



**School of Nursing, Midwifery  
and Physiotherapy**

**Understanding home, homeland, and family at the end of life:  
a qualitative study of older South Asians in  
East London**

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## Abstract

**Background:** 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 and its related care.

**Aim:** To explore and critically examine views and perceptions about end of life issues among older South Asians living in East London.

**Methodology and methods:** After gaining ethical approval, five focus groups and 29 in-depth, semi-structured interviews were conducted with 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 through 11 local community organisations. Where possible the focus groups and interviews were conducted in the participants' preferred language. Tape recorded multilingual data were translated and transcribed into English. Using a constructive grounded theory approach, data analysis resulted in the development of a theory of “continuity and reconstruction” that captured three categories of ‘home’; ‘family’ and ‘trust’ at end of life.

**Findings:** The theory of “continuity and reconstruction” is explored in three ways. Firstly, the theory is explored through examination of beliefs, attitudes and expectations about the place of ‘home’ and ‘homeland’ in care of the dying. Secondly, the theory is explored as accounts of “family” in terms of how family are bound towards caring for their dying relatives at end of life and the importance of support from social networks in family care giving. Finally, the theory is explored in terms of how participants place “trust” in their family and medical professionals to lead any related discussion and to make decisions related to their death and dying.

**Conclusion:** The theoretical framework of “continuity and reconstruction” explains how older South Asians make efforts to adhere to important social and cultural values relating to death and dying, while rebuilding and adapting those values during the challenges of living in an emigrant society. This study highlights the need for further exploration of family care giving needs among South Asian population and concludes by drawing attention to some practical implications for health professionals who are responsible for initiating end of life discussions and are involved in end of life decisions when caring for people from these ethnic minority groups.

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*“Your mother, father, and your teacher are the visible Gods”*

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## CHAPTER 1

# Introduction

This opening chapter consists of three sections. The first introduces the study by presenting the genesis, context and purpose of the research. The second describes my personal motivations, which include my ethnic background and personal experience of providing end of life care. After explaining the terminologies used in this study, the final section provides a brief outline of the each chapter of this thesis.

### 1.1 Genesis of the research

From the outset of this study, I chose to explore end of life issues among older South Asians living in the East London. This position was assumed after an initial request from one of the end of life care service providers and research partner of my university, St Joseph's Hospice, East London, who indicated a paucity of empirical evidence that could help them to better serve particular ethnic communities, notably South Asians, residing around them. My literature review also indicated a dearth of research and highlighted the importance of addressing ethnic and cultural differences in health care (Gerrish 1999, Koffman *et al.* 2007, Lees & Papadopoulos 2000, Merrell *et al.* 2006, Nazroo 1998, PRIAE 2005, Smaje 1998, Smith *et al.* 2000, Szczepura 2005, Vydelingum 2006).

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Asians, primarily South Asians, constitute the single largest ethnic minority group (4%) in the UK (ONS 2001). Research demonstrates that older people from ethnic minorities who are living with chronic diseases, particularly South Asians, tend to under-use available palliative and end of life care services (Ahmed *et al.* 2004, Fountain 1999, Gaffin *et al.* 1995, Jones 2005, NCHSPCS 2001, Smaje & Field 1997, Worth *et al.* 2009). Some argue that there is a lack of ‘cultural transferability’ in existing Western palliative service models (Gunaratnam 1997, Gunaratnam 2001, Nyatanga 2002, Owens & Randhawa 2004).

Most of the older South Asians living in the UK are first generation immigrants (Ballard 1994, Hatton 2005). Although there are traces of acculturation in such immigrant communities (Gilbert & 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) highlighted 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) . In addition to this, language barriers (Diver *et al.* 2003, Jack *et al.* 2001) may further reinforce their preconceptions around end of life care services, especially about hospice and cancer facilities (Elkan *et al.* 2007, Randhawa & Owens 2004). This in turn may significantly impede their awareness of, access to and uptake of palliative care services

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(Gaffin *et al.* 1995, Jones 2005, NCHSPCS 2001, PRIAE 2006, Smaje & Field 1997, Worth *et al.* 2009).

Health professionals providing care in multi-cultural environments have been shown to experience several dilemmas, such as ambivalence, ignorance or uncertainty whilst caring for older South Asian people (Gunaratnam 2001, Vydelingum 2006). Furthermore, existing research has highlighted a lack of cross-cultural linguistic skills and inadequate cross-cultural end of life care knowledge among health professionals (Diver 2003, Richardson *et al.* 2006). In such situations, poorly informed and inadequately trained health professionals may adopt a ‘culturally distant position’ (Owens & Randhawa 2004). Indeed, this kind of ‘staying back’ as a stranger may hinder their efficiency in defining exact needs, preferences and undertaking detailed palliative and end of life care assessments (Diver 2003, Owens & Randhawa 2004, Richardson *et al.* 2006).

Previous studies have highlighted the impact of immigration, socio-cultural factors on palliative needs (Gunaratnam 2007, PRIAE 2006, Spruyt 1999), beliefs around death and dying (Deshpande *et al.* 2005, Firth 2005, Gatrads 1994, Rashid & Sheikh 2002, Steele 1977, Werth *et al.* 2002), knowledge about existing palliative and end of life care service provision (Elkan *et al.* 2007, Gunaratnam 2001, Randhawa & Owens 2004, Somerville 2001) and communication barriers (Ackroyd 2003, Jack *et al.* 2001, Somerville 2001) with regard to the South Asian population. However, little is known about experiences, preferences and attitudes towards end of life in this population, despite calls advocating further research to inform service development (Gunaratnam

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2007, PRIAE 2006, Somerville 2001, Worth *et al.* 2009). Hence, the purpose of this study is to explore and critically examine views and perceptions about end of life issues among older South Asians living in East London.

## **1.2 The ‘insider’**

Introducing and understanding my ethnic and cultural background is essential for any readers of this thesis. This is because as I stood as an ‘insider’ in the research study, who came from a similar (South Asian) ethnic background to the participants. This I believe definitively influenced the way I have collected, interpreted, analysed and constructed the outcome of this study. At many times I acted as research instrument, whereby I was useful to access and understand the hidden, unspoken words of the participants.

I am a young Hindu man from a South Asian country (India). I was born and brought up in India and moved recently to the UK as an immigrant nurse. I am able to speak five languages, including four South Asian languages (Tamil, Telugu, Malayalam and Hindi) and English. I retain my cultural and religious values, rooted in my Indian heritage, informed by my schooling, family and social network. I worked as a nurse in one city in South India. Apart from participating in death rituals for the people in my local community, I also observed many deaths and gave care to many dying patients as a nurse. However, by narrating my own cultural experience of caring my father for his last days, I believe I can set the scene about death in India. In turn, this can perhaps explicate some issues in current end of life perspectives that are likely to emerge from the

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accounts of other South Asian people. This then is the base for interpreting the findings of the study.

I still feel guilty and unconvinced that I made the right decision to withhold ventilator support and cardio-pulmonary resuscitation (CPR) for my father. Five years before I started my PhD, my father suddenly faced death at his age of 72. He was admitted to hospital after he collapsed suddenly at home, and was diagnosed with a massive stroke. I was dubious when I saw his tears in unconsciousness, apprehensive of whether he agreed or cursed my decision. However, at that time, by instinct, I did not want my father to be mutilated or to see him suffering. In addition, I did not want other family members to suffer. Around 20 to 25 family members had stayed around the clock outside the ICU (Intensive Care Unit) ward for four days (including at least two to three relatives around his bedside), crying and shouting for him even though the doctors had declared the prognosis was poor.

When doctors asked for someone to discuss my father's condition, my family sent my elder brother to the doctors' office. However my brother asked me to accompany him, since, as a nurse I was considered medically knowledgeable by my family. The doctors discussed the poor prognosis and asked us to take my father back home if we preferred. However, we strongly refused the idea. Firstly, as the male decision makers in the family, we decided to uphold our duty to care for my father at hospital, to give as much comfort as possible. In so doing, we believed everyone in the family, including my dying father, would feel that we had done our duty and fulfilled our responsibilities in caring for him in his last days as much as possible. Secondly, we believed that if we



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took our father home, our society would comment that my family had decided to let my father die without providing the highest possible treatment – this might have affected our social prestige.

We decided to let my father die naturally without any life-saving treatments. When I told my family, they agreed with my decision to withdraw life-sustaining therapies. However this may have been due to the societal norms (whereby men make all the decisions) or the dominance of medical decisions and views in India. I stood near to his bedside and read the holy book which he always read. We gave chips of milk as a ritual during the last minutes of his life. Finally he died with most of our family members around. We all felt that he had a good death, since he was healthy until he collapsed suddenly, and he died within four days surrounded by family. However, many of relatives felt sorry for my father as he was not able to finish his duty to complete his responsibilities; he died before he was able to arrange my marriage.

After death, as a son, I attended to the rituals to send my father's soul to God's lotus feet. This custom involved 16 days of *puja* (prayers), with 30 to 40 neighbours and relatives attending daily. The whole family was supported by the local community to ease our grieving process. However, internally I felt confused as I did not understand the meaning of many rituals but felt obliged to observe them due to societal pressure.

