

Practice paper

Raising the profile of palliative care services for BAME groups within Leicester city: Challenges with recruiting and training volunteers

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What is known about this subject?

- Palliative care is not a term that is known or understood within many minority ethnic communities.
- Patients from Black, Asian and Minority ethnic communities access palliative care services less and later than other groups of patients.
- Peer volunteers can be an effective way of influencing change in health related behaviours.

What this paper adds

- The recruitment of volunteers to discuss palliative care within their community networks, whilst complex, can be successful.
- Such volunteers will require bespoke training and support to develop their knowledge and skills to discuss traditionally taboo subjects and develop appropriate language for their community.
- Volunteers thought their role of unique value and great importance and gained a high level of satisfaction.

ABSTRACT

The Broadening Horizons (BH) project in Leicester UK found that, for members of Black, Asian and Minority Ethnic (BAME) Communities, a key obstacle to accessing hospice support was a lack of knowledge of the hospice and hospice services. In its second phase the project aimed to address this issue by recruiting and training volunteers from within these communities to provide information about the local hospice and palliative care. This paper presents an account of the complexities of recruiting and training these volunteers. These complexities included the concept of volunteering, the

challenges of ensuring in-depth training to provide lay workers from BAME communities with knowledge of palliative care and hospice services, and the fragmented local service delivery. Over a two-year period and despite many challenges, volunteers made contact with over 3000 people at events in Leicester and considered they engaged in something of great importance to their communities.

Keywords: Black, Asian and Minority Ethnic (BAME) communities, volunteers, training, palliative care, end of life care, hospice, accessibility

Introduction

According to the 2011 census, the total population of England and Wales was: 13% were born outside the UK and one in five identify themselves as being from a group other than White British. In England, both the numbers and proportions of people from Black, Asian and Minority Ethnic (BAME) communities, have increased in the past 20 years. In 2011 Other White was the second largest ethnic group in England (almost 2.5 million people or 4.6% of the population, an increase of more than one million people since 2001), followed by Indian (almost 1.4 million people or 2.6%) and Pakistani (1.1 million or 2.1%)

(Calanzani, Koffman and Higginson, 2013) The largest increase has occurred among those aged over 65 and is predicted to continue. In England and Wales by 2026 there will be over 1.3 million people from BAME groups aged 65+ compared to around half a million in 2001 which has implications for end of life care and palliative care services (Calanzani, Koffman and Higginson, 2013).

There is evidence that, nationally, members of BAME communities are under-represented as users of specialist palliative care services (Department of Health, 2012). The reasons are well-documented and are accepted to include low

referral rates (Worth *et al.*, 2009) differing patterns of disease (Gunaratnam, 2007) and communication issues (Richardson and Koffman, 2011) which can involve difficulties with access (Johnson, 2009), poor satisfaction and mistrust (Frearson, Henderson and Ravat, 2013). The clinical activity figures for (2009 – 2010) for the Leicestershire and Rutland hospice (LOROS) which serves the whole of Leicester city, indicated that referrals for patients from BAME backgrounds formed less than 40% of those received for the white British population. This was a particular cause for concern as the hospice is located in a city projected to have a non-white majority population sometime after 2011. In addition, the current end of life care strategy requires services to '*bring about a step change in access to high quality care for all people approaching the end of life*' (Department of Health, 2008: 33). It was in this context that the Broadening Horizons Project was developed.

Broadening Horizons Project and the Volunteer role

In response to the apparent inequality in access for people from BAME communities, LOROS developed a 36-month project in 2011-13 to improve access to specialist palliative care services. The project aimed to examine awareness and understanding of specialist palliative care services among the BAME communities in Leicester city and then provide better information through outreach through trained BH volunteers.

The project was divided into two interrelated parts. In part one the objectives were to gain more understanding of why members of local BAME communities were not using the available palliative care services, to explore what they perceived the barriers to be, what information they would welcome about available services and the most appropriate format for this information (Markham, Islam and Faull, 2014). The first part of the project highlighted that the main barrier to accessing services was lack of awareness of what was available. Such findings supported the need for the second part of the project which recruited and trained volunteers from the minority groups, to engage with some of the diverse populations and raise awareness of the services on offer.

The purpose of the volunteering role was to inform members of the public about the hospice and the palliative care services available in the area and included attending public events in the city, such as health fairs; planned awareness-raising sessions at GP surgeries; any relevant community event willing to host volunteers manning an information stand and speaking directly to interested members of the public. Volunteers were also to speak to particular interest groups that requested a visit such as elderly persons' luncheon clubs at neighbourhood centres. Direct patient contact was not in the brief of the project or the volunteer role.

Volunteers: a strategy to improve access and inclusivity

For the purposes of this paper the following definition of volunteering in end of life care is used: '*volunteering in end of life care is unpaid activity conducted for the benefit of others beyond close relatives provided in connection to an organisation that provides end of life care, support or services.*' (Naylor *et al.* 2013, p.2).

There is an indication that volunteers in hospices provide strong reciprocal links to the communities they live in (Scott and

Howlett, 2009). They bring local knowledge of the community and can act as 'bridges' between the hospice and its surrounding community, thereby promoting community cohesion (Naylor *et al.* 2013). The presence of volunteers therefore helps the organisation to be more responsive to the needs of the local community, creating social identity and developing social capital (Seymour *et al.* 2011).

Historically studies mention that members of BAME groups are under-represented in formal volunteering (MEM-VOL report, 2003; Machin 2005; Low, Butt, Paine and Smith 2007). Recruitment of volunteers from BAME communities has traditionally been considered to be difficult and the concept of volunteering, as understood in a western construct is described as paradoxical by Lukka and Ellis (2003). By this they appear to mean that it lacks a clear definition of what it involves. Previous studies, have shown that while there was a paucity of BAME volunteers in formal 'civic participation' such groups have a long history of informal involvement within their communities (MEM-VOL, 2003; Reilly 2004). There is no word for 'volunteer' in many Asian languages – English is usually substituted – and informal helping frequently comes from shared cultural and or religious values (Lukka and Ellis, 2003; Reilly 2004). People living in deprived areas are least likely to volunteer and concentrations of ethnic communities are found mostly in poorer areas of the country (MEM-VOL, 2003).

Although they give their time freely, there are costs associated with the recruitment, induction, support, management and coordination of volunteers to enable them to become effective (Department of Health, 2011). Poor volunteer management services lead to unhappy volunteers (Bates, 2009). This paper describes the complexities of recruiting and training volunteers from BAME communities to work in their local communities to enhance knowledge of hospice and palliative care services.

Leicester city, UK

Leicester city is located in the East Midlands of England. It is a poor city, with lower than average wages, and a high incidence of poverty (Leicester City Council, 2013). BAME communities comprise half the population and are mainly of South Asian heritage. South Asians are defined as those with ancestral origins in Pakistan, India and Bangladesh. According to the 2011 census they comprised 37% of the city's population of 329,000, an increase from 30% in 2001 (Leicester City Council 2012). Leicester has the highest proportion of residents identifying Indian heritage than anywhere else in England and Wales. Gujarati, the native language of the Indian state of Gujarat, is the second most spoken language after English in Leicester.

Significant numbers of people from other communities also form part of the diversity of the city's make-up. The black population (including: Black/African/Caribbean/Black British) doubled from 3% to 6% in the last 10 years (Leicester City Council 2012). The 2011 census data shows that the total migrant population in Leicester increased by 71.7% in 10 years, with 33.6% of residents born outside the UK; slightly less than half of them arrived between 2001–2011. There are several factors that contribute to this: high rates of migration from EU accession states; arrival of third country nationals; and Leicester's status as a national asylum seeker service dispersal city.

Volunteer recruitment

A project steering group included management from the hosting hospice, local authority and community health trust professionals, a General Practitioner (GP) and a hospice trustee. Workers from two charitable organisations were also included. These organisations were the Race Equality Centre, which focuses on challenging discrimination as defined by the Equality Act 2010 and further strengthened by the Human Rights Act 1998 and Age Concern (now Age UK), the banner title used by a number of charitable organizations specifically concerned with the needs and interests of older people over the age of 50. More than half the members of the steering group were from BAME minority communities. Members were asked to identify opportunities for the recruitment of volunteers.

Two project workers (SM and AV) promoted these opportunities using a multi-modal strategy including:

- Participating in awareness-raising events in part one of the project.
- Attending health fairs and events in areas of the city which had the highest number of BAME households.
- Broadcasting on Asian radio stations i.e. Ramadan Radio, the BBC Asian network and Kohinoor Radio, a Punjabi language station.
- Advertising through community centres and libraries.
- Articles in the local daily newspaper, The Leicester Mercury, several short pieces in local special interest magazines and the hospice in-house newsletter.
- Members of the steering group circulated information to their networks
- Posters at health events.

Two open information events were held at the hospice to explain the project and the nature of the volunteering opportunities. Initially, no organisation requested that a volunteer of a specific gender attend a planned meeting; however, as the project progressed, several religious and social organisations, some linked to places of worship, were delighted to be able to have a same-gender speaker for specific groups.

Volunteers were recruited in two cohorts and received training for their roles.

Training BH Volunteers

The training programme was developed and informed by analysis of findings from part one of the project (Markham, Islam and Faull, 2014). These findings revealed a lack of knowledge of palliative care, its meaning, its availability and significance among members of BAME groups. Hence the aims of the training were to enable participants to

- Understand the need for the BH project.
- Develop an understanding of specialist palliative care services.
- Be able to speak with confidence about specialist palliative care services to individuals and groups.

- Feel able to fulfil the volunteer role (Table 3).

Four volunteer training programmes were delivered, lasting for 17 -20 hours, over 3 or 4 sessions, depending upon the size of the group, and further needs that emerged or were identified by the trainees. The components of the training programme are outlined in (Table 3).

The training was based on an informal, flexible learner-centred approach. Face to face learning was supported by resources which could be customised by the volunteers to suit their own needs. It was essential that the volunteers had a comprehensive understanding of end of life and palliative care services so that they could explain these to members of the BAME public and answer any questions they might have. This was not straightforward because, in Leicester, specialist palliative care services are delivered by a combination of providers. Consequently, emphasis was placed on learning 'who did what'. When possible, health professionals working in the various services came to the sessions and explained their roles, and answered questions.

Challenges in the recruitment and retention of BH Volunteers

Recruiting BH Volunteers was a challenging and lengthy process details of which are provided in the Attrition Chart (Figure 1). In the first cohort of 30 interested individuals 16 were viewed as being suitable by the project workers and invited for an interview; 13 were accepted as volunteers. Two of the 13 could not attend the four training dates but additional funding in the second year of the project facilitated their training together with a further 12 more volunteers. A total of 25 volunteers were recruited and their characteristics are shown in Table 2.

Over two thirds of the volunteers spoke Gujarati. All those who were offered and accepted volunteering roles had previous experience either as volunteers or in roles working with health or social care.

Initially, an expectation of 6 to 8 hours per month was suggested as minimum BH volunteer hours but these hours proved to

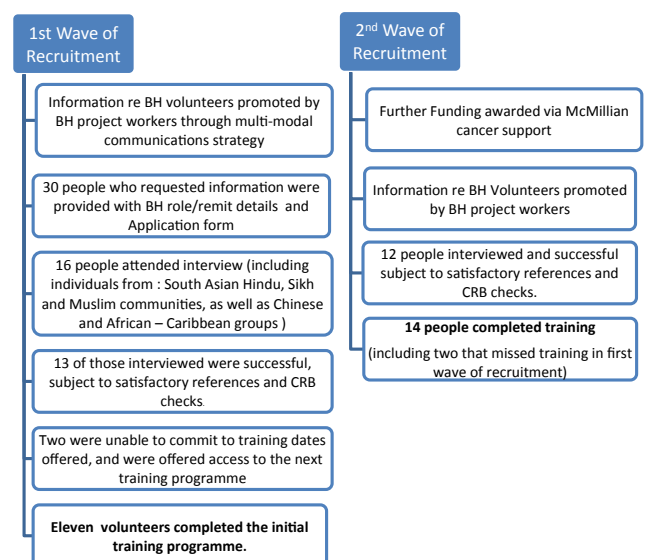


Figure 1: Volunteers.

be difficult for many to sustain alongside jobs, families, and other commitments. Eight volunteers decided not to continue to work with the project at the end of 6 months for a variety of reasons including: being offered student placements abroad, work demands, getting a paid job. Some individuals simply faded away; they either did not respond to requests to commit to attend events or repeatedly offered reasons why they could not do so. By the end of 2013 there were 17 volunteers active within the project each filling regular slots in the engagement/ events diary.

Forging a service and supporting volunteers

Table 1: List of Abbreviations.

Abbreviation	Definition
BAME	Black Asian and Minority Ethnic
BBC	British Broadcasting Corporation
BH	Broadening Horizons
DBS Check	Previously known as a CRB (Criminal Records Bureau) check, a DBS (Disclosure and Barring Service) check is a record of an individual's Convictions, Cautions, Reprimands and Warnings and can also include intelligence held by the police and/or the DBS that relates to that individual and their suitability for a job. www.gov.uk/government/organisations/disclosure-and-barring-service
EU	European Union
GP	General Practitioner
LOROS	The Leicestershire organisation for the relief of Suffering known as the Leicester, Leicestershire and Rutland Hospice.
UK	United Kingdom

Some volunteers had met previously, either socially or through work or religious events. Others were reluctant to initiate direct communication with members of the opposite gender, particularly in the early stages of the project when most were strangers to each other. However after two or three training sessions, most were chatting freely and sitting casually with different group members. This included a female Muslim volunteer, who had expressed a preference for working solely with females.

The project manager proposed a buddying system so that at least two volunteers always attended events together and kept in touch with each other. This was not taken up by the volunteers who preferred to nominate themselves for events via email with little contact outside meetings. All were given full contact details, and did, when necessary, speak to each other to organise replacement personnel if they had to effect last-minute changes.

Initially, either SM or AV attended events with the volunteers. This was to support them and give them confidence, and to confirm that they were able to give the appropriate information and messages to the general public. Some of the volunteers, particularly those with experience of working with groups, were soon able to manage health events themselves, with minimal input from paid project workers.

It was also noticeable at events that having both male and female volunteers was beneficial; male members of the public gravitated towards the male volunteers, and often engaged in lengthy conversations. Women from some cultures were clearly more comfortable conversing with someone of the same gender. At events staffed only by one gender of volunteers engagement was still very effective but fewer extended conversations seemed to occur.

Support meetings were held at approximately two monthly

Table 2: Characteristics of Volunteers at each of the waves of recruitment.

	Gender	Indian	African Caribbean	Chinese	Malay Chinese	Dual heritage	Religion	Language additional to English
1 st wave of recruitment	15 Female 10 Male	20	2	2	1	1	13 Hindu 2 Sikh 2 Muslim 3 Christian 5 Not known	16 Gujarati 3 Punjabi 3 Urdu 9 Hindi 2 Cantonese 1 Malayam 1 Mandarin 1 Patois 1 Swahili 1 Marathi
2 nd wave of recruitment	9 Female 8 Male	14	1		1		10 Hindu 2 Sikh 1 Muslim 2 Christian 2 Not known	12 Gujarati 2 Punjabi 2 Urdu 9 Hindi 1 Cantonese 1 Swahili 1 Marathi

Table 3: BH Volunteers Training Components.

Number of Training Component	Description of Training Components
1	Discussion of volunteering role. Requirements and boundaries, development of relationships with members of the public
2	Understanding of the concept and services around end of life and palliative care: Principles of palliative care, clarity regarding ethics - no assisted dying - dignity and respect for patient and family
3	Developing presentation skills: Public speaking, use of hospice literature and a virtual tour available on line
4	Using Hospice materials i.e. information leaflets. At the same time, the use of the organisation's name only in appropriate settings was examined, along with the reasons for this.
5	An overview of safeguarding. Mandatory for all health workers and volunteers, to be aware of any issues regarding the welfare of any vulnerable group such as children, disabled, elderly - who to ask for advice, reporting. Statutory obligations and organisations
6	Understanding relevant hospice policies regarding confidentiality. Essential for all connected in any way with patients or families.
7	Health and Safety. Mandatory for all health workers and volunteers. Includes personal safety, training in use of any equipment ie -erecting stands and banners. Awareness of fire risk and safety in any public building or space.
8	Good practice in community working. Including health and safety. Guarding personal information i.e. not giving personal details, telephone numbers etc. Being aware of promoting the good name of the organisation and not jeopardising this by any behaviours.
9	Explanation of informal monitoring document and the mechanics of obtaining and using this. For example, collect anonymous data regarding numbers of events attended, members of the public informed, hours given by volunteers, etc.
10	A tour of the hospice and meeting some key personnel. Reinforces value of volunteers to the organisation, helps a sense of belonging to the hospice team, and familiarises volunteers with the organisation.

intervals. These were held in the early evening, at the hospice at the volunteers' suggestion. It was apparent that these were as much a vehicle for socialising and getting to know each other as for the agenda items that the project team planned to discuss. Feedback from volunteers indicated that this support system was essential for them to fulfil their role:

'As a new recruit, [name] has been a great support in partnering me at the first few events I participated in. This really helped me to gain an insight into how events are run, how the volunteers should be interacting with the public and I felt I had a point of referral if I needed whilst I 'learnt the ropes'. The other more experienced volunteers have been supportive and welcoming too and made me feel a part of the team. During training and in subsequent meetings, events [and] email communication, I have found that [name] has been readily available to answer any questions, listen to suggestions [and] feedback, take on board and implement recommendations and provide help wherever required. I really appreciate this support.' (P5)

Evaluation of training and the role of BH volunteers

Evaluation methods

Towards the end of the project volunteers (n=17) were invited to either attend a focus group led by ZI or to complete a questionnaire. Both methods were used to explore the role and expectations of volunteers, the extent to which the training helped them to fulfil their role and whether they had benefited from their experience. In addition a small number

of potential applicants (n=7) were willing to briefly discuss with the project workers their reasons for not proceeding as BH volunteers. All data were analysed thematically and findings were integrated.

This project was an evaluation of an aspect of the current hospice and other palliative care services thus approval from an NHS research ethics committee was not required. Respondents were members of the general public attending social groups and were not patients. Verbal assent was requested from the group for the purpose of the discussion and for the use of the data. The most significant ethical consideration for the study was of confidentiality for participants and all quotations from the discussion groups have been anonymised.

Findings

Of the 17 volunteers contacted, four agreed to attend a focus group and one completed a questionnaire. Four of the volunteers were Indian and one Chinese. Three themes emerged in relation to their training and their role the volunteers: *Developing Knowledge and Understanding; Addressing Culture & Developing Trust; Benefits for Volunteers*. Quotes have been used to illuminate key points.

Developing Knowledge and Understanding

The concept and terminology of 'palliative care' could be difficult for those not immediately involved in this area of work. Each training session included explaining, reviewing and

refining the understanding of the volunteers. The complexity of service providers was even more opaque. Volunteers found training on these aspects to be valuable and necessary.

'For me personally LOROS was a place to come for end of life [before the training]. I was really surprised that there is chaplaincy... you can come here to have your symptom control... respite which is lovely. I can tell others [ethnic minorities] about that' (P1).

'The training helped me gain a solid understanding of the various facets of palliative care, especially with regards to how this care is provided and delivered through the various LOROS services. This was most useful in order to be able to deliver information sensitively, accurately and confidently to members of the public at events.' (P5)

Addressing culture and developing trust

All volunteers emphasised that their role was essential in spreading knowledge about the role and benefits of palliative care services within local BAME communities. Volunteers' understanding of cultural nuances and their language skills enhanced their effectiveness and facilitated discussion with people who might otherwise be hard to reach.

'BH volunteers can raise awareness amidst various communities who may not be so familiar with palliative care or LOROS. Many people who are unable to understand English do not know of these services or if they can access them. BH volunteers can provide this information in a very informal manner, help to dispel any common myths or apprehensiveness, and allow individuals to know that services do exist should they ever require to access them.' (P5)

'The Gujarati community are very reserved they don't like to talk about anything...you have to assure them that what they tell you won't get out to anyone.' (P4)

'People are likely to be more receptive to people they recognise [and] can relate to and thus having [BAME] volunteers breaks down the barriers and people can feel comfortable receiving information from them. An element of trust also exists as [BAME] communities will understand and communicate with volunteers in a better manner rather than perhaps healthcare professionals in hospital settings who may not have the time or relevant language skills. This enables LOROS to engage with many ethnic minorities, in order to continue achieving its objective of caring for people when they need it the most.' (P5)

Benefits for Volunteers

The BH volunteers identified important benefits to themselves in undertaking this work. Some gained a new perspective of their lives and self worth:

'Voluntary work is food for the soul' (P3); 'You feel good about yourself' (P1). 'It's a good feel factor for yourself. It makes you realise the importance of life' (P3).

Some volunteers had previous personal experience of loss of a loved one, and chose to talk about it, describing how they felt. In many cases, volunteers identified with the life-line that services could offer. This endorsed their desire to make such information available to others. Such benefits were emphasised

by BH volunteers when asked what the most important and valuable part of their role was:

'To be able to share knowledge and raise awareness of palliative care, which may help make a difference to someone's life. To make a positive contribution towards supporting LOROS and local health care services in their aim of being accessed by all members of the community who may need their care.' (P5)

Reasons why people did not wish to volunteer for the role

Seven people who had expressed interest at recruitment events subsequently withdrew. One reason given by two people who did not wish to become volunteers was attributed to stigma and taboo, manifested as the anticipated disapproval of family members regarding any involvement with death. One enquirer said, when asked if she was going to apply, that her husband did not want her having anything to do with people dying, as it might bring home the chance of it happening to them. Wishing to work only with a specific gender was also given as a reason.

The need to attend three or four training sessions was an issue for three potential volunteers and most applicants (n=6) took some time to realise that they could not choose dates to suit themselves but would need to work around the established timetable. Lack of patient contact and a desire to spend time with a dying person was also cited as volunteering opportunities individuals specifically wanted by two individuals. This was not part of the BH volunteers' role and could not be offered within the project but these applicants were directed to other volunteering opportunities at the hospice.

Discussion

Communication issues (Richardson and Koffman, 2011) and poor satisfaction and mistrust (Frearson, Henderson and Ravat, 2013) have all been shown to have an impact on accessibility and acceptability of palliative services for BAME communities. The BH volunteers brought their own insights and experiences to bear on understanding the barriers and obstacles perceived by differing BAME communities. Having fluency in many of the most frequently used languages made for ease of both communication and acceptance. The volunteers' own cultural knowledge enhanced their ability to connect and engage with members of their own and other communities and groups. This made easier engagement in many situations and also aided to dispel mistrust and in turn acceptability and accessibility of services.

Training was a key part of equipping the volunteers to fulfil their role. Palliative care is complex and delivered by a range of services and organisations with little overt co-ordination; many languages do not include palliative terms. For instance, there is no word for cancer in Hindi or Gujarati and no acceptable term for breast cancer (Symonds *et al.* 2012). Discussion of these linguistic issues during training, facilitated agreement on suitable words or phrases which conveyed the correct meaning.

The benefits of volunteering to individuals have been well researched and this work suggests volunteers receive health and social benefits, as well as personal growth from volunteering. These include, for example, increased self-esteem, well-

being, social engagement, self-worth, and a sense of purpose (Warburton, 2006; Claxton-Oldfield and Claxton-Oldfield 2008; Claxton-Oldfield 2015). Casiday *et al.* (2008) suggest that volunteering is shown to decrease mortality, improve self-rated health and mental health, improve life satisfaction, improve the ability to carry out activities of daily living, support health behaviours and improve the ability to cope with one's own illness. Volunteer satisfaction is also associated with the experience of fulfilling volunteer goals and feeling accepted as part of the hospice family (Claxton-Oldfield and Claxton-Oldfield 2008; Claxton-Oldfield 2015).

Recruiting volunteers presented a considerable challenge for a range of reasons. Cultural beliefs within some BAME groups considered that physical contact with a dying body was something done only by those of a lower caste, such as 'sweepers' and 'untouchables' in South Asian countries. That 'good', that is pure, chaste, religiously observant women would touch and clean a dying man, even as health professionals, is still anathema to some religious sects (Nair and Healey, 2006). Thus, by association, description and discussion of matters linked with death is also discouraged (Neuberger, 2004). Stigma and taboo around these topics are joined, and frequently involve gender.

The volunteers all had backgrounds in either health, social or youth care, volunteering, or were under graduate or post graduate students. All were open to discussing issues around perceptions of death and dying within known cultural or religious groups. More emphasis is needed on recruiting volunteers from other less established but increasing BAME communities.

The project team had to recognise that the volunteers had other priorities which sometimes took them away from regular volunteering. These included family weddings or engagements, school holidays, caring for grandchildren, visits to family abroad, religious fasting times and preparation for pilgrimage. These have to be accommodated if high calibre volunteers are to be retained. Additionally the requirement for a formal application process, including references and Disclosure and Barring checks could well have been inhibiting (Claxton-Oldfield and Claxton-Oldfield 2008; Claxton-Oldfield 2015).

Conclusion

The aim of the Broadening Horizons project was to raise awareness of specialist palliative care services amongst the BAME communities of Leicester city, in order to improve access to such services. To achieve this, volunteers from diverse ethnic, cultural and religious groups were recruited. This posed considerable challenges but a team of committed, trained volunteers had contact with over 3000 people, discussed traditionally taboo subjects and raised awareness of the role and benefits of palliative care. These volunteers thought their role of unique value and great importance and gained a high level of satisfaction. Working with volunteers from BAME necessitates recognising that there are other drivers which compete for their time and commitment. Being able to accommodate these, and capitalise on the unique contribution many volunteers bring enables contact with individuals who might otherwise remain 'hard to reach' for attempts to deliver sensitive end of life services.

Endnote

Definitions of all abbreviations are provided in Table 1

Acknowledgments

Anjana Vaja (AV), cultural support worker at the hospice was a key facilitator of the discussion groups without whose input this work would not have been achieved.

We wish to thank all the individuals who participated in this work. We are grateful for their involvement and helpfulness.

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