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**Talking about end-of-life care: the perspectives of older South Asians living in East London**

The National End-of-life Care Strategy for England identifies that a lack of open discussion about death and dying can be a barrier to achieving good quality end-of-life care. South Asians constitute the single largest ethnic minority group in the United Kingdom, yet little is known about their attitudes and expectations towards the discussion of death and dying. In this study, set in East London, five focus groups and 29 in-depth, semi-structured interviews were conducted with total of 55 older adults aged between 52 and 78 years. Participants from six South Asian ethnic groups were recruited from 11 local community organisations. Constructive grounded theory was used as data analysis approach. Findings revealed two key themes which capture the perspectives older South Asian study participants had towards end-of-life care discussions. The theme ‘avoidance as a cultural norm’ relates to the relative absence of discussions around death and dying experienced participants. Participants neither expected to have discussions about their own death and dying within their family, nor to assume any involvement in related issues of decision-making. The second theme ‘avoidance as protection’ relates to beliefs and experiences about the delegation of decision making to family members. Future research should explore the perspectives of second-generation adult children towards end-of-life care discussions.

**Key words:** Advance care planning, Minority ethnic, End-of-life care, Qualitative, South Asians, Death and Dying

## INTRODUCTION

The National End-of-life Care Strategy for England identifies 'the lack of open discussion between health and social care staff and those approaching the end-of-life and those who care for them, as one of the key barriers to the delivery of good end-of-life care' (p50)(DH, 2008). There is some evidence that lack discussion may result in patients receiving end-of-life care which is out of step with their wishes (Wright et al., 2008). Recently, the concept of advance care planning (ACP) has been introduced, which means a 'voluntary process of facilitating any discussions and review between patients, health care professionals and family members or other significant members to set an record of choices or decisions about future care in the event that they lose capacity to decide once their illness progresses' (p5) (Henry and Seymour, 2008). Recent evidence about the outcomes of ACP shows that it helps to avoid unwanted hospitalisation and achieve better end-of-life care (Detering, 2010; Zhang et al., 2009). ACP is dependent upon the willingness of patients, family carers and staff to talk about difficult subjects. However, evidence suggests that end-of-life care discussions between patients, carers and professionals remain uncommon and very little is known about the initiation, timing, nature and quality of such discussions (Momen et al., 2012). Almack et al., (2012) have shown that both patients and health professionals tend to wait for the other to initiate conversations and that this can result in missed opportunities.

Health professionals providing care in multi-cultural environments have been shown to experience several dilemmas, such as ambivalence, ignorance or uncertainties (Gunaratnam, 2001; Vydelingum, 2006) due to their lack of cross-cultural end-of-life

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care knowledge and skills (Diver, 2003; Richardson et al., 2006). In such situations, health professionals may adopt a ‘culturally distant position’ (Randhawa and Owens, 2004). In palliative care contexts when working with people of an unfamiliar culture and background, this stance may hinder their ability and confidence in initiating end-of-life care discussions (Diver et al., 2003; Owens and Randhawa, 2004; Richardson et al., 2006).

**Background**

Asians, primarily South Asians, constitute the single largest ethnic minority group in the UK (ONS, 2001). Most of the older South Asians living in the UK are first generation immigrants (Ballard, 1994; Hatton, 2005). Although there are traces of acculturation-a process of immigrant communities selective adaptation, and integration with the value and culture systems of host community-in such communities (Gilbert and Khokhar, 2008; Palmer et al., 2007; Robinson, 2005; Smith, 2000), older South Asians may prefer to retain or refer to their original cultural beliefs when faced with critical life events such as death and bereavement (Spruyt, 1999). Blakemore (2000) highlights that growing older in a ‘foreign country’ is associated with multiple social disadvantages such as poverty, inadequate health care and poor housing; these may render immigrants ‘vulnerable’ members of society. This may lead them to either hide or fail to disclose their wishes and preferences for care, or lead them to push themselves to learn to live in an ‘ethnocentric society’ (Vydelingum, 2006).