I am proud to tell how the community supported us from the day my father was admitted to hospital to the day we completed our rituals (a period of nearly a month). The first thing that came to my mind was that the majority of people from my village visited us in

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the hospital, often bringing food, sharing our workload and giving us a rest by staying at my father's bedside and giving emotional support for both my father and for my family. Most importantly, our close relatives economically supported us so that we could care for him in a high-cost private hospital. The children of our extended family stayed in the homes of our relatives and neighbours, so that they could continue to attend their schools. The employers gave generous leave (at least for the men in the family) until they completed all the rituals. We did not cook any food for almost a month in our home, because cooking and eating the food in the house is treated as inauspicious and as disrespectful to the soul of the departed, which we believe may linger until we liberate its bond from this world by completing all the rituals. Thus, my relatives and neighbours gave food for us. We were not allowed (especially men) to enter others' homes until the final rituals. At last we felt quite easy during our bereavement period.

With the above experience of bereavement, I am interested to investigate how older South Asians experience and adopt the end of life care while living in the Western country (i.e. in the UK). In other words, it is a particular topic of interest about how they conduct themselves culturally with regard to end of life care within a new social context.

## **1.3 Terminologies explained**

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### 1.3.1 Palliative care

This study adopted and used the definition of palliative care provided by the World Health Organization (WHO 2003):

*An approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.*

### 1.3.2 End of life care

In light of the recent call to define end of care in the UK, this study used the term end of life proposed by National Council for Palliative Care (2006) and accepted as a working definition for end of life care strategy (DH 2008):

*End of life care is care that helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support.*

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### 1.3.3 Ethnicity

This study appreciates that the meanings and definitions of terms like race, ethnicity and culture are controversial (Bhopal 2004, Bhopal *et al.* 1991, Bradby 2003, Drevdahl *et al.* 2006). This study uses the term ethnicity in a pragmatic way that recognizes the purpose of defining and narrowing the study limitations and also in accordance with the methodological congruence of this study. Therefore, the term ethnicity in this study refers:

*the social group a person belongs to, and either identifies with or is identified with by others, as a result of a mix of cultural and other factors including language, diet, religion, ancestry and physical features traditionally associated with race* (Bhopal 2004).

### 1.3.4 Culture

This study understands culture to be a:

*social construct which is characterized by the behaviour and attitudes of a social group based on their individual beliefs and choices* (Bhopal 2004).

However, culture is a melting pot (Bisin & Verdier 2000), which continuously changes based on one's own socio-environmental factors (Green & Ingleton 2010). Nevertheless, preservation and practice of cultural is an individualized decision; therefore, it is

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notoriously difficult to measure in health services research (Aspinall 2001, Bradby 2003). Given that reason, this study obtains views about end of life care based on self-classified ethnic category rather than by culture.

### **1.3.5 South Asians**

Another ill-defined term in both academic and media fields is Asian; this particularly causes confusion among health service personnel (Aspinall 2003, Bhopal *et al.* 1991). Some scholars argued that studies using the term Asian should clearly inform readers about how the term is being used and provide details of the background and origins of the ethnic minority groups under the study (Bhopal 2004, Bhopal *et al.* 1991, Drevdahl *et al.* 2006). In this study, the term South Asians refers:

*A person whose ancestry is in the countries of the Indian sub-continent including India, Pakistan, Bangladesh, and Sri Lanka (Bhopal 2004).*

Another key variable observed in this study is the use of term ‘first generation’ South Asians. Despite the fact that the country of birth and/or nationality may exclude second and third generation groups, this study intended to research South Asians aged 50 and older. Post-Second World War immigration of these people from and the ageing of this population is the rationale for the inclusion of only first generation South Asians.

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### 1.3.6 Older people

The effect of ethnic and cultural dissimilarities may influence the meaning and description of the term ‘older people’. Variant social disadvantages, accessibility to resources, self classification about age and health may define one’s own sense of ageing. Most of the ethnic minority people, for example, aged 50 and older felt ‘early’ ageing (Smith *et al.* 2004), possibly due to unemployment, poverty and other social disadvantages (Sin 2006). Given the above snapshot of the situation of ageing in ethnic minorities, this study will use the terminology of older South Asians as a self-classification of as ‘older’ and aged 50 and over.

## 1.4 Organisation of the thesis

### **A theory of continuity and reconstruction in context of end of life among South Asians**

In overview, continuity and reconstruction is the principal theoretical construction of this research study. This theory provides an explanation of the perspectives of older South Asian emigrants in this study, showing how they tried to achieve cultural continuity at the time of death and dying. In many cases, they reconstructed traditional values attached to end of life situations in the context of living in an immigrant country.

The thesis has eight chapters. The second chapter provides a literature review. Chapter three presents the methodology and methods I adopted for this study. The following

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chapters four, five and six present the findings of the study. Chapter seven presents discussion and chapter eight concludes the thesis. Below I outline the structure of the thesis.

In chapter two, I review existing literature to provide background and context to the research study presented in this thesis. This chapter has four sections. The first section explains immigration patterns and socio-demographic structures of South Asians in the UK. The second section introduces South Asians' perspectives on health and illness, cultural and religious beliefs and practices around end of life. Drawing on key studies from the palliative and end of life care research, in section three, I explore the views and experiences of health professionals involved in caring for South Asians with palliative care needs. This chapter concludes by identifying gaps in current knowledge and lists the aims and objectives of this study.

Chapter three outlines the methodology and methods of the study. This chapter has two sections. This study took a constructive grounded theory approach. An overview and implications of this methodology is provided in the first section. Following this, section two describes the design and conduct of fieldwork and analysis. Fieldwork took place in 11 community organisations and participants' homes. Over eight months, I conducted five focus groups and 29 one-to-one interviews with 55 older South Asian participants in East London. The chapter includes descriptions of how I faced various challenges during the research process, from accessing the participants to issues around data analysis.

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The subsequent chapters four, five and six present the findings of the study. In chapter four, findings related to the first category, participants' views about 'home' at end of life are presented. The first sub-category, 'home as a haven', describes participants' accounts of how their home is a physical place in which it is possible to perform various cultural and religious rituals. The second sub-category, 'reconsidering the homeland', presents various arguments about returning to their 'homeland' - the country from which they emigrated for their end of life.

The second category of experiences of 'family' care giving at end of life is described in chapter five. The duty to provide family care giving for dying relatives was driven by two predominant cultural values: 'honour within family' and the value placed on extended family and social networks. The former sub-category deals initially with the experiences of providing end of life care within marriage, and later the expectations of 'filial responsibility' in the provision of such care at the end of life. In the second section I present findings in relation to how the extended family and the wider community are considered key in supporting the dying person and their immediate family.

Chapter six presents the findings related to the final category of 'trust'. In this chapter, I report the study findings that relate primarily to the attitudes and beliefs participants expressed towards the discussion of death and dying and decision making. The first sub-category on avoidance of discussion relates to the relative absence of discussions around death and dying among participants. The second sub-category on locus of authority in decision making relates to beliefs and experiences about the delegation of decision making to family members.



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Chapter seven discusses the findings of this study and brings them together with the existing body of literature on death, dying and bereavement for ethnic minorities, in particular South Asians. This chapter has two sections. In first section, it describes the methodological strengths and limitations of the study. Following this, the second section summarises the contribution of this thesis to new knowledge; the theory of ‘continuity and reconstruction’. The theory of ‘continuity and reconstruction’ portrays how participants made efforts to adhere to important social and cultural values relating to death and dying, while rebuilding and adapting those values as they accepted the challenges of living in an emigrant society.

Chapter eight is the final chapter of the thesis. It aims to analyse the extent to which this study has answered its research questions, and whether it has met the criteria set for evaluating constructive grounded theory. This chapter also describes recommendations and implications for policy, future research and practice.

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## CHAPTER 2

# Literature Review

This chapter reviews the existing literature to provide the background and context of the research study presented in this thesis. A search was conducted to identify relevant literature concerning South Asians' views towards death, dying and end of life care. The following electronic databases were searched: EMBASE, AMED, British Nursing Index and Archive, CINAHL, PsychINFO, Medline (Ovid), Web of Science, Science Direct (Elsevier), Health Sciences SAGE (full text) and Google Scholar. Hand searches were carried out of relevant journals such as Palliative Medicine and the International Journal of Palliative Care Nursing and the bibliographies of identified articles. Search terms were identified with the help of the library subject specialist and from trawling the MeSH headings attached to key papers. These included: 'culture', 'ethnicity', 'attitudes', 'preferences', 'beliefs', 'experiences', 'end of life', 'end of life care', 'death and dying', 'funerals', 'burial rituals', 'heath', 'illness' 'palliative', 'cancer', 'cancer care', 'minority ethnic groups', 'ethnic minorities', 'older South Asians', 'British South Asians', 'Indians', 'Gujarati', 'Pakistani', 'Bangladeshi', 'Punjabi', 'Hindus', 'Muslims', 'Buddhist', and 'immigrants'. The search was conducted at regular periods during the study period (August 2006-November 2010) to maintain currency.

In this chapter, the initial sections explain immigration patterns and socio-demographic structures of South Asian emigrants in the UK. The subsequent sections introduce South

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Asians' perspectives on health and illness, cultural and religious beliefs and practices around end of life. Further sections explore the views and experiences of health professionals involved in caring for South Asians with palliative care needs. This chapter concludes by summarising the gaps identified in current knowledge and lists out the aim and objects of this research study.

## **2.1 Older South Asians in the UK**

### **2.1.1 Immigration and settlement of South Asians in the UK**

Migration has become one of the most important determinants of global health and social development (Carballo *et al.* 1998, Koven & Götzke , Light 2004). In fact, the millennium marked 200 years of large-scale immigration from other countries into UK (Ballard 1994). Working-class South Asians first came to Britain as domestic servants and sailors in the early Seventeenth Century (Ballard 1994, 2002), in the service of the East India Company, which later ruled the Indian subcontinent until 1947. From the early Eighteenth Century, travellers, emissaries, and petitioners such as those seeking redress for lands lost to the East India Company came to the UK (Spencer 1997). By the mid-Nineteenth and early Twentieth Century immigrants from diverse backgrounds were settling in Britain, including professionals, students and political activists, mainly located in London (Fisher 2007).

