEME 4: ACCESSING PALLIATIVE CARE SERVICES

The effectiveness and helpfulness of GPs was discussed with some vigour, the consensus being that they often did not know or did not refer patients for further assistance. The exposure to healthcare in other countries allowed some of the participants a view on how things could work differently:

‘Compared to Holland the NHS is not so developed – you get a better service if you pay.’ (Somali female)

Acute hospital doctors and nurses were perceived as sources of help, support and guidance, but many obtained this from other patients and their visitors in the acute hospital setting. The majority either did not know where to go for help, or stated that they did not like to ask perhaps because of pride, tradition, or implied that this would cause a stigma and risk for family. There were many concerns about getting equipment, lack of 24-hour support from nurses, and rude and unhelpful staff. There was also anxiety about lengthening waiting lists, staff shortages and the resultant stress this caused both staff and patients. A small number of usually younger participants cited the internet, radio and television as sources of help, but others wanted more local channels for seeking information.

THEME 5: PERCEIVED BARRIERS TO ACCESSING PALLIATIVE CARE

The main perceived barriers to palliative care were lack of awareness of available services and dietary concerns. The provision of appropriate food, be it halal or strict vegetarian, was said to matter greatly. The preparation or serving of vegetarian food should not be contaminated by contact with any utensils that had touched meat products; several groups of older Hindu ladies were united in saying that a ‘pure vegetarian kitchen’ was essential. Family bringing in food to a hospital or hospice was generally acceptable, though local policies were found to be inconsistent.

Communication was a key issue for many people, including those with good spoken English. Participants reported reverting to mother tongue at times of stress and illness; there was concern for those who did not speak English. The fact that most hospital wards did not have the space or facilities to permit someone to stay with the patient all the time was criticised by some, who felt that when ill and vulnerable, someone to ‘be with them’ was very important.

The use of family as interpreters was contentious. Many participants spoke of the burden of directly giving bad news to close relatives, but some felt it important that this was in fact done by family members if doctors were unable to communicate in the same language. Some younger participants were

willing to challenge the use of jargon. Several older persons commented that the younger generation spoke excellent English, but were frequently unable to converse fluently in their original family language.

Disclosure of illness, both within the family and to the wider community, was raised by groups of all ages because cancer incurred stigma which inhibited requesting or receiving help. Disapproval from those in the locality was a powerful force, and having frequent or regular visits from health professionals, or 'putting your mum in a hospice' could let the community discover the illness and bring censure on the family. Admission to an institution could show lack of love – 'families are brought up to care'. The apparent lack of care by the family would be viewed by the community as shameful. Families and communities needed educating.

Finance was a common concern. When it was explained that all the services were free, there was still concern that despite reassurances, families might be presented with a bill. The cost of travelling to get treatment and to visit relatives was also considered to be an issue. There was concern that the home might have to be sold which suggested confusion about services.

Religious beliefs provoked much discussion. Lack of knowledge among staff was raised but not seen as a major problem. Spiritual advisors were also criticised for being insensitive. Aspects of beliefs and religious practices were acknowledged to have a diversity of expression which spiritual leaders did not always recognise or allow.

Fear was an issue for many people. Recent media coverage of poor care in hospitals and in nursing and care homes was frightening. Fear of complaining was common, along with the potential for loneliness and isolation amongst strangers they didn't want to share accommodation with, poor discharge arrangements, uncooperative GPs, all contributed to vulnerability. Actual fear of the hospice was also voiced, though not everyone shared this.

THEME 6: HOW WOULD YOU LIKE TO FIND OUT ABOUT WHAT IS AVAILABLE?

Leaflets were universally popular. People wanted something to take home with them, to keep and study; many wanted leaflets in their own language. One youth group member wanted leaflets to be handed out in shopping centres, so that they reached everyone.

GP surgeries were identified by all groups as a source of essential information. Leaflets, posters and the use of television screens in waiting rooms were all regularly brought up. Pharmacies, libraries, community centres, places of worship, acute hospitals, banks and

shops were all nominated as places where people could find out what they needed to know. Website-based information was suggested by the youth groups and some more mature respondents. Lack of local knowledge, and thus of which key words to enter, were a real handicap. Social media, such as Facebook, were also discussed; again, the need to have a key word was a crucial issue.

Several groups recommended person-to-person contact in the form of link workers, talks, awareness-raising sessions, visits to pubs and clubs, and appearances on local Asian TV and radio. Some felt that religious authorities should be information sources too.

Discussion

In Leicester, widespread ignorance of available services coupled with lack of appropriate referrals are the likely major reasons why BAME people do not use palliative care services. Other issues are of a lesser or greater importance to individual patients and their families, but flexibility in communities and suggested strategies for overcoming them show that they are more easily surmountable and arguably appear less of a barrier.

GP knowledge of specialist palliative care services, especially in BAME communities, is a decisive factor in access to palliative care services (Karim *et al*, 2000). GPs either made assumptions or were unaware of services. There is a need to focus on this issue since concerted attempts to engage GPs who served the communities in Leicester were unsuccessful in this project.

Few participants could identify local or national providers of palliative care. LOROS was the most recognised service but by less than half the participants. There was little knowledge of where or how the money was raised or used. This lack of awareness is echoed in findings of Frearson *et al* (2013) in a small study with Hindu families in London.

The diversity of understanding of 'palliative care' was complex and in all likelihood, not limited to the BAME groups who participated (Calanzani *et al*, 2013). However, the concept of hospice care and the widespread recognition of Macmillan nurses, all facilitated by national culture and common language, probably contribute to a broader understanding of palliative care in non-BAME communities. In contrast, participants in our study had little knowledge of Macmillan or its services. Our findings demonstrate that the term palliative care is itself an issue.

Whilst BAME educated in the UK will speak and read English, older migrants and many new arrivals may not, and so lack of appropriate and accessible

information or interpreters may act as barriers to palliative care (Phelps *et al*, 2011). In addition, competent English speakers may revert to their first language in times of illness and stress; managing complex discussions about illness, prognosis and future expectations is difficult. Furthermore, there may be no direct equivalent of technical words. For instance, there is no word for cancer in Hindi and Gujarati and no acceptable term for breast cancer (Symonds *et al*, 2012). Equally, the words 'palliative care' and 'terminal care' do not translate directly into most non-European languages. The Gujarati-speaking project assistant, who was very experienced in working with nurse specialists in palliative care formulated a sentence which described 'giving care to someone who was not going to get better, who could not be cured of their illness.'

Advance Care Planning (ACP), including making choices about preferred place of care and death, is a major feature of the End of Life Care Strategy (Department of Health, 2008). Components of the predominant model of ACP include clarifying that a patient understands their illness and treatment options; gaining understanding of the patient's values, beliefs and goals of care; and identifying their wishes as their illness deteriorates and as they die (NHS National End of Life Care Programme, 2011). This framework for ACP discussions depends on an acceptance by professionals, patients and their families of individualised and autonomous decision-making; the acceptability of discussion of illness progression and deterioration and the acceptability of thinking ahead and planning for death. This framework does not reflect the diversity of religious and cultural worldviews, where for example a social framework can be paradigm for decision making (Koenig 1994; Blackhall 1995; Rhunke *et al*, 2000), where non-disclosure of diagnosis and prognosis may be the preference (Kaufert *et al*, 1998) and when planning for death is not culturally acceptable (Bowman and Singer, 2001). Our discussion groups revealed tensions between cultural taboos about discussing death or dying and informing individuals about their situation. If BAME people are not offered or do not engage with ACP with care providers, they risk receiving aggressive care that may not be consistent with their wishes (Searight and Gafford 2005; Carr, 2007) and may adversely affect their care outcomes. However, the views and preferences of BAME groups on models of ACP or End of Life Care Planning have not been documented in England.

Expectations and prejudices among BAME communities create barriers to services and increase the burden on patients and families. In addition, nursing may be associated with low caste 'dirty work' which pollutes the women who do it (Nair and Healey, 2006). Many participants supported standing up

against cultural mores and shared their thoughts on sharing information, and on providing and accepting care that is focused on the needs of the patient and their immediate family.

Finally, it seems that the main barrier to accessing services is lack of awareness of what is available. BAME communities require education to understand the types of services provided, dispel myths and promote a sense of 'it's for us as well'. Dietary concerns could be included here as an aspect of culture which is an exemplar of much that is pertinent about culturally sensitive care (Gunaratnam, 2001). Cultural beliefs and practices could also be explored in terms of their effects on seeking help (Kleinman, 1978; Helman, 2007). Information giving alone is not enough in promoting choice and empowerment (Chiu, 2003; Chiu and West, 2007). There is a need for more research to consider how and why minority ethnic groups adopt attitudes to death and dying in the new, changing societies in which they live. This is likely to have a twofold effect: the results will influence culturally sensitive and appropriate palliative care, whilst the work itself will raise awareness amongst minority communities of the services that are available and how they can use them effectively.

Limitations of the study

The methodology was intended to facilitate recruitment but the lack of verbatim transcripts limited the richness of the data analysis. Despite strategies to maximise participation, recruitment required tenacity, utilising multiple networks of both professional and personal nature. The topic-led discussion usually followed a planned meeting, thus was not the main purpose of the gathering. Some sections of the population remained elusive; Herodotu (2012) describes similar experiences. Whilst the findings appear generalisable and have congruence with previous work, communities and groups that did not engage may have additional concerns. The structure of the discussion topics may have inhibited some participants. Some of the larger meetings were likely not to have given sufficient opportunity to quieter or shy attendees who disagreed with the general consensus to voice their thoughts.

Conclusion

The concept of palliative care is unfamiliar to many BAME people and the phrase itself lacks any common meaning. Once explained, BAME people welcomed both the concept of palliative care and access to

services that provide such support, and they would like information to empower them to do this. There was a perception of a lack of signposting by those that might refer, especially GPs.

Information needs to be multifaceted and multi-layered. It should be proactive and include community education about services, posters and leaflets in numerous venues such as pharmacies, libraries, community centres, places of worship, GP surgeries, acute hospitals, banks and shops, as well as promotion via media. Services could also work collaboratively with cultural and religious leaders who may in turn serve as a point of information and encourage uptake of services (Phelps *et al*, 2011) and destigmatise palliative care. Professional education is also needed to promote cultural competency when dealing with patients with diverse ethnic backgrounds (Phelps *et al*, 2011; Rabiee and Smith, 2014).

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CONFLICTS OF INTEREST

SM is the project worker for the LOROS Broadening Horizons project. AV is the hospice cultural support worker, seconded to the project. None declared by CF or ZI.

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ADDRESS FOR CORRESPONDENCE

Christina Faull, Consultant in Palliative Medicine, LOROS Hospice, Groby Road, Leicester LE3 9QE.
Email: christinafaull@loros.co.uk