Research demonstrates that older people from ethnic minorities tend to under-use available palliative and end-of-life care services (Ahmed et al., 2004; Jones, 2005;

NCHSPCS, 2003; Worth et al., 2009). Some argue that there is a lack of 'cultural transferability' in existing Western palliative service models which may make them unacceptable to some non-western people (Gunaratnam, 2001; Nyatanga and Molassiotis, 2003). In addition to this language barriers (Diver et al., 2003; Jack et al., 2001) may there are barriers to access of reliable information about end-of-life care services, such as hospice and cancer care facilities (Elkan et al., 2007; Randhawa and Owens, 2004). This may significantly impede awareness and uptake of palliative care services (Jones, 2005; PRIAE, 2006; NCHSPCS, 2003).

### Study Purpose

This paper reports one aspect of a larger study and focuses on the perspectives of older South Asians living in East London towards talking about death and dying. Existing research already evidenced views from patients (Samsi and Manthorpe, 2011; Singer et al., 1998); different health care professionals on end-of-life care discussions (Seymour et al., 2010; Taubert and Nelson, 2010). In spite of well-defined English policy and legal directives propose the culture to embed initiating end-of-life care discussions as routine clinical practice (DH, 2008; DH, 2011), yet concerns around initiating end-of-life conversations with ethnic minorities remains uncharted. This paper seeks to extend the very limited evidence regarding initiation of end-of-life care conversations among older South Asian ethnic minorities living in East London.

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**Methods**

***Recruitment***

This was a qualitative study involving focus groups and semi-structured interviews. Older South Asians were recruited 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 self-classified as being of South Asian ethnicity; were aged 50 years or over; could speak Tamil, Malayam, Telugu, Hindi, Urdu, Gujarati, Bangali or English; were able to give written and informed consent; and 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. Interested individuals were able to seek further information from MV. 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 approached potential participants to determine if they met the study inclusion criteria. For those that did meet the criteria, and remained interested in participating, an information sheet was provided and explained and written consent 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 as preferred by the participants. 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 (Tamil, Malayalam, Hindi and English) of the participants. 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. The focus groups lasted between 44 and 90 minutes. Focus groups were used to access and explore people's experiences, expectations and beliefs about end-of-life care in their own terms and to generate data to inform the subsequent interview phase of the study (Merrell et al., 2006; Kuo and Fagan, 1999). A preliminary aide memoire that was developed from existing literature guided the discussions that included experiences of and thoughts about end-of-life and end-of-life care. Focus groups usually started by attempting to build a rapport with the participants by talking about their life history, country, cultural festivals, local temples and religion (Seymour et al., 2002). In turn, this enabled a transition into a discussion of more sensitive topics, including the experience of growing older in a foreign country.

All individual interviews were conducted by MV, depending on the participant's wishes, in their own home, the home of a family member, or in the community group from which 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 (providing end-of-life care at home, caring for dying relatives, gender in end-of-life care, end-of-life care discussions and decision

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making). Recruitment was discontinued once three consecutive interviews raised issues which were similar to those elicited in earlier interviews, i.e. theoretical saturation was achieved (Charmaz, 2006 ). As there was a risk that discussion about late life, end-of-life and loss could be upsetting to participants, they were all given information about how to access bereavement support services. Ethical committee approval was gained prior to the start of the study (Camden & Islington Community Local Research Ethics Committee, London: 08/H0722/10).

***Data management and analysis***

The audiotapes 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 (Twinn, 1997) .

Data analysis conformed to the set of flexible principles and practices described by Charmaz (2006 ), which involved three steps. The first step was constructing initial codes by using line-by-line coding in Nvivo version 8. This resulted in identification of 627 initial codes. The second step involved grouping the initial codes into 14 themes, which then reduced into six sub categories. Finally the six sub categories were reduced into three categories and then into one core category in the hierarchal structure. MV independently developed initial categories then met with his supervisors (AA and JS) at frequent intervals to discuss and agree the development of the analysis. This paper reports the category the ‘meaning of end-of-life care discussions’.



## 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 Study Participants' Characteristics**

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

In this study, many participants reported that they were not used to discussing death and dying or aspects of decision making, either for themselves or for others. Our data analysis revealed two themes relating to 'avoidance' which together help to explain the relative absence of discussions around death and dying reported by participants: 'avoidance as a cultural norm', and 'avoidance as protection'.

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**Theme 1 Avoidance as a cultural norm**

There was a clear absence of experiences of discussions related to death and dying among the older South Asians who took part in this study. This included participants who were quite willing to express in the interview context some end-of-life care preferences. However, these individuals reported that it would be ‘highly unusual’ in their community to have discussions about such issues or to make any future plans and decisions concerning death and dying:

*Yes, discussing and planning would be fantastic. But there is hardly any such planning in my community. We don’t plan for death. Today, it is highly unusual for me to be talking about death* (Kamruz, Bangladeshi male aged 58).

Living as part of an extended family was claimed as a rationale for a common perception that it was unnecessary to have discussions involving death and dying. Many believed that their family would ‘know what to do’ and would do what they could for them when it was their time to face death and dying. Moreover, it was clearly indicated by some that pre-planning is unnecessary, since any decisions will depend on ‘family circumstances’:

*No I never thought of discussing my death. Because the reason is, it all depends on their circumstances. My family lives with me, and according to them, they know what to do. They will do that what they can* (Prakash, Gujarati male aged 76).

Participants described various beliefs with regard to discussing death and dying, including waiting until the end of one’s life to discuss such things, the uncertain

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3 nature of death, and family preferences for not engaging in any decision-making  
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5 discussions. In addition, participants reported how they expected that discussing death  
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7 and dying would bring illness and death forward. Importantly, some described how  
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9 their family had asked them not to 'think about it yet' perhaps when they had  
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11 attempted to discuss it. Those participants who had experienced this communicated  
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13 that they perceived that such family restrictions were helpful to them in the sense that  
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15 they avoided causing distress and helped them to keep a positive attitude:  
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20 *MV: You said that you want to be kept at home when you are dying. Did you ever think at*  
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22 *any time if such decisions needed to be discussed with someone?*  
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27 *Kanjana: When the time comes, I will. My daughter told me that I shouldn't think about*  
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29 *it yet. When you start thinking about it, you get very sick. We don't know when, or what*  
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31 *will happen to us (Kanjana, Bangladeshi woman aged 58).*  
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35 Others argued that positive thinking in late life (with the hope of living longer) might act  
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37 as a barrier to thinking about one's own death and dying. They claimed that initiating  
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39 discussions and making decisions usually takes place within the family when the health  
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41 of older individuals deteriorates towards the final stages of their life. Interestingly, some  
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43 acknowledged their own preferences in relation to the last days of their life, which  
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45 included their preference of dying at hospital and the use of life prolonging treatments.  
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47 However, until their 'ripened stage', they preferred not to hold such related discussions  
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49 with their family: They pointed out that age and health status would remain factors that  
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51 influence their preference to participate in end-of-life discussions and decision making.  
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*MV: So, did you have informed your son that you have plans concerning the end of your life?*

*Ramalingam: I have not reached that stage yet. Because I feel, I will be living for more years. In that ripened stage, I will discuss these types of things with my son. So that stage has not yet arisen*’ (Ramalingam, Sri Lankan Tamil male aged 78).

Similar to above participant, most of them in this study highlighted that not only the culture of avoiding discussion, but also a denial to accept death at old age would also impede such discussions. Other participants refused to talk about death in their interview demonstrated that denial to accept death at an old age would be another factor linked to avoidance of discussions. Instead, they claimed that they trusted that their children would ‘carry out everything’ for them:

*MV: Could you tell me why you do not like to talk about such topics?*

*Neela: I think you don’t want to die. You know (laughs) you don’t want to die, or even think about it.*

*MV: If not, what will happen?*

*Neela: My children will carry out everything for me*

*MV: Is it belief or expectations?*

*Neela: It is trust* (Neela, Indian Malayalee woman aged 74).

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3 Other participants stated that generally in South Asian families, children would avoid  
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5 discussing death and dying, or involving older relatives in any such discussions. They  
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7 said that the family would come forward to take their responsibility, and make any  
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9 necessary decisions on behalf of their older relatives, and thus shelter their older  
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11 relatives from topics perceived to be unpleasant to avoid distressing them:  
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16 *I don't think people ask where you die. I think the family makes that decision* (Simrita,  
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18 Punjabi woman aged 72).  
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22 A few participants reported that although they would trust children as decision  
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24 makers, they expected these decisions to be based on their preferences, which they  
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26 would share with their children when they became terminally ill:  
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31 *MV: Have you spoken these decisions to any one?*  
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35 *Malar: No. I never spoke [laughs]. I used to keep it in my heart. I did not tell my*  
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37 *daughter. Yesterday, I gave some money to them and told them to keep the money, and if*  
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39 *anything happens to me, they should use that money.*  
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42 *MV: So, you made some decisions?*  
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46 *Malar: No. I did not. I have my children with me to decide. When the stage comes, I will*  
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48 *tell them about my preferences. When I go to their house, I will tell them that I want to go*  
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50 *back to India and die, like my husband* (Malar, Indian Malayalee woman aged 68).  
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**Theme 2 Avoidance as protection**

Our data analysis also revealed that another barrier to discussions about death and dying was the perceived need among participants to avoid any early discussions featuring the subjects, in case this upset their family members. In turn, participants reported how their families also would try to protect them from the adverse effects of discussing such inauspicious and discouraging topics. In addition, some participants reported that avoidance was also enforced because of their language barriers.

Participants indicated that discussions around death and dying with their family were difficult to initiate. Some reported that they had had opportunities to discuss with their family member, however, they said that their family refused to discuss these issues with them, and encouraged them to think positively:

*MV: What discussion did you have about this?*

*Baseema: I haven't yet decided [she laughs].*

*MV: So you haven't had any discussion with anybody?*

*Baseema: No. I try to talk to my son. But he does not like to discuss these things. He says that you have only turned sixties. He is soft and he is a completely different type of child. He doesn't want to discuss things related to death. He doesn't even want to listen (Baseema, Bangladeshi woman aged 64).*

Some took a positive stance towards the idea of planning and talking about end-of-life issues but said that they could not discuss any issues that could impact on the occurrence of any auspicious or religious events at home. This reflected a culture in which talking

about death and dying is a taboo subject within the family and customs in South Asian culture whereby people would prefer not to use words related to death and dying at home:

*MV: You said you didn't want to discuss your preferences about the final stages of your life. Could you tell me what stopped you thinking that way?*

*Archana: I don't know when I am going to die. Whether I will be here or in India at the time? Yes. It is good to plan these things, but it would be better to start planning now, although it may not be a good plan in the future. But I don't want to discuss anything now*

*MV: Ok?*

*Archana: Yes, because, my daughter is getting married this year. So I don't want to upset her (Archana, Gujarati women aged 74).*

Some participants argued that early discussions within their family would be unproductive, as their children would refuse to listen if they initiated any discussion about their death and dying. They said that instead they preferred to discuss these issues with their friends or people in their age group who had similar concerns:

*Rajendran: May be another person of my same age, with the same concerns might be more suitable to discuss these things with. See for example, if I go and tell my son that I am talking about the end of my life, they ask me if I don't have anything else to do? That is the answer.*

*MV: So you don't discuss anything with your family then?*

*Rajendran: No. They're not interested. They won't want to. They see me the way I am, and won't understand why I'm thinking about things that haven't happened yet. Do you understand what I am saying? The thinking stage will come in its own time. But the companion of similar this one will be good.*

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*MV: Have you ever discussed anything?*

*Rajendran: No. we always thought think positively, not negatively (Rajendran, Indian Malayalee man 65).*

In contrast, some participants claimed that practical difficulties were the reasons for avoidance. They reported that language difficulties prevented them from being involved in any discussions or decisions with doctors about end-of-life care when their loved ones were ill. They assumed instead that the doctors had discussed with their children any decisions that needed to be made during the last days of their loved one's life:

*No he did not say anything to me or my husband. But, because he too was not able to speak English, the doctors might have been able to discuss this with my children. But they did not tell us because we felt very bad. But from the way they spoke and their faces, I was able to understand that my husband was serious. But he did not know what the doctor said (Chitra, Indian Malayalee woman aged 67).*

**Discussion**

This study sought to examine the attitudes and beliefs expressed by older south Asians towards the discussion of end-of-life care issues. Initiating or being involved in any end-of-life discussions within their family was neither expected, nor was any involvement assumed in related issues of decision-making, by the study participants. Instead, they placed trust in their families to discuss their needs with health care professionals when the time comes, and take any decisions required on their behalf. The findings of this study are consistent with existing literature that has reported limited open discussion of



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3 death and dying among South Asian Sikh and Muslim patients with life-limiting illness in  
4 Scotland (Worth et al., 2009). More generally, a NatCen (National Centre for Social  
5 Research) survey (2009) reported a decreasing trend of public engagement in end-of-life  
6 discussions in the UK, with that less than one third of people (29%) compared to 34% in  
7 2006, reporting some sort of end-of-life discussions either with their family or friends.  
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16 One of the reasons reported by the participants in this study for avoidance of discussion  
17 was their preconceptions concerning death and dying. For example, they reported a belief  
18 that thinking about death and dying would bring death closer to them and was thus an  
19 inauspicious topic for discussion. Similar beliefs have also been reported among Muslim  
20 participants in another study (Rashid and Sheikh, 2002), while in a survey of ethnically  
21 diverse people aged over 65 years, ethnic minority elders were more likely than white  
22 elder to express extreme fears about death (Bowling et al., 2010). This finding about  
23 'fear' was echoed by Worth et al., (2009) in their study of South Asian Sikhs and  
24 Muslims living in Scotland.  
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38 In this study, participants also reported that they believed younger family members  
39 wanted to protect them from engaging in conversation about subjects perceived to be  
40 distressing. Participants reported that their family would encourage them to focus on  
41 what were considered more positive aspects of life. Worth *et al* (2009) also reported that  
42 such resistance was a manifestation of common coping mechanisms to avoid feeling  
43 negative, by using positive thinking, fighting spirit, and denial and humour techniques.  
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53 This study finding suggests that there is some ambiguity about the role of family in  
54 contributing to the avoidance of end of life care discussions in South Asian ethnic  
55 minorities. While some participants expressed their preference to discuss with their  
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family and perceived as their family members are to be the final decision makers, others reported that such end-of-life discussions with their family members remain culturally inappropriate. This is in contrast to previous studies, which reported that people tend to prefer to discuss any issues related to end-of-life with family members rather than with health professionals (Kahana et al., 2004; Salmond and David, 2005; McDonald et al., 2003).

Our findings also highlight that preferences to towards the discussion of death related issues are dynamic, and are likely to depend on the family circumstances. A review by Seymour *et al.* (2009) has highlighted that public attitudes towards death, dying and bereavement are ‘highly contextual, contradictory and shift according to the circumstances and past experiences’ (p 4). In the study reported here, participants seemed to use the interviews and focus groups to construct and reconstruct their perspectives and beliefs about death and dying, through narration of their past experiences and through consideration of their current living conditions.

**Methodological limitations**

The scope of these findings is clearly dependent on the methodological limitations of this study. Firstly, exploring such a sensitive topic by an inexperienced qualitative interviewer was a crucial limitation of the study. Secondly, our initial inclusion criteria were broad, to include any older South Asian residents in the selected boroughs of East London; this study attracted some people with dominant voices in those communities. This obviously impacted on the quality and richness of the data. Thirdly, the ethnic subgroup identity of the interviewer (MV) influenced the data content and quality. As MV come from a particular South Asian ethnic subgroup, we observed some participants from other South

Asian subgroups distanced themselves from him. Such distance was evident both in the level of involvement and depth of information that was given during the interview. Finally, the age and gender would have had some influence on the data we collected. Being younger than the participants, culturally they did not feel completely free to discuss sensitive subjects with our interviewer MV in the interviews and focus groups. In addition, gender was another factor important in considering the process by which our data was generated. Being male, MV felt some women participants were reluctant and reticent during the interviews.

### **Implications for clinical practice**

Some evidence is available about the issues faced by health professionals responsible for caring for older South Asian people in hospital (Vydelingum, 2006) and in palliative care settings (Gunaratnam, 2001). The findings from the study reported here provide insights into issues of relevance when caring for older South Asians at the end of their lives. Here we present some practical recommendations about the practice of end of life care communication with older South Asian people and their families (Table 2).

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**Table 2 Initiating end of life care conversations with South Asian ethnic minorities**

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| <p><b>With whom to discuss?</b></p> <ol style="list-style-type: none"><li>1. Do not presume who in the family takes any decision. The right person for making decisions in the family may depend on gender, who lives around and often hierarchy of family system. Sometimes older spouses themselves may be preferred to take their own decisions.</li><li>2. Ascertain older people’s genuine willingness to engage in any individual/private discussions; often they may agree just to mark the respect for the doctors, but may covertly believe their involvement is potential source of family conflicts.</li><li>3. Discuss any issues in detail with their children, who are often considered as more knowledgeable.</li></ol> <p><b>When to discuss?</b></p> <ol style="list-style-type: none"><li>1. The preferred time to discuss is when the older person is diagnosed with life-limiting diseases and in real situations of dying. Often healthy people may refuse such discussions.</li><li>2. Do not hold joint discussion both with family and the dying individual; family will not discuss in detail and openness in front of elders as a mark of respect; do not cause distress.</li><li>3. Adult children may often resist disclosing information to their parents.</li><li>4. Check any life events and festival times before you plan for any discussion.</li></ol> <p><b>Who is the appropriate person to initiate discussion?</b></p> <ol style="list-style-type: none"><li>1. Acknowledge their trust in medical professionals who were highly valued for their knowledge and expertise; build on any discussion from such trust.</li><li>2. Be aware that, though people trust their doctors, negative discussions such as those about death and dying may lead to mistrust about medical decisions.</li><li>3. Use/involve any family members or relatives if any work as health professionals in the discussion.</li></ol> <p><b>How and what to discuss?</b></p> <ol style="list-style-type: none"><li>1. Always remember that talking about death and dying is normally culturally inappropriate and a highly unusual topic. Try not to use the direct words such as death and dying; use alternative terms for example, passing on.</li><li>2. Consider the decisions based on how and where their rituals and family preferences could be well accommodated.</li><li>3. Acknowledge and value their beliefs about alternative health systems when prognosis is poor, and try not to talk against such beliefs.</li><li>4. Make them aware of various available options for the last days of life, such as services to support at home, hospice, and hospital as they may have less knowledge about existing services.</li><li>5. Always consider family circumstances while planning, since family circumstances are paramount important for the dying older people than their own wishes.</li></ol> |
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## Conclusion

As in many cultures, our study findings suggests that older South Asian ethnic minorities may prefer to avoid any discussions around death and dying, mainly because they place trust in their family members to hold such discussions and make decisions. However, as this study represents only the gathered reports of perspectives on end-of-life care discussions, further research is needed to observe end-life-care discussions in 'action' among these ethnic minorities to authenticate our study recommendations. In addition, as our study explored that often in South Asian families, older people trust their adult children to be involved in their end of life care discussions, further exploration of attitudes of their second generation adult children towards end-of-life care discussions is needed.

### KEY POINTS

1. Older South Asians considered that initiating or being involved in any end-of-life discussions and related issues of decision-making within the family were not expected.
2. Often the rationale for an avoidance of end-of-life discussions among older south Asians was their preconceptions concerning death and dying and their changing family circumstances.
3. Older South Asians believed that their younger family members would want to protect them from engaging in conversation about death and dying and encourage them to focus on what were considered more positive aspects of life.

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| 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<br>16 Females             | 8 Bengali<br>4 Punjabi<br>4 Gujarati<br>9 Malayalee<br>2 Urdu<br>2 SriLankan<br>Tamil | 8 English<br>15 Mixed<br>English and their own language<br>2 Tamil<br>4 Malayalam | 8 Bangladeshis<br>17 Indians<br>2 Pakistanis<br>2 Sri Lankans | 10 Muslims<br>3 Sikhs<br>11 Hindus<br>4 Christians<br>1 Non religion |
| Focus groups (n=5) | 2 Male<br>3 Female<br>focus groups | 1Tamil<br>1 Malayalee<br>1 Gujarati<br>2 Bengali                                      | 2 English<br>2 Mixed<br>English and their own language<br>1 Bengali               | 1 SriLankan<br>2 Indian<br>2 Bangladeshi                      | 2 Muslims<br>1 Christian<br>1 Hindu<br>1 Mixed                       |

254x190mm (96 x 96 DPI)

Figure 2: How to initiate any end of life discussions with South Asian ethnic minorities?

**With whom to discuss?**

1. Do not presume who in the family takes any decision. The right person for making decisions in the family may depend on gender, who lives around and often hierarchy of family system. Sometimes older spouses themselves may be preferred to take their own decisions.
2. Ascertain older people's genuine willingness to engage in any individual/private discussions; often they may agree just to mark the respect for the doctors, but may covertly believe their involvement is potential source of family conflicts.
3. Discuss any issues in detail with their children, who are often considered as more knowledgeable.

**When to discuss?**

1. The preferred time to discuss is when the older person is diagnosed with life-limiting diseases and in real situations of dying. Often healthy people may refuse such discussions.
2. Do not hold joint discussion both with family and the dying individual; family will not discuss in detail and openness in front of elders as a mark of respect; do not cause distress.
3. Adult children may often resist disclosing information to their parents.
4. Check any life events and festival times before you plan for any discussion.

**Who is the appropriate person to initiate discussion?**

1. Acknowledge their trust in medical professionals who were highly valued for their knowledge and expertise; build on any discussion from such trust.
2. Be aware that, though people trust their doctors, negative discussions such as those about death and dying may lead to mistrust about medical decisions.
3. Use/involve any family members or relatives if any work as health professionals in the discussion.

**How and what to discuss?**

1. Always remember that talking about death and dying is normally culturally inappropriate and a highly unusual topic. Try not to use the direct words such as death and dying; use alternative terms for example, passing on.
2. Consider the decisions based on how and where their rituals and family preferences could be well accommodated.
3. Acknowledge and value their beliefs about alternative health systems when prognosis is poor, and try not to talk against such beliefs.
4. Make them aware of various available options for the last days of life, such as services to support at home, hospice, and hospital as they may have less knowledge about existing services.
5. Always consider family circumstances while planning, since family circumstances are paramount important for the dying older people than their own wishes.

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