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During the course of the Second World War, as well as the thousands of enlisted South Asian soldiers in the British armed forces, many South Asians were encouraged to enter Britain to fill the wartime labour shortages (as cheap industrial labour), filling the so-called ‘pedlar’s jobs’ (Adams 1987, Gardner 2002). Consequently, when the UK experienced a post-war economic boom, which lasted right up until the end of the 1970s, there were plenty of jobs to be had. As a result, more and more migrant workers from India, Pakistan and Bangladesh came to join these early pioneers (Adams 1987, Spencer 1997). Furthermore, due to political reasons, Indian Sikhs and Gujarati’s who were settled in East African British colonies also immigrated to the UK when those countries were given independence from British colonization, becoming so-called ‘twice migrants’ (Bhachu 1985). In recent years, Tamil refugees, a product of the civil war in Sri Lanka, swelled the ranks of the immigrant population (Bloch 2000, Spencer 1997).

More than 95% of South Asians in UK have ancestral roots falling into one of three broad population groups: migrants from the Punjab region of north-western India and Pakistan; those from Gujarat, on the sea coast to the north of Mumbai (Tambs-Lyche 1975); and those from Sylhet district, to the far east in Bangladesh (Adams 1987, Gardner 1998). By 2010 the immigration pattern clearly showed a sizeable number of South Asians growing older in Britain, as those who migrated as young workers between 1950 and 1970 exceed 60 years of age (Phillipson 2000).

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## 2.1.2 The ethnic demographic structure of UK

The inclusion of ethnicity in the 1991 UK census was strongly criticized and at times described as the ‘zoological classification’ of human beings (Bhopal 2004). However, I agree with many scholars who have argued that such categorization is important for monitoring people’s movements and for planning and designing population-based social and health care services (Bhopal 2004, Drevdahl *et al.* 2006). This is particularly important in the context of an existing multi-ethnic society such as the UK, which sometimes faces marked increases in immigration, leading to a constantly evolving ethnic composition of society (Hatton 2005).

According to the Office of National Statistics (ONS) Census 2001, nearly 7.9 % of the population in the UK is made up of people from ethnic minority groups (ONS 2001). In the 2001 census, South Asians populations had grown 53% compared to 1991, due to factors such as a high birth rate and net international immigration among these populations (Hatton 2005). South Asians constitute the single largest ethnic minority group (50.3% of ethnic population) in the United Kingdom (ONS 2001). In particular, Indians and Pakistanis respectively made up 1.8% and 1.3% of the total population of the UK in the ONS Census 2001. In some cities such as Bradford, London, and Leeds, South Asians make up the majority of the inner city population, exceeding the majority (CRE 2005, 2007). The table 1 explains the population of the UK by ethnic group, based on ONS 2001 Census (ONS 2001).

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**Table 1 The population of United Kingdom, by ethnic group, 2001 ( ONS 2001)**

<b>Ethnic group</b>	<b>% of Population</b>	<b>% of Non-White Population</b>
<b>White</b>	<b>92.1</b>	
<b>Mixed</b>	<b>1.2</b>	<b>14.6</b>
<b>Asian or Asian British</b>	<b>4.0</b>	<b>50.3</b>
<b>Indian</b>	<b>1.8</b>	<b>22.7</b>
<b>Pakistani</b>	<b>1.3</b>	<b>16.1</b>
<b>Bangladeshi</b>	<b>0.5</b>	<b>6.1</b>
<b>Other Asian</b>	<b>0.4</b>	<b>5.3</b>
<b>Black or Black British</b>	<b>2.0</b>	<b>24.8</b>
<b>Chinese</b>	<b>0.4</b>	<b>5.3</b>
<b>Other ethnic groups</b>	<b>0.4</b>	<b>5.0</b>
<b>All minority ethnic population</b>	<b>7.9</b>	<b>100</b>

### **2.1.3 Social circumstances of older South Asians in the UK**

Existing studies have highlighted the variable health, social and economic experiences of South Asian emigrant people that lead towards inequalities in access and use of health and social care services (Chandola 2001, Nazroo 2003, Smith *et al.* 2000). Policy makers and researchers often use the contentious phrase of ‘social exclusion’ (Scharf *et al.* 2005). The Social Exclusion Taskforce (2007) defines social exclusion as a ‘shorthand term’ for people with multiple disadvantaged circumstances such as

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unemployment, poor skills, low incomes, living in high crime areas, poor health and often with state benefits as a main income. There is evidence to suggest that these vulnerable people must contend with multiple hazards and risks as they get older (2005). This includes living alone, poor competency in English, multiple health problems with less or no knowledge about accessing and availing existing health and social care services (Chandola 2001, Smaje 1998, Smith *et al.* 2000).

Young adults who migrated from the South Asian countries between the 1950s and 1970s to the UK are now reaching old age (PRIAE 2005, 2006, Scharf *et al.* 2005). Despite personal accounts of their contribution to rebuilding the post-war economy of the UK from the 1940s onwards, their individual experiences of ageing will be unique (Ini *et al.* 2004). Many have faced various forms of economic and social exclusion resulting in different levels of poverty (Spinder & Kangis 2006). Shelton and Grundy (2000), in their study on the experience of ageing in deprived communities, highlighted that older South Asians are living with multiple forms of deprivation, such as 45% of the urban ethnic people living in poverty.

Scharf *et al.* (2005) used the term ‘multiple exclusion’ to highlight the social disadvantages of those older people in urban areas who were considered vulnerable. This study investigated the concept of ‘social exclusion’ among older people by using a survey of 600 people aged 60 and over in deprived neighborhoods of three English cities. This study found that nearly 70% of these people older people living in deprived urban neighborhoods had experience of more than one form of social exclusion, including lack of social relationships; unawareness of basic services, including health and social care

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services; and not participating in any neighbourhood or local community activities. This study concluded that multiple social exclusion was significantly correlated with respondents (Scharf *et al.* 2005). Research has also revealed that a sizable population of South Asians are living alone, particularly South Asian women (30%) in the UK (Wenger & Burholt 2004).

### **2.1.4 Disease patterns among South Asians**

The influx of immigration may not only change the demographic ethnic makeup, but may also change the epidemiological profiles of the host society (Smith *et al.* 2000). It is extensively documented that variable patterns of diseases may force health care providers to alter their delivery of services (Goel *et al.* 2003, Nazroo 2003, Unson *et al.* 2004). Nazroo (1998) reasoned that factors such as distinct lifestyles, food habits and genetic composition might influence the morbidity and mortality pattern compared with the majority population. Moreover, immigration may also leave footprints of isolation, loneliness, family conflict, economic dependence, and less coping levels (Chandola 2001, Nazroo 1998). These social problems nevertheless an important component of the problems faced by migrants.

South Asian men living in the UK have 30 to 40% higher rates of cardiovascular diseases than men from the general population (Health Survey for England 2001). Data from enhanced tuberculosis surveillance (ETS) reported that 86% of tuberculosis cases



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in London were from non-white ethnic minorities, in particular 35% were from black Caribbean and 31% were from the Indian Subcontinent (Anderson *et al.* 2007). In addition, diabetes mellitus and Cerebro-Vascular Accidents (stroke) occur twice as often among Caribbean and South Asian people compared to the general population (Bhopal *et al.* 2005, Bhopal *et al.* 1999). Apart from the high prevalence of those diseases, recent studies demonstrated increasing rates of cancer among the South Asian population (Smith *et al.* 2003).

Older South Asians in the UK have better living conditions with longer average life expectancy than older people in their countries of origin (Nazroo 2003). However, the dominance of certain diseases that have high prevalence among these ethnic groups has led many Asians to live out their last years with chronic health conditions. Studies have shown that living with advanced chronic disease can lead older South Asians to feel that they are a burden to themselves and their families (Bhopal *et al.* 2005, Smith *et al.* 2003, Spruyt 1999). This is particularly important in South Asian communities where caring for older parents is considered a filial responsibility and duty (Katbamna *et al.* 2004, Merrell *et al.* 2006). Other studies also highlighted difficulties in caring for older people for the family members, if they observe such responsibilities (Hensel *et al.* 2005, Koffman & Higginson 2001).

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## 2.1.5 Older people and palliative and end of life care

A plethora of literature has described the relationship between older people and palliative care services (Gaffin *et al.* 1995, Koffman *et al.* 2007, Smaje & Field 1997, Worth *et al.* 2009). Davies and Higginson in a WHO Report (2004) highlighted the cumulative effect of multiple chronic illnesses that increase disability and psychological stress among older people and emphasised the extent of their palliative care needs. This report also pointed out the tendency of health services providers to ‘under assess and under treat’ older people more frequently than younger people.

National policy makers and service frameworks acknowledge the need for providing comprehensive and high quality palliative care provision for all age groups, diagnosis and geography (DH 2001, 2006, NICE 2004). However, the reality is different. Burt and Raine’s (2006) systematic review of the effects of referral to and use of specialist palliative care demonstrated that people aged between 65 to 80 years accessed the services more than those in older age groups. In contrast, greater severity of illness, higher death rates and increased incidence of cancer and related chronic illness are more common among the very old. For example, patients with breast cancer aged under 75 years with physical and psychological distress had an increased likelihood of receiving community specialist palliative care compared to highly dependent older people (Addington-Hall *et al.* 1998a) .

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These examples of mainstream age bias may have clear implications for older people in minority ethnic groups in the immediate future. This is because, although most of the older ethnic minority people in the UK who are relatively younger than the majority population, their numbers are set to increase quite dramatically over next decades (PRIAE 2005). Another reason is the presence of ethnic specific, disease-specific differences in palliative care service usage (Addington-Hall *et al.* 1998b, Jakobsson *et al.* 2007, Koffman *et al.* 2007, Smaje & Field 1997). There is evidence also to suggest that due to the impact of social disadvantages, ethnic minorities use less palliative and hospice services (Evers *et al.* 2002). The National Council for Palliative Care (2007) and PRIAE (Policy Research in Ageing and Ethnicity) (2006) emphasised the need for delivering palliative care services for older ethnic minorities by highlighted greater prevalence of life-limiting non-malignant diseases among South Asian people compared with the majority population. However recent attempts by policy makers and service providers are promising. For example the traditional cancer-centred palliative care programme is now being transformed and expanded to also include non malignant diseases (Addington-Hall *et al.* 1998b, Catt *et al.* 2005, Gaffin *et al.* 1995).

### **2.1.6 Ethnicity and end of life**

Eliciting and meeting end of life care needs have been considered as markers of the quality of end of life care (Walshe *et al.* 2007). Existing literature illustrates various end of life care preferences and under-use of palliative and end of life care services among ethnic minorities (Jones 2005, Koffman *et al.* 2007, Kwak & Haley 2005, Worth *et al.* 2009). However, the reasons for these trends are unclear and under researched. Spruyt's

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(1999) study among bereaved primary carers' Bangladeshi patients in East London concluded that there are ethno-specific needs in this particular community, many of which arise from socio-economic factors, recent migration and religious beliefs, and which are highlighted by terminal illness.

In most studies, ethnicity remains a significant factor in uptake and awareness of palliative and end of life services (Randhawa & Owens 2004, Scanlon & Wood 2005, Smaje & Field 1997). Worth et al. (2009) in a qualitative study that investigated the care experiences of 92 South Asian Sikh and Muslim patients in Scotland with life-limiting illness and their families reported that most services struggled to deliver responsive and culturally appropriate care. They identified various institutional barriers including, occasionally, personal racial and religious discrimination, limited awareness and understanding among South Asian people of the role of hospices, and difficulty discussing death. Studies from the USA (Blackhall *et al.* 1999, Phipps *et al.* 2003) showed that attitudes towards using life-sustaining therapies vary between ethnic groups. A study in the UK found that the majority population showed more positive attitudes towards the hospice and its purpose compared with those from ethnic minority groups (Seymour *et al.* 2007).

Some studies pointed to how cultural beliefs influence the end of life (Randhawa & Owens 2004, Richardson *et al.* 2006). Existing literature also described South Asians' religious beliefs about end of life (Firth 2005, Rashid & Sheikh 2002, Sheikh *et al.* 2003). Other studies also compared and showed marked differences between the attitudes of Black Caribbean people with majority populations in relation to end of life

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(Higginson & Koffman 2003, Koffman & Higginson 2004, Koffman *et al.* 2008). Based on the existing literature, the preceding paragraphs illuminate cross-cultural views on palliative and end of life amongst Black Caribbean, Chinese and South Asians.

## **2.2 Cross-cultural views of end of life care**

Existing research showed concern for ‘absent minorities’ in palliative and end of life care services (Addington-Hall *et al.* 1998b, Bowes 2006, Gaffin *et al.* 1995, Gunaratnam 2001, Owens & Randhawa 2004, Smaje & Field 1997). Although several reasons were proposed, a key factor that has been suggested is that modern practices of Westernised palliative and end of life care such as truth telling, patient rights to information, and decision making may not be applicable for some ethnic communities (Gunaratnam 1997, 2001). In fact, some researchers argued that during sensitive life events, many ethnic minority people tend to practice their own rituals based on their cultural beliefs (Gunaratnam 1997, Owens & Randhawa 2004, Payne *et al.* 2005).

Demographically, researchers have attempted to gain the palliative and end of life care views of major ethnic minority communities including South Asians (Diver *et al.* 2003, Gunaratnam 2001, Jones 2005, Spruyt 1999, Worth *et al.* 2009), Chinese (Payne *et al.* 2005, Seymour *et al.* 2007), and Black Caribbean’s (Koffman & Higginson 2004) living in the UK. These studies either considered individual ethnic groups (Spruyt 1999) or compared them with the majority population (Koffman & Higginson 2004). However,

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they have mainly focused on end of life care experiences, service evaluation, and care-giving experience from the perspectives of health professionals. Interestingly, some studies have attempted to enable education in end of life care by using ‘listening events’ techniques for older groups from most ethnic origins (Clarke *et al.* 2006).

### **2.2.1 Black Caribbean people and end of life**

Studies in the UK of Black Caribbean people and their end of life revealed several marked ethnic differences. Data from a cross-sectional survey of 252 oncology outpatients show that understanding the role of Macmillan nurses, hospice and the term ‘palliative care’ and awareness of palliative care and related services was low among black and minority ethnic groups, and such groups were less affluent than those who were classified as being White British (Koffman *et al.* 2007). Another study (Koffman & Higginson 2004) demonstrated that a greater proportion of Black Caribbean people wished to die at home (34% vs. 27%). The same study found that people who expressed a wish to die at home were more likely to do so regardless of ethnicity. Similarly, another study revealed that attitudes to timeliness of death are similar in both black Caribbean and white patient groups (Higginson & Koffman 2003).

Criticism has also been directed towards the poor referral, accessibility of information and ethnocentric views of health professionals, rather than a lack of palliative care provision (Koffman *et al.* 2007). Koffman & Higginson (2004) demonstrated these

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inequalities, such as in the gate-keeping nature of some GPs that led to ‘restricted knowledge’ among Black Caribbean people concerning such services. In another study, data from a semi-structured interviews with 26 Black Caribbean and 19 White British patients with advanced cancer showed that despite both ethnic groups’ positive input from religious belief and faith in their self-reported cancer experience, Caribbean patients had stronger religious beliefs (Koffman *et al.* 2008).

### **2.2.2 Chinese perspectives of end of life**

Approximately 473,000 Chinese people live in the UK and they make up 0.4% of the total population (ONS 2001). There is very little research concerning end of life care for Chinese people in the UK. Despite their difficulties in communicating in English, beliefs around death practices, rituals and varying levels of acculturation, studies have identified distinct cultural attitudes regarding cancer and hospice services among this population (Papadopoulos *et al.* 2007, Seymour *et al.* 2007). A study by Papadopoulos *et al.* (2007) that investigated about the meanings and experiences of cancer of Chinese emigrants found that the focus group participants showed great reluctance to talk about cancer. Furthermore, they also found widespread misunderstandings and lack of knowledge and information about cancer treatments, though they understand cancer to be life threatening disease among the participants. Likewise, Payne *et al.*’s (2005) review of Chinese cultural perspectives on end of life care illuminated several evidences for differences in several end of life issues, including stronger preferences for family

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role in decision making, place of death, preference related to life sustaining treatments and preference for non disclosure of poor prognosis.

Similarly, Seymour *et al.* (2007) presented a comparative analysis of experiences and expectations in relation to end of life care provision at home and in hospice from the two linked studies of white (n=77) and Chinese (n=92) older adults living in the UK. In their study, some obvious differences were that white people regarded death in a hospice as a good death, whereas Chinese older people viewed this as inauspicious, and claimed that a good death may not be achieved in the hospice. However, attitudes towards place of death for Chinese participants in same study stated that after visiting a local hospice their view became more optimistic. Furthermore, Chinese people in the same study reported that they preferred dying in hospital, in marked contrast to the preference of many ethnic groups to die at home (Seymour *et al.* 2007).

## **2.3 South Asians' perspectives of health and illness**

In general, there is no single South Asian culture, which could explain South Asian perspectives of health and illness. Hinduism, Islam, Buddhism, Sikhism, Jainism and Christianity are the major religions practiced by these people. These religions contribute towards their attitudes and cultural beliefs (Puchalski & O'Donnell 2005). Cultural traditions such as family system and values, traditional health systems, care of older people, style of decision-making, alternative therapies, attitude towards health care providers, and male dominated social structures are deep-seated core elements, which



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have implications in their health behaviour (da Costa *et al.* 2002, Jones 2005, Robinson 2005, Shanmugasundaram *et al.* 2006, Shanmugasundaram & O' Connor 2009).

### **2.3.1 South Asian Muslims' perceptions of health and illness**

South Asian Muslims are the second largest faith group among ethnic minorities (consisting of 52% of the non-Christian religious population) in the UK (CRE 2005). Followers of the Islamic faith believe that life is a 'trip' with the purpose to discover and appreciate the work of God in this world (Gatrad 1994, Rashid & Sheikh 2002). Therefore, Muslims believe in using this world as a midpoint to stay in whilst worshiping God and performing good deeds (Gardner 1998, Sarhill *et al.* 2001).

Sachedina (2005) described about how religious beliefs influence end of life from an Islamic point of view. He stated:

*Health, illness and death are the pre-planned trials from God, who test individual to decide what kind of afterlife He will grant. Therefore, good health is a gift from God. Muslims need to treat their body as a sacred temple, so it should be kept neat and clean by eating a healthy diet and exercising regularly to keep the body fit.*

Muslims may believe illness is an effect of Satan's evil power, and that it is a sign of bad luck (Ismail *et al.* 2005). The study by Ismail *et al.* (2005) stated that some Muslims

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believe epilepsy was caused by spirit possession, and many attributed it to ‘the will of Allah’. There is a verse in the Quran (28:80-81) cited by Hedayat (2006) which may partially explain Muslims attitude towards end of life :

*And when I am sick, then [God] restores me to health; And He it is who will cause me to Die, then give me life (in purgatory and again on the Day of Judgment).*

This suggests that Muslims believe that everything is in God’s hand or happens due to God’s will. Therefore, having made every effort to alleviate the illness, they place their trust in God. On the other hand, Rashid and Sheikh (2002) suggested that this kind of ‘fatalistic approach’ needs to be considered when caring for Muslims at their end of life. It is noteworthy to remember that this fatalistic attitude may quickly lead to adopting the sick role and causing Muslims to take a less proactive attitude towards disease management.

The South Asian Muslim patients may prefer the medicines for immediate relief of symptoms and conditions. Indeed, the Prophet Muhammad took medicine and encouraged people to seek cure for their illnesses. Natural causes of illness such as contagion, seizures, congenital defects, and environmental factors were also acknowledged by the Prophet Muhammad (Hedayat 2006). Thereby Muslims may believe that medicine should help humanity to alleviate pain and provide cure if not care (Sachedina 2005).

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### **2.3.2 South Asian Hindus' perspectives of health and illness**

Hinduism is widely practised in the Indian subcontinent. Within Hindu philosophy there is an understanding that for Hindus, their every single activity leaves an imprint on their soul (Laungani 1999). Every Hindu is obliged to perform activities (karma) based on the dharmic path, a personal righteous conduct to remove layers of ignorance to achieve self realisation or athma (Firth 2005). Once the soul has completely stripped off all the layers of ignorance, the pure soul will merge with 'Brahma' a supreme being in perpetuity (Firth 2005).

Hindus believe that an individual's karma is a reason for good health and illness (Blackburn 1985). A true Hindu should try to perform his karma in a self-disciplined way (called dharma) to avoid illness. Illness, pain and suffering may be viewed as the effect of sinful actions (adharma) in this life or a prior life (Sheikh *et al.* 2003).

Hindus also believe that until they remove all the layers of ignorance or bad imprints on the soul, they will be born repeatedly in order to clean the soul. They believe all acts and thoughts have consequences in the next life. Good karma will lead to good birth or release, bad karma to a bad birth. However, they believe that trusting and surrendering oneself to God may help oneself to reduce these imprints or purify the soul (Sheikh *et al.*

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2003). To achieve self purification, every Hindu is required to perform prayers and meditation for good health and relief from suffering.

### **2.3.3 Traditional health practices among South Asians**

Older South Asian people may have strong faith in the power of traditional medicine (Firth 2005). Focus group participants in a study of South Asian immigrant women in Canada revealed that traditional health practices included home remedies, dietary regimens, prayers, rituals, consultation with ‘Divine Healers’ such as *hakims* (for Muslims); *veds*, *babajis*, *pundits* (for Hindus), homeopaths, and *jyotshis* (Hilton *et al.* 2001). These traditional remedies included herbal drinks, roots and other herbs worn in amulets or around the neck, specific diets, observance of the confluence of the heavenly bodies, and the use of precious and semi-precious gems. The choice of traditional health practice was influenced by family members, the nature and severity of problems, beliefs and prior experiences, and the feasibility of using these practices (Shanmugasundaram *et al.* 2006).

In traditional South Asian medicine, disease is often perceived as a result of bad karma, the evil eye or just bad luck. Often religious rituals are conducted to rid the patient from the evil influence and give hope and confidence to the patient and the family (Smith 2000). Women rarely use traditional health practices exclusively (Laungani 1999).

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Traditional health practices are preferred for minor ailments and when Western medicines are believed to have failed (Hilton *et al.* 2001).

Cultural hybridity refers to when professional and folk sectors overlap in contributing to an individual's 'health belief system'; they may simultaneously seek help from a doctor and from a religious healer (Small *et al.* 2005). However, in the study by Ismail *et al.* (2005), more than half of epilepsy patients sought help from traditional South Asian therapies, which usually are used as complementary rather than an alternative to anti-epileptic therapies. They concluded that family or friends remain a strong persuading factor in adopting these therapies.

South Asians practice two kinds of healing based on their religion. Muslims visit religious medical practitioners called *hakims* (Ismail *et al.* 2005, Rashid & Sheikh 2002). They may practice any one of the alternative therapies named as *sidda* (herbal medicine), *ayurveda* (combination of herbal and home remedies), homeopathy (Home remedies) and *unani* (an Arabic medical approach) in an effort to alleviate or cure their disease (Shanmugasundaram *et al.* 2006). Diseased people sometimes drink blessed water or recite from holy texts. Some Muslims are instructed to wear an amulet (*taweez*) containing verses from the Quran. As a South Asian Hindu myself, I have experienced that when Hindu people are sick they visit Muslim *hakims* in Mosques for prayers, *pujas* and to receive amulets to seek cure from their sufferings.

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### 2.3.4 Medical care

Traditional medical practices in South Asian countries include the use of *ayurvedic*, *siddha* and homeopathic medicines (Shanmugasundaram *et al.* 2006). Often alternative medicine is used in conjunction with Western medicine, particularly when people believe in the efficacy of both the Western medical system and the traditional healing methods (Ismail *et al.* 2005). It is usually in rural villages in South Asian countries that home grown medical systems are still widely practiced (Patil *et al.* 2002).

South Asians perceive health care providers as being in positions of authority (Patil *et al.* 2002). They feel their role is to be passive, respectful and obedient in the provider's presence (Kemp 2005). Depending on the level of acculturation, it is customary for the patient to expect the relationship with the provider to be formal. The patient or family will seldom ask questions as it might be deemed rude to do so.

If a Western treatment is at odds with the traditional treatment in South Asian communities, the family is likely to ignore the Western medical provider in favour of the tradition healer (Firth 1999, Shanmugasundaram *et al.* 2006, Shanmugasundaram & O'Connor 2009). However, as a South Asian nurse, I have noticed that many South Asians do approach Western medicine for most of their health problems. Studies also support my view, that people from South Asia tend to use most of the health services available including acute hospitals and GP clinics (Firth 2005, Small *et al.* 2005).

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The medical provider is expected to offer tangible solutions and to be confident about proposed treatments or surgery. If this is not the case, the South Asian patient may conclude that the provider lacks skill and may refuse to follow the provider's advice (Blakemore 2000). Most South Asians are not accustomed to being informed of every negative aspect of a prescribed treatment (Barnes *et al.* 1998). The Western model of informing patients may lead to confusion and fear (Rashid *et al.* 2003). The patient's family needs to be consulted if health professionals decide the older people require hospitalisation (Grewal *et al.* 2005, Kwak & Haley 2005). Although blood transfusions, bone marrow or organ transplants are acceptable to most South Asians, organ donations are seldom approved of because of religious implications (Gatrad 1994, Morgan *et al.* 2006).

Hospitals should be aware of religious practices involving the wearing of sacred symbols. Such symbols should not be cut or removed without the patient or family's permission. Examples are a sacred thread worn by high-caste Hindu men over one's shoulder and around the waist, a Sikh man's bracelet and *kirpan*, and 33 beads worn by Muslims around the neck or wrist. Sikh men may not wish to cut their hair. If it must be cut, the reason must be explained fully to both patients and families (Rashid & Sheikh 2002).

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### **2.3.5 Role of family in health and illness**

The deeply rooted joint family network may offer a naturally evolved strong system of social support among South Asian communities (Blakemore 2000, Katbamna *et al.* 2004, Shanmugasundaram & O' Connor 2009, Sheikh *et al.* 2003). The nature of dependency among family members has influenced their attitudes for health behaviour (Gray 2002, Grewal *et al.* 2005). This could lead towards a family decision making style, that may have implications on health seeking, and health care preferences (Kwak & Haley 2005). Hierarchical or collective family decision making are the common forms of health care decision-making among this population (da Costa *et al.* 2002, Shanmugasundaram & O' Connor 2009).

Living with and caring for older parents are established practices within many South Asian families (Gupta 2009). They prefer not to discuss personal, physical or mental problems with anyone outside the family. This originates from a belief that it is shameful to be known as a person with a particular disease, evoking a sense of guilt (Sheikh *et al.* 2003, Spinder & Kangis 2006). There is a prevalent social stigma with certain diseases such as cancer, diabetes, HIV infections among the South Asian population (Randhawa & Owens 2004, Sheikh *et al.* 2003, Yoshioka & Schustack 2001). Sometimes this leads to anxiety and depression, which in turn negatively influences access to, utilisation of, and compliance with health care provision. Matters of personal hygiene are a delicate subject that often preferably done by family members (Shanmugasundaram & O' Connor 2009). South Asian customs in relation to bathing



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and personal clothing are very different than in the West, often imbued with deep religious significance (Katbamna *et al.* 2004, Owens & Randhawa 2004).

## **2.4 South Asian people's cultural attitudes towards end of life**

### **2.4.1 Hinduism and end of life: death as a transition**

Hinduism and its philosophies about end of life are universal. Its core philosophy is accepted and practiced by the vast majority of Hindus living in the UK and elsewhere (Laungani 1999). Hinduism is a way of life with a diverse umbrella of beliefs and practices. Hindus have specific beliefs in common that influence their attitudes towards death and dying (Firth 2005, Sheikh *et al.* 2003). Firth (2005) described that Hindus believe that death is not the end of life, but a transition to another life reincarnation, life in heaven with God or absorption in to *Brahman*, a supreme power. Since *Athma* (inner soul) is a permanent state, this life is a temporary opportunity for Hindus to clean their soul by doing karma. This may indicate, for many Hindus, that fear of death may not exist or may be diluted (Blackburn 1985, Deshpande *et al.* 2005, Sheikh *et al.* 2003). This viewpoint of death may dramatically change Hindus attitudes on end of life care options. Moreover, their views may radically differ from Western palliative care tradition, which views life as finite with an absolute ending (Firth 2005, Sheikh *et al.* 2003).

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#### **2.4.1.1 Notions of good and bad death: views of Hindus**

According to Hindus, a good death is one that has been prepared for throughout life and entered into consciously and willingly with fulfilled life responsibilities (Firth 1999, 2005). Life responsibilities (*karmas*) dictate that all affairs be set in order, unmarried family members (especially girls) should be married, and any long-standing conflicts should be resolved (Deshpande *et al.* 2005, Holloway 2006).

Firth (1999) asserted that according to Hindu beliefs, a good death is one that happens in older age, at the right astrological time and in the right place if on home ground, or on the bank of the sacred River *Ganga* (Ganges) otherwise. It is preferred that *Ganga jal* - water, or milk as an alternative - will be placed by or given to the dying individual by their loved ones (Deshpande *et al.* 2005).

Violent, premature and uncontrolled death occurring in a wrong place, at a wrong time and signified by vomit, faeces, urine and unpleasant circumstances would be considered a bad death (Deshpande *et al.* 2005). Incomplete post-mortem rituals or bad deaths may prevent the soul from moving on, leaving a haunting prospect for relatives, causing bad luck, nightmares, illness and infertility (Blackburn 1985). Death on particular days causes concern in Hindu beliefs. Deaths on Saturday for example may force a dead Hindu's soul to bring another death to their family (Sheikh *et al.* 2003). Hence, according to Hindu's belief, a bad death is greatly feared.

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### 2.4.1.2 Hindu death practices

Many Hindu patients prefer to die at home, whereas others travel to places near the River *Ganga*, which runs in the north of India (Firth 1999). Dying with anger or fear could lead to a lower level of rebirth. Suffering during end of life is often viewed as a reflection of how one acted (karma) in his past life (Sheikh *et al.* 2003). Therefore, it is essential that a terminally ill or dying person make the effort to resolve any unfinished duties or responsibilities.

Many older Hindu people live in state of ‘emotional withdrawal’ and live like a *sanyashi* (an ascetic, free from all worldly responsibilities) in their homes (Laungani 1999). They detach themselves from material and emotional concerns and prepare for death through prayer, scripture reading and meditation. In particular, dying Hindus should use words and thoughts that focus on God. They believe that the nature of one’s thoughts at the time of death will determine the destination of their departing soul (Sheikh *et al.* 2003).

In the event of terminal illness or death, the family performs certain rituals. Culturally, family members will recite prayers or hymns around the dying person and place holy water or a holy leaf on the person’s mouth; Muslims also practice this ritual (Laungani 1999). They believe that rituals can smooth the transition from life to afterlife for the dying patient, and that it is the duty or *dharmic* way for family members to perform these rituals (Gardner 1998). Post-mortem rituals may vary, from disposal of ashes in the river to performing complex rituals lasting from 10 to 16 days (Madan 1992).

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Interfering or neglecting this dharmic obligation will potentially incur bad karma for family members or bring bad health and bad luck for them.

## **2.4.2 Views of death and dying among Muslims**

Islam teaches that death is inevitable. Death does not occur without God's permission, since God is the origin and destiny of this sacred life. The Quran states that life, death and illness are controlled by God, as in the verse:

*'And Allah has created you and then He will cause you to die; and of you there are some who are sent back to senility, so that they know nothing after having known (much). Truly, Allah is All-Knowing, All-Powerful' (16:70).'* (Hedayat 2006).

According to Muslims, being free of illness at the time of dying could be viewed as a good death (Sachedina 2005). Muslims may feel that any interventions that prolong life could interfere with the natural death process, since death is God's plan. This implies that health care providers may need to consult individual Muslim preferences about using life-sustaining therapies (da Costa *et al.* 2002, Gardner 1998).

Many Muslims view experiencing pain as a way to understand God. They believe God will reward those experiencing pain with the rank of a true believer (Sachedina 2005). However, this stand should not be taken to mean Muslims should suffer pain to satisfy their God. It should be interpreted as a means of spiritual support for those who lose

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hope during their illness (Rashid & Sheikh 2002). The Holy Quran teaches that pain is a trial, and an outcome of misconduct and punishment to compensate for a sin – similar to the concept of *karma* (Sachedina 2005). As individuals are responsible for causing pain, it is their responsibility to do righteous acts to get rid of pain. Hence, Muslims support pain relief measures as in the Quranic verse ‘for sure, the good deeds will drive away the evil deeds’ (30:13)(Kemp 2005).

Muslims believe that they need to maintain their body without any illness to prolong life and wait for natural death at God’s call (Rashid & Sheikh 2002). The Quran teaches that Muslims have to accept their own limitations and allow nature to take its course in situations beyond their control, such as when death is imminent. This stand would allow Muslims to withdraw any invasive life sustaining treatments which may be viewed as ‘standing against Gods will’ to end this life (Kemp 2005).

## **2.5 End of life care perspectives among South Asian communities**

### **2.5.1 Advance care planning**

Advance Care Planning (ACP) is a ‘process of discussion’ that may facilitate documented guidelines for individual future care preferences (Henry & Seymour 2007). Data from an Australian prospective randomized controlled trial of 154 of the 309

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legally competent medical inpatients aged 80 or more who received usual care with advance care planning show that 86% of patients' ends of life wishes are much more likely to be known and followed, compared to only 30% of the patients who received only usual care. Furthermore, this study also evidenced that family members of who died had reduced stress, anxiety and depression and greater family satisfaction(Detering *et al.* 2010). However, previous studies in multicultural environments also shown the difficulties in exploring such preferences and needs, due to lack of public knowledge about available palliative care services (Seymour *et al.* 2007, Worth *et al.* 2009), while another study that showed how community nurses struggled to implement advanced care planning (Seymour *et al.* 2010).

Islamic tradition supports ACP as its core teachings calls all the Muslims to prepare a will to give their wealth to their family (Rashid *et al.* 2003, Sachedina 2005). This may provide an opening for discussing ACP with Muslims. However, as aforementioned, South Asians' believe that death is willed by God (for Muslims) and that the nature of death is based on their *karma* (for Hindus) (Firth 2005, Sachedina 2005). This in turn may indicate that end of life decisions, such as ACP, are mostly associated with negative feelings and attitudes. These attitudes may result in non-participation in end of life discussions and unwillingness to complete any form of ACP. Research in the USA reported low levels of completion of advanced directives among Asians compared with Native Americans (Kwak & Haley 2005).

Studies have also shown that in extreme suffering of pain and severe illness, many South Asians frequently rely heavily on the advice of doctors (da Costa *et al.* 2002). Another

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study found that even if religious teachings support suffering in pain as the means of expiating for sins, the practical reality is that patients prefer medications that can make death more comfortable (Njobvu *et al.* 1999). However, there is a dearth of studies that have investigated the views of ethnic minorities, particularly South Asians, on end of life care preparatory documents such as ACP.

## **2.5.2 Decision making in end of life**

Making end of life decisions is a difficult task for everyone, particularly in cross-cultural situations where differing belief systems may exist between service provider and user. This is because, as Gunaratnam (1997) argued, health providers often do not offer end of life care that are choices compatible with cultural traditions or individual preferences. She further highlighted that:

*more frequently care choices for the older people do not simply reflect their own choices...rather those choices were often struggled over, negotiated and evolved in relation to knowledge about services, personal values, changing family roles, relationships and the progression of diseases.*

It is generally accepted that the principles of patient autonomy and individual decision making in Western society may be not completely transferable to Black and ethnic minority populations (Lapine *et al.* 2001, Owens & Randhawa 2004, Searight & Gafford

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2005). In the UK, Rashid & Sheikh (2002) suggested that health providers need to discuss with the family prior to informing patients about any disclosure. Owens & Randhawa (2004) advocated the importance of recognising cultural variations within the different ethnic groups as well as power relations within families in relation to end of life care decision making. Sadler *et al.* (2001) found that low uptake in breast cancer screening services among South Asian women was not only affected by low literacy levels, but also by the gate-keeping role of the men in their family. Arguably, the notion of family decision making *de facto* means male decision making, which may silence some hidden family members such as women (Grewal *et al.* 2005) and frail older people (Gupta 2009).

### **2.5.3 Disclosure**

Western bio-ethics of disclosing disease information is based on patient autonomy and right to information (Carey & Cosgrove 2006, Lapine *et al.* 2001). It is believed that open disclosure may facilitate preparation for an individual's death, and help them to fulfil any unfinished life wishes (Samuel & Susan 2002). In contrast to this, studies from the USA found high rates of desired non-disclosure of cancer diagnosis among the Asian oncology population who practiced family-centred decision making (Sadler *et al.* 2001).

As a practising Asian Hindu, I can appreciate that older Hindus are more open compared to younger people in discussing sensitive issues. They may welcome such discussions to



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show their experiences or demonstrate their emotional maturity and ability to discuss such sensitive topics. However, Firth (2005) observed that South Asians preferred non-disclosure, because disclosure may precipitate loss of hope for their older parents. Therefore, as Rashid *et al.* (2003) concurred in the case of older South Asians, it is better to allow the relatives rather than health professionals to make the decision of whether to disclose information to the dying individual.

Culturally, South Asians will make this decision collectively rather than individually. However, while family hierarchy will determine the final decision about disclosure and prognosis, elders may be excluded from decision making, assuming this may cause them distress for them (Deshpande *et al.* 2005). The higher ranked family members, for example the eldest men in the family, will seek information regarding specific details from the health professionals (Kagawa-Singer & Blackhall 2001), and normally the details may be withheld from older people if it they would cause distress.

In India, a dying person can be taken from the hospital to home, which implicitly discloses to the patient that death is imminent (Laungani 1999). However, little is known of the perspectives of older South Asians about how *they* want to receive information. Furthermore, the acceptable methods whereby health professionals can disclose prognoses to older South Asians are also less known.

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## 2.5.4 Euthanasia and withdrawal of treatment

South Asians (Muslims, Hindus and Jains) believe that through following a path which leads to a willed death, the body is relinquished voluntarily to God. Voluntary deaths were practiced by previous generations of Jains and Hindus (Laungani 1999). An example of a voluntary death is fasting to death. The terminally ill patient may prefer a 'fast to death' in order to attain spiritual purification, which prompts detachment and ensures no signs of bad smell from bad death (Firth 2005). In other words, South Asian religious people often aspire to the ideal of dying naturally rather than with chronic suffering or sudden suicides.

A person who views pain as a means to clean up any sin may refuse treatment in order to die with a clear, unclouded mind. This is important for health professionals as these beliefs conflict with modern Western values of maintaining life without suffering through using symptom management until death (Rashid *et al.* 2003). Many older Hindu patients may accept death much more than the average Western agnostic or atheist, since they believe that life is a continuum rather than an end (Searight & Gafford 2005). Therefore, once the prognosis for recovery is nil, the family may opt for comfort care to provide a peaceful death and ensure a smooth transition to next life.

Obtaining consent for the withdrawal of life sustaining therapies from a dying person who cannot give consent is often complicated, particularly if the family are resistant. Life sustaining interventions such as ventilators and artificial tube feedings may be

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viewed as making a struggle for the soul that would prefer liberation from the body, which is simply a dress for the soul to continue living (Rashid & Sheikh 2002). Thereby, life sustaining interventions may be potentially viewed as interfering with an individual's' *Karma* (Firth 2005). However, feeding the body and treating infections which would bring comfort rather than prolong the life are likely to be acceptable (da Costa *et al.* 2002, Firth 2005).

### **2.5.5 Preferred priorities of care**

Studies have demonstrated that culture, ethnicity and socio-economic factors may influence preferred place of death (Crawley 2005, Higginson *et al.* 1999, Koffman & Higginson 2004, Phipps *et al.* 2003, Spruyt 1999) of older people. Apart from this, the context factors such as previous experience with services, common places of death, knowledge about services such as hospice care may also influence people's attitude towards their preferred place of end of life care (Rashid & Sheikh 2002, Seymour *et al.* 2007).

South Asian Muslims may prefer a home rather than a hospital or hospice death (Boussarsar & Bouchoucha 2006, Merrell *et al.* 2006). Islamic traditions of supporting the dying persons' family through visiting their homes, prayer recitals and large group gatherings to console the immediate family are considered as *sunnah* (a practice of the Prophet Mohammad), but may not be possible in hospitals or hospices (Spruyt 1999).

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The dying person may use this opportunity to make amends for any sins committed during their lifetime.

Sometimes relatives may want to consult their religious healers such as *hakims* and *pirs* to consider alternative opportunities for recovery (Gardner 2002, Rashid & Sheikh 2002). Conversely, these practices may not be possible in a hospital setting (Sheikh *et al.* 2003). Therefore, to facilitate such cultural practices, families may prefer to bring the dying persons to their home, if it is known that death to be anticipated (Gardner 1998). A study by Spruyt (1999) for example evidenced this as among 18 reported palliative care experiences of bereaved primary carers; fourteen patients died in East London, ten occurred at home, but thirteen were buried in Bangladesh.

Firth (2005) reported various observations about deaths among Hindus in India. She described that in the Indian subcontinent, many older Indians die at home. Therefore, relatives take the dying persons to the home to facilitate dying around the family rather than dying in the hospital. In some parts of India, dying Hindus may leave or go voluntarily to Varanasi, a holy place where the holy River Ganga runs, as they believe that dying in this place may give *motsha*, 'to attain God's feet' (Firth 2005). A qualitative study among six family members of terminally ill Indian migrants in Australia also suggested how family members experience difficulties whilst receiving palliative care services due to distinct Indian support systems, cultural issues that dramatically influenced their caring experience (Shanmugasundaram & O' Connor 2009).

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In contrast, existing literature about South Asians living in the UK portrayed different perspectives. For example, Laungani (1999) in his paper about death among Hindus in India and England found home is the second choice for older South Asians who live in Britain. Furthermore, he described that hospital death is usually their first choice in order to relieve relatives from the burden of care. Similarly, another paper illustrated the belief that attending or visiting specialist palliative inpatient units may bring bad luck to their families (Sheikh *et al.* 2003), and therefore prevent them from using a hospice or hospital as a preferred place of death. Consequently, they often may view these units as foreign places which may raise cultural stigma about these places among these people (Vydelingum 2000). Vydelingum explored the ‘lived experience’ of 10 South Asian patients and their six family carers of acute hospital care, and found that patients seemed to want to cause as little disruption as possible to the ward environment and tried to fit in to what they refer to as an ‘English place’, where they expected their cultural observances would be inhibited (Vydelingum 2000).

## **2.6 Health professionals, South Asians and end of life**

Caring in multi-cultural environments, especially in palliative and end of life care settings, remains one of the challenges for health professionals. This is particularly difficult when service users such as older South Asians present diverse beliefs and practices. Recent policy initiatives, including end of life care strategy (2008), urge health professionals’ responsibility to deliver a quality of end of life care, irrespective of ethnic and culture differences among service users (DH 2006, 2007, 2008). However,

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existing literature has highlighted the diverse needs, barriers and inadequate training and education among health professionals caring for older South Asians during their end of life care (Diver 2003, Gunaratnam 2001, Owens & Randhawa 2004).

## **2.6.1 Communication**

In several studies, health professionals have stated that one of their major difficulties in providing quality end of life care for minority ethnic people is communication barriers (Diver 2003, Gunaratnam 2001). It is particularly important given that many older South Asians living in the UK lack fluency in English (Clegg 2003, Diver *et al.* 2003, Gunaratnam 2001, Merrell *et al.* 2006). Interviews with bereaved primary carers of 18 Bangladeshi patients in the East London found that communication difficulties were one of the common issues in their reported palliative care experience for their dying relatives (Spruyt 1999). This study showed that the fluency in English of patients was low, with reliance on family members, especially children, for translation. In fact, this study also found that anecdotal records of local community palliative care team recorded how the entire team was dissatisfied with their communication with local Bangladeshi patients in 16 cases. Furthermore, Diver (2003) argued that poor cross-cultural linguistic skills among health professionals may hinder their efficiency in defining exact needs, preferences and undertaking detailed assessments in relation to palliative and end of life care.

Hospice staff who participated in Gunaratnam's (1997) qualitative study that investigated caring experiences of hospice nurses advocated the increased use of

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interpreters and using family members or written boards to help to resolve communication issues. Conversely, Diver (2003), in her study that examined palliative care nurses' experiences of caring for ethnic minority patients showed mixed views regarding the use of interpreters in relation to limited availability and their competency in discussing personal and sensitive issues around end of life care. There are also similar views concerning the use of family members as effective interpreters (Gray 2002, Merrell *et al.* 2006).

In Owens and Randwaha's (2004) phenomenological study of ten staff who worked in community-based palliative care settings found various challenges faced by those trying to develop 'culturally competent' palliative care for South Asian cancer patients. Some staff in their study reported how they were suspicious of the accuracy of translation which could influence the quality of care they provide (Owens & Randhawa 2004). Similarly, 24 palliative care staff who participated in the focus groups in Richardson *et al.*'s (2006) study felt that it was more difficult to work with interpreters, as well as family members, both of who could be reluctant to translate important information to the dying patients.

Data from the study among district nurses who cared for South Asian patients showed that staff have also used alternative means of communication, such as using body language (Gerrish 2001). However, it is unlikely that such measures provide a solution to minimise their communication barriers, particularly in situations where health professionals need to inform clients or elicit more information on their preferences concerning end of life care. Health professionals working in specialist palliative care

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settings need to be familiar with the cultural beliefs of older South Asians. This cross-cultural end of life care knowledge could serve as a resource for trained interpreters such as Macmillan ethnic minority liaison officers (Ackroyd 2003).

## **2.6.2 Cultural awareness**

There has been emphasis on the need for increased cross-cultural knowledge for health professionals to provide culturally competent palliative care (Canales & Bowers 2001, Owens & Randhawa 2004, Somerville 2001). Arguably, the elements of cultural competency may attribute a one size fits all attitude of culture-specific care, which may promote a checklist approach to caring in other cultures (Gunaratnam 1997). Findings from Vydelingum's (2006) study of 43 nurses in a general hospital found evidence of various ethnocentric practices. These included a tendency for professionals to treat all minority ethnic patients the same, with false consciousness of equity and victim-blaming approaches, mainly due to their limited cross-cultural knowledge. Moreover, this crude formulaic approach may result in stereotyping South Asians, particularly in palliative care settings, where sensitivity of issues need to be addressed not only holistically, but also in an individualised manner (Jones 2005).

Diver (2003) advocated that health professionals need insight into cultural awareness and understanding that may act as an essential step towards providing holistic and individualized care. Gunaratnam (1997) also argued that health professionals not only



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need to have better understanding about cross-cultural specific knowledge, but also self-awareness about their own culture, which may be essential to appreciate and reduce cultural differences and tensions.

### **2.6.3 Preferred priorities of care**

The acute ward nurses in Vydelingum's (2006) study felt that when patients died in hospital, families are often left with 'rushed images' in comparison to the 'peaceful memories' that they have a right to receive from hospice care. Nonetheless, community palliative care staff in another study (Owens & Randhawa 2004) also mentioned that having a strong 'Christian image' of end of life care settings such as in hospices may have resulted in poor access to information and use of such services among South Asians. Firth (2005) noted that South Asians need large spaces to host family visits and prayer. Hence, hospice staff in another study (Diver 2003) reported that they have increasingly appreciated that home and community remains the 'locus of cultural identity' and can offer a place for privacy, intimacy and emotion for caring South Asians.

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## 2.6.4 Family

The system of South Asians living as a joint supportive family network, and their influence in care decisions particularly during the end of life is well-documented (Blakemore 2000, Diver 2003, Shanmugasundaram & O' Connor 2009, Worth *et al.* 2009). Data from an Australian study among family members of terminally ill Indian migrants also suggested how family members experienced difficulties whilst receiving palliative care services (Shanmugasundaram & O' Connor 2009). This study highlighted how such issues were heightened due to distinct Indian support systems, and cultural issues that dramatically influenced their caring experience. This study concluded the importance of family in assessing and improving culturally appropriate care in a palliative care context, in which the family, rather than just the individual, is the focus of care.

In fact, another study in the UK showed that health professionals have shown positive attitudes about family involvement during end of life (Merrell *et al.* 2005). This included family support in the decision-making process, helping in physical needs, and psychological support for the dying persons and supporting the health professionals to access their patients when they have poor English-speaking competencies (Merrell *et al.* 2005). However, Gunaratnam (2001) described how hospice staff faced 'dilemmas' in practicing anti-discriminatory procedures when other patients from dominant cultures tend to 'make ethnic minority people to feel inferior'.

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## 2.7 Summary

There are inequalities in access to health services including palliative and end of life care services among ethnic minorities. Increased longevity coupled with the higher incidence of malignant and non-malignant diseases (Shavers & Brown 2002, Smith *et al.* 2003) mean that many older South Asians are living with unmet palliative and end of life care needs in the UK (Smaje & Field 1997, Worth *et al.* 2009). There is evidence that older people from ethnic minorities who are living with chronic diseases, particularly South Asians, face particular challenges in relation to their use of available palliative and end of life care services (Rashid *et al.* 2003).

Despite recent policy initiatives that urge valuing patients' choices (DH 2007), health professionals may still experience ambivalence, ignorance and uncertainty whilst caring for older South Asian people (Fountain 1999, Owens & Randhawa 2004, Richardson *et al.* 2006). The evidence suggests a lack of cross-cultural linguistic skills and inadequate cross-cultural end of life knowledge amongst palliative care professionals (Diver 2003, Worth *et al.* 2009) and general practitioners (Burt *et al.* 2006). In such situations, poorly informed and inadequately trained health professionals may adopt a 'culturally distant position' that may obstruct their ability to meet individual needs (Gunaratnam 2001) and result in poor referral rates (Ahmed *et al.* 2004). It has been argued that eliciting preferences for end of life care may be one approach to address these issues of inequality (Diver 2003, Randhawa & Owens 2004, Richardson *et al.* 2006). Hence the focus of this study is to explore the end of life perspectives of older South Asians with the following aims and objectives.

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## **2.8 Aim and objectives of this study**

This study aims to explore knowledge, experiences, preferences and attitudes about end of life issues amongst older South Asian people living in selected boroughs in East London.

### **Specific objectives**

- To explore older South Asians' attitudes and preferences relating to death and dying.
- To examine older South Asians' experiences of providing end of life care.
- To explore older South Asians' knowledge, attitudes and preferences related to end of life discussions and decisions.

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## CHAPTER 3

# Methodology and Methods

Previous chapters have informed the need for further research to explore and critically examine views and perceptions about end of life issues among older South Asians. This chapter provides details of the methodological considerations that informed the design of the study. In the first section of this methodology chapter I describe the methodological approach taken. The second section describes the methods used to undertake study including the process of fieldwork, ethical considerations and data analysis.

### 3.1 Overview

This study adopted a constructive grounded theory approach to explore the end of life issues among older South Asians living in East London. After gaining ethical approval, five focus groups and 29 in-depth, semi-structured interviews were conducted with a total of 55 participants. Participants were recruited through 11 community organisations. Gender-specific focus groups were conducted with a minimum of six and a maximum of 12 participants. Focus groups were conducted mainly in community halls, although one was conducted at a participant's home. Most of the interviews were conducted in the

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participants' own homes or the homes of a member of their family (n=23), with the remainder conducted in a hall where the participant was a member of a local community group (n=6). As a multilingual researcher, I conducted most of the interviews and focus groups in the participants' preferred language, except one focus group which was conducted with the support of an interpreter. An aide-memoire was used as a prompt to conduct the focus groups and interviews.

## **3.2 Methodology**

Methodology refers to an appropriate set of actions or 'guiding principles' that any researcher devises to find answers for his or her research problem (Backman & Kyngäs 1999, Greckhamer & Koro-Ljungberg 2005). This study adopted a constructivist grounded theory approach (Charmaz 1983, Charmaz 2000). This approach was considered appropriate for the aims of the study in order to obtain the collective views of older South Asians and develop a theoretical framework within which to explain their existing common shared meanings towards end of life.

### **3.2.1 Grounded theory**

Grounded theory is the most extensively cited qualitative research method in social sciences (Bryant & Charmaz 2007b) and also a popular qualitative design in nursing

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studies (McCann & Clark 2003, Schreiber & Stern 2001). The origins of grounded theory are associated with two American sociologists, Barney Glaser and Anselm Strauss, and their study of hospital staff's experience of caring for dying patients entitled *Awareness of Dying* (Glaser & Strauss 1965). Two years later they published *The Discovery of Grounded Theory* (Glaser & Strauss 1967), which described how their newer inductive, qualitative procedures could generate theory while maintaining rigour that hitherto was seen as the domain of quantitative methodologies (Babchuk 2008 )... This 'qualitative turn' (Bryant & Charmaz 2007a), has been viewed by Denzin and Lincoln (2005) as a 'golden age of qualitative analysis', as it rejected traditional positivistic quantitative inquiries that were based on an external or objective reality. Since then, it has 'served at the front of qualitative revolution' (Charmaz 2000), as it aimed to transcend qualitative enquiry beyond description towards explanatory frameworks. However, since its conception, various versions of 'doing' grounded theory have emerged. Thus the 'methodological spiral' of grounded theory (Mills *et al.* 2007) has travelled from positivist realism (Glaser & Strauss 1967) to social constructivism (Charmaz 2000), through hermeneutics (Rennie 2000) and postmodernism (Adele E. Clarke 2003).

This study adopted a constructivist grounded theory approach (Charmaz 1983, Charmaz 2000). Nevertheless, I agree with Bryant & Charmaz (2007b), who suggested that the 'researcher needs to be familiar with grounded theory method, in all its forms, in order to understand how they might adapt it in use or revise it into new forms and variations'. Therefore in this chapter I examine different positions of grounded theory within a broader family of grounded theory methods that have emerged since its inception.

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Following this, I discuss the philosophical underpinnings of constructive grounded theory and present why I chose this as the methodological basis for my study, drawing on examples of studies from the field of end of life.

### **3.2.2 Contribution of grounded theory in the ‘second moment of qualitative research’**

Grounded theory (Glaser & Strauss 1967) has drawn its philosophical roots from the theoretical foundations of symbolic interactionism and pragmatism (Clarke 2003, Jeon 2004, Payne 2007). Originated from the work of George Mead (1934)(Jeon 2004), heavily informed by interpretivism, Lomborg and Kirkevold (2003) described symbolic interactionism assumes ‘human beings construct and reconstruct the meaning of reality in a constant interaction with the self and others’. Pragmatism asserts that truth is relative to the time, place and purpose of the investigation and it rejects any speculation on questions that have no practical application (Chenitz 1986). Charmaz (2006, p.2) portrayed ‘pragmatism informed symbolic interactionism’ as a theoretical perspective that assumes society, reality and self are constructed through interaction, and thus rely on language and communication.

Glaser and Strauss (1967) themselves have had their own conflicting interpretations of their original method, particularly at points about the appropriate procedural and methodological basis of the approach. As a result Glaser called for an extension of



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classic or original grounded theory in his books on *Theoretical Sensitivity* (Glaser 1978) and *Emergence vs. Forcing: Basics of qualitative research* (Glaser 1992). In contrast, Strauss launched his own trajectory in *Qualitative Analysis for Social Scientists* (Strauss 1987), and furthered the work with his student Juliet Corbin in *Basics of Qualitative Research* (Strauss & Corbin 1990, Strauss & Corbin 1998). Fundamentally, Glaser (1992) argued that Strauss and Corbin's grounded theory method consisted of numerous smaller steps that stood as a highly structured coding paradigm often 'forces the data through full conceptual description' (p. 3), which he claimed reverts to a quantitative paradigm of verification methods. Bryant and Charmaz (2007b) also contested Strauss and Corbin ