Dying at home: A qualitative study of the perspectives of older South Asians living in East London

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Abstract

South Asians constitute the single largest ethnic minority group in the United Kingdom, yet little is known about their perspectives and experiences on end-of-life care. **Aim:** To explore beliefs, attitudes and expectations expressed by older South Asians living in East London about dying at home. **Methodology and methods:** Five focus groups and 29 in-depth semi-structured interviews were conducted with a total of 55 older adults (24 men and 31 women) aged between 52 to 78 years. Participants from six South Asian ethnic groups were recruited via 11 local community organisations. Data were analysed using a constructive grounded theory approach. **Findings:** Two key themes were identified. The theme of 'reconsidering the homeland' draws on the notion of 'diaspora' to help understand why for many participants the physical place of death was perceived by many as less important than the opportunity to carry out cultural and religious practices surrounding death. The second theme 'home as a haven' describes participants' accounts of how their home is a place in which it is possible to perform various cultural and religious rituals. Cultural and religious practices were often seen as essential to achieving a peaceful death and honouring religious and filial duties. **Conclusion:** Older people of South Asian ethnicity living in East London perceive home as more than a physical location for dying relatives. They make efforts to adhere, but also adapt, to important social and cultural values relating to death and dying as part of the wider challenge of living in an emigrant society.

Keywords

Ethnic minorities, South Asians, Dying, Home, End-of-life care.

Introduction

In the UK, palliative and end-of-life care policy is directed at trying to increase the proportions of death that occur at home (currently around 20%) because this is seen as an 'ideal' environment in which to be cared for and to die (in terms of largely untested claims about 'dignity'; 'choice' and 'quality' of care) and because cost savings are anticipated once a shift occurs from secondary to community care [1-4]. This mirrors similar trends in gerontological practice and policy, which emphasise 'ageing in place' and the importance of supporting older people in their own homes for as long as possible. In the latter, the promotion of 'autonomy' and 'independence' have been important themes [3, 5]. The direction of policy seems to be supported by evidence from cross sectional surveys which suggest that most people (whether members of the public or patients) express a preference for a home death when asked [6]. The clearest statement of policy is contained in the English 'End-of-life Care Strategy' published in 2008 [2]. The strategy aims to deliver the highest possible quality of care for everyone approaching the end of life, 'irrespective of age, gender, ethnicity and religious beliefs' and to increase the proportion of adults being cared for and dying at home, where this is their choice.

In spite of the centrality of home based care in national end-of-life care policy, there has been comparatively little study of how different groups of people understand and

perceive ‘dying at home’, either from the perspective of looking forward to their own future final illness and death, or from the point of view of reporting on their end-of-life care giving experiences or thinking about the care they may need to give to their relatives at some point in the future. Existing research suggests that there are a diversity of meanings and experiences between and within cultural and ethnic groups [7]. A comparative qualitative interview study of white and Chinese older people living in the UK suggested that both groups were concerned about the demands on the family that may flow from having to manage pain, suffering and the dying body within the domestic space, with Chinese elders additionally being concerned, for deep seated cultural reasons, about ‘contamination’ of the home by death [8]. A UK survey of the family and friends of deceased first-generation black Caribbean and native-born white patients with advanced disease people [9] found that black Caribbean patients were more likely to be reported as wanting to die at home. The authors of the latter study argued that there is a need for a deeper qualitative understanding of the cultural and other factors that may facilitate or prevent home deaths. This is important since practitioners may struggle to provide culturally competent care if they do not appreciate the complexities underpinning patients and carers’ concerns and preferences [10].

Asians constitute the single largest ethnic minority group in England and Wales [11]. Indian and Pakistani people respectively made up 2.5% and 2% of the total population

of England and Wales, while in cities such as London, Bradford, Leicester and Leeds, South Asians make up the majority of the inner city population [12]. Almost half of the ethnic minority population of England and Wales (45%) lives in London [11], with the largest groups being Asians (18.5%), followed by black African and Caribbean people (13.3%) [11]. East London has one of the most ethnically diverse populations, with South Asians being one of the largest ethnic minority groups [11]. Compared to other regions in London, East London also has a higher proportion of people with a lower socio-economic status [12]. This paper seeks to interrogate the meanings and understandings associated with home as a place of care at the end of life by reporting aspects of a study of the views and experiences of older South Asians living in East London relating to end-of-life care.

Methods

Recruitment

This was a qualitative study involving focus groups and semi-structured interviews. We recruited older South Asians to the study through local community organisations based in the East London boroughs of Tower Hamlets, Hackney or Newham. Members of these organisations were eligible to participate if they: (1) self-classified as being South Asian; (2) were aged 50 years or over; (3) could speak Tamil, Malayam, Telugu, Hindi, Urdu,

Gujarati, Bengali or English; (4) were able to give written and informed consent; and (5) had not been bereaved in the previous six months.

Following discussion with community organisation leaders, open meetings were conducted to inform members of the nature and purpose of the study. Community leaders publicised the study by displaying posters and giving study invitation letters to their members, which included a card to return to indicate their interest to participate. MV then approached potential participants to determine if they met the study inclusion criteria. For those who did meet the criteria, and remained interested in participating, an information sheet was provided and verbally explained, before written informed consent was requested.

Fieldwork

Focus groups were conducted with a minimum of six and a maximum of 12 participants. Participants were allocated to focus groups on the basis of their ethnicity. Men and women were interviewed in separate groups. Four groups were conducted in community halls and one in a participant's home, at the request of group members. Four focus groups were facilitated by MV in the preferred language of the participants (Tamil, Malayam, Hindi and English). An interpreter assisted MV in facilitating one focus group with Bengali speakers. In most cases, participants used a mixture of their own language and English, reflecting their day-to-day language. The focus groups lasted between 45 and 90 minutes. Focus

groups were used to access and explore participants' experiences, expectations and beliefs about end-of-life care and to generate data to inform the subsequent interview phase of the study [13]. Focus groups started by attempting to build a rapport with participants by talking about their life history, country of birth, cultural festivals, local temples and religion[14]. This enabled a transition into a discussion of more sensitive topics, including the experience of growing older in a foreign country. An aide memoire then guided discussions towards experiences of, and thoughts about death, dying and care at the end of life. Individual interviews were conducted; depending on the participant's wishes, in their own home, the home of a family member or in the community group meeting place from where they were recruited. Interviews were conducted in the participant's preferred language (Tamil, Malayalam or English). The interview aide memoire was refined on the basis of the findings of the earlier focus groups along the broad subject areas of: providing end-of-life care at home, caring for dying relatives, end-of-life care discussions and decision making. Recruitment was discontinued once three consecutive interviews raised issues similar to those elicited in earlier interviews [15]. As there was a risk that discussions about ageing and late life, end-of-life and loss could be upsetting to participants, information about how to access bereavement support services was provided to all those who took part.

Data management and analysis

The audiotapes from the focus groups and interviews were initially transcribed into the languages spoken by participants and then into English. To enhance accuracy of the transcription process, the transcripts were verified by a second translator and also checked against field notes taken at the time of data collection[16] .

Data analysis conformed to the set of flexible principles and practices described by Charmaz[15], which involved three steps. The first step was constructing initial codes by using line-by-line coding in NVivo version 8. The second step involved grouping the initial codes into sub-categories, which were then reduced into categories. Finally the categories were reduced into one core category in the hierarchal structure. All researchers (MV, AA & JS) met at frequent intervals to discuss and agree the development of the analysis. Ethical committee approval was gained prior to the start of the study (Camden & Islington Community Local Research Ethics Committee: 08/H0722/10).

Findings

Five focus groups and 29 in-depth, semi-structured interviews were conducted with a total of 55 participants recruited from 11 community organisations. The participants' characteristics are shown in table 1.

Table 1 Characteristics of Study Participants

Type of Data	Gender	Primary language of the participants	Actual language of data collection	By origin of their Country	By Religion
Interviews (n=29)	13 Males 16 Females	8 Bengali 4 Punjabi 4 Gujarati 9 Malayalees 2 Urdu 2 Tamil	8 English 15 Mixed English and their own language 2 Tamil 4 Malayalam	8 Bangladeshis 17 Indians 2 Pakistanis 2 Sri Lankans	10 Muslims 3 Sikhs 11 Hindus 4 Christians 1 Non religion
Focus groups (n=5)	2 Male 3 Female focus groups	1Tamil 1 Malayalee 1 Gujarati 2 Bengali	2 English 2 Mixed English and their own language 1 Bengali	1 SriLankan 2 Indian 2 Bangladeshi	2 Muslims 1 Christian 1 Hindu 1 Mixed

Two key themes were identified that shed light on meanings and understandings of dying at home. The theme of 'reconsidering the homeland' highlights participants' ideas about returning 'home' and 'laying down new roots', while the second theme, 'home as a haven', describes participants' accounts of how they perceived home to be a place in which it is possible to perform various cultural and religious rituals.

Reconsidering the homeland

Many of the older South Asian participants in this study often referred to their experiences of the culture of their homeland and their memory of practices surrounding death and dying. This was particularly notable amongst those who retained economic and social ties to their country of origin. Findings revealed two patterns of attitudes: 'returning home', and 'laying down new roots'.

Returning home. When looking towards the end of their lives, many participants spoke about their earlier lives prior to emigrating to the UK. For some, returning to their country of origin at the end of their lives was a deeply held aspiration, although they were aware that this could be considered idealistic and accepted that they now had dual identities. When talking about 'going back', most of these participants believed that this would enable congruence between the end and the beginning of their lives. Many claimed that dying in their 'own soil' or their own village would allow for a peaceful death:

Kamruz: Yes. I would like to die in Bangladesh. May God prove my wish? Definitely I love to die on my own Bangladeshi soil. Yes I am British. This is my country as well. But I was born in Bangladesh. I came to this country during my adulthood. I adopted this country. I love this country as well, but for my death, my own village will be the best place to die.

MV: Could you tell me more?

Kamruz: Because I was born there. I want to die there. Because that will be more comfortable than dying here actually [Kamruz, Bangladeshi male aged 58].

Participants acknowledged that returning to the country of their birth would be costly and that both the expense and the decision would be the responsibility, at least in part, of their adult children. This issue raised uncertainties among some about what would be decided by their children:

Some people they send their father and mother back to Bangladesh … It is happening to 50% of our communities. If you go and check-in any one flight, you will find one or two people who will be going back to Bangladesh for their last days….Because the thing is, these old people were born and brought up back in Bangladesh. So they still love their childhood memories. They want to go back. Sometimes if our people don't have money, their children will take out a personal loan and send them back home to live out their last days [Jameela, Bangladeshi woman aged 62].

The need to return to the homeland did not necessarily have to occur prior to death. One man expressed a wish to have his ashes returned to, and scattered in, India:

Yes, once I told myself that I would rather be cremated than buried. I want my ashes to be sprinkled in river called 'Barathapuzla' (in Kerala, in Southern India) [Sivasakthi, Indian Malayalee male aged 75].

Laying down new roots. For other participants the notion of 'going back' was seen as a retrograde step that held little attraction. This group of participants talked about how they had laid down new roots and how subsequent generations of their family were settled in the UK with little knowledge of the life that their parents and grandparents had left behind:

No. My son was born and brought up here. I think he will make me to stay here, that's what I'm led to believe [Halima, Bangladeshi woman aged 64].

For these participants, returning to the homeland was not a viable option. Some explained that as well as having family ties in the UK; connections with their country of origin were now loose or non-existent, so even if the idea of returning held some emotional or romantic appeal, it was impractical:

Vanaja: My family is settled here, so why should we go back?

Mariyanayaki: Another thing is that no-one is there in our country. Our children and our grandchildren are here, so what is the purpose in going back?

Kamala: I think at my age, nobody wants to go. We want people in our own country to care. But if no one is there, what is the point in going back? (Focus group with Indian Malayalee women).

Vimala: Actually it is a question of emotion and practicality. You might decide emotionally that you would like to go India, but if you think practically, we cannot go to India [focus group with Gujarati Women].

All participants felt strongly attached to the cultural heritage of their homeland but were concerned that this might be lost over subsequent generations. For this reason, they talked about the importance of maintaining and nurturing their heritage so that it would survive across subsequent generations of relatives living in England:

Sreeja: India is our root. We shouldn't forget our culture. It should go through all the generations. At the end of the day, it is our culture. We can still respect our culture even if we are not in our own country, so that we won't lose our culture. Then we wish we could send our ashes back to India.

Jayanthi: If we don't follow our culture, our son or daughters will not do the same for us. They won't care for you when you are dying. But some people will die here and send their ashes to India. [But] my daughter said to me, look mum. If you die, I am going to spread your ashes here. I don't want to fly to India for that [focus group with Indian Malayalee Women].

Home as a haven

Most participants reported that home provides space for religious practices and cultural rituals at and around the time of death. They talked about how being at home gives an opportunity for a dying person to complete their familial responsibilities and for the family to show their allegiance to the dying person. Participants also reported that home was an environment where the family could find safety and comfort while providing care, and in turn provide a private space and a sense of security, so that those who were dying could do so peacefully.

Home as a religious place. Many participants had a sense of what constituted a 'good death'. However, participants were realistic about what was attainable and were clear that compromises would have to be made. The domestic home played a central role in this, both as a place where religious rituals could be practised at and around the time of death, and as a place in which deeply held cultural values of family obligation and respect for one's parents could be honoured:

A true Muslim should die at Mecca, or Medina, and facing east. The Day of Judgment comes there. If it is not possible, then he should die at home with his family around him. And also, dying on a Friday is considered to be a good death. People say it is a blessed death (Amir, Pakistani male aged 58).

I want someone to be near me so they can pray. But it won't happen if we die in hospital. I would prefer to have my children with me, and if that's not possible, then I at least want to be with someone that I can trust if am conscious. If am not conscious, I don't know. But I will be pleased to have someone stay with me and pray to God when I die. I would prefer to die in a nice way, and be with someone who can pray to Jesus. I need someone to whisper prayers in my ears. In our community, we call the priest. That is very important in our religion [Mariyanayaki, Indian Malayalee woman aged 68)].

Views of home as a place where religious needs at the point of death could be met contrasted sharply with most participants' perceptions of what death might be like in hospital. There was a belief that dying in hospital would restrict the family in their ability to perform caring and religious tasks and in providing comfort:

If it is at home, we can do our prayers like in my country, if someone dies we give something, like we can give some water and thank God, which is nice for the person who is going to die. But in hospital, I don't see it like that [Rajeswari, Gujarati woman aged 58].

However, a few participants felt that the death of a loved one at home might make it difficult for the family to subsequently stay and live in the same home. For example, one woman was particularly concerned about how her husband and family would feel about continuing to live in a house in which her own death had occurred:

It is hard to die at home. That is not a good way. If I die at home on the same bed and in the same room, my husband will feel this for the rest of his life. So, it is not a good thing to do. Our children also will feel that their mother died in their house with a lot of suffering. This is too bad for me. If I die suddenly, all you will think of is where your mum died. Will you able to see while your mum dies? [Gujala, Indian Malayalee woman aged 68].

Similarly, participants who lived alone or without children tended to argue that hospital would be more suitable as a place of death since living with extended families in the limited space available in their London homes was impractical. For those in this situation, familial religious practices conducted at home at the end of life seemed to assume less significance:

Yes. I do like to do prayers and pujas for when someone is dying at home. But it may be a concern for the one who has a lot of people in their home. But we are only two in my home [Sreeja, Indian Malayalee woman aged 72].

Here there is a further element of compromise in which the perceived value of religious practices and the practicalities of living alone are balanced. Participants often sought to adapt to the culturally unusual situation of living at great distance from their children, something that would be unthinkable if they were still living in South Asia.

Finding safety and comfort. Alongside the perception that home created an opportunity to engage in religious practices, most of the study participants reported that home would provide a comfortable physical environment for the dying person. This sense of comfort was made up of: privacy, a sense of security, lack of disruption to the practice of customs, being around family, a calm and clean environment and the ability to observe a traditional mourning process. Most participants reported that they believed that their homes provided security and comfort in a way that hospitals would not. There was a sense that the everyday activity of a busy hospital would impede the peace needed at the end-of-life. The emotional climate of the home could be regulated while hospitals were considered too busy, too crowded and non-private:

I prefer home. I will not go to the hospital. That is a dangerous place and so crowded. No, no, and no. During the last days any man and woman wants to have a quiet and private place where only relatives can stay with the patients [Kamruz, Bangladeshi male aged 58].

However, participants also highlighted that with no extended family to provide support, and with adult children who often struggled to manage their own day-to-day commitments, the time-consuming nature of care, lack of space, and lack of social commitment would encumber the home as a place of care in the UK:

It is easy in our country. Although it was a poor country but still it was easy. But here there are lots and lots of problems, lots of restrictions, lots of time consuming and space extra. It is very, very hard. Although they think that they can look after their parents, but it is not possible. It is not good for the older people and also it is not good for the family who want to do that [Syam, Bangladeshi male aged 74].

Some participants believed dying was likely to be better managed in hospital than at home. These participants argued that it would be burdensome for the family to manage a dying person at home and those hospitals could provide better care for dying people:

It is very hard to tell, because it depends. People love to stay at home. I know that. But during that time, home is not sweet home. Because other people, how can they care for the

patients at home? That is different for the person-to-person or environment-to-environment or patient-to-patient, isn't it? Some patients are in a vegetative state and don't know what's going on. But they still want to stay home. But it is hard for the relatives and friends to look after those kinds of patients, especially if the hospital is not giving proper support like nursing or providing them with trained carers for the last couple of days [Vasantha, Punjabi woman aged 64].

Some participants argued that, irrespective of the place, a calm and clean environment was essential for a comfortable and peaceful death in which it would be possible to pray for the deceased and begin preparations for the burial:

The best thing is a clean environment, either in a hospice or a home; this is most important to terminally ill person. And also, as a Muslim or whatever the faith a person has, the holy books should be recited with tolerable sound [Shohail, Bangladeshi Muslim aged 61, in focus group with Bangladeshi men].

Discussion

There is growing evidence about the palliative care needs of diverse groups (16-19), but less evidence as to what may help to explain cultural differences in preferences for place of death (12,27-29). In this qualitative study, the views of older South Asian people living in East London about the meaning of home at the end of life were explored.

This study found that when most respondents considered their own death, their thoughts turned to their homeland - the countries from which they had emigrated. Diaspora is a concept that is commonly used to refer to the experiences of Jews, invoking their traumatic exile from an historical homeland and dispersal throughout the nations [17-19], and more recently as a source of cultural identity [18]. Applying this concept to the data in this study

draws attention to the importance of participants' observations in relation to 'homeland' and, at least aspirationally, as a place to consider living out the final stages of life or for returning after death. Similar findings were reported in a study of Bangladeshi carers living in East London [20].

While returning to the homeland for the last days of life was an aspiration for many participants, it was also regarded with ambivalence and seen as a challenge. Some perceived that the social networks that existed prior to their emigration no longer existed. Existing research suggests that migrants from South Asian countries increasingly view 'home' as where their family lives, leading to a new understanding of 'homeland' in terms of cultural values [20]. This observation resonates with the perceptions of South Asian participants in the current study.

Consistent with other studies[21-24], we also found that some participants perceived that dying in settings other than their home would create a barrier between them and their family and in particular, was seen as hindering opportunities for cultural and religious practices seen as essential to peaceful death. Previous studies have highlighted the importance of religious aspects in the delivery of end-of-life care, particularly among ethnic minorities[20, 25-28]. For instance, a study of Bangladeshi caregivers in East London found that South Asian people express a need to conduct religious practices during death and dying [20].

Many older people in this study were conscious of the complexities and practical difficulties of expecting their children to care for them at home. These findings are supported by studies of social network theories[29-31], which suggest that changes surrounding family and kinship mean that presence of family at the time of death is no longer assumed. Although study participants preferred family to be around them to perform religious duties, they accepted the need to be flexible to fulfil their religious responsibilities, or at least to achieve a comfortable death.

Limitations:

Findings from our study provide new insights into the perspectives on death and dying among older South Asians living in East London. However, these findings need to be considered alongside the methodological limitations of the study. This study was conducted by an interviewer who belongs to a South Asian ethnic sub-group. The 'insider' identity of the interviewer (MV) may have influenced data content and quality. Furthermore, we are aware that some dominant voices (i.e. Community leaders) had an impact on the study findings. At times the presence of 'third party' others (including family members and friends) during some interviews and their interruption into the flow of conversation may also have had an impact on data quality. Finally, the age and gender of the interviewer (MV), (young and male), meant that some female participants may not have felt completely free to discuss sensitive subjects.

Conclusion

This qualitative study of the accounts of older South Asian people living in East London has shown us that when considering death and dying, the notion of 'home' gives rise to considerations which range far beyond those of physical locale. 'Home' was regarded by older South Asians as space for exercise of religious and cultural practices around the time of death, and a place in which it was possible for the person who was dying to gain comfort from the presence of those close to them. In contrast, dying in settings other than their home was seen as potentially creating a barrier between the dying person and their family and providing little opportunity for religious and cultural practices. However, these ideas were balanced with considerations of burden on the family that may flow from care of the dying. When most respondents considered their own death, their thoughts turned to their homeland - the countries from which they had emigrated- but they balanced aspirational and idealistic notions of 'homeland' with pragmatic considerations associated with living and establishing new roots in the UK. An emphasis on the importance of adaptation, while preserving cultural identity, was visible.

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Conflict of interest statement

None declared

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Appendix 1

Table 1 Study Participants Characteristics

Type of Data	Gender	Primary language of the participants	Actual language of data collection	By origin of their Country	By Religion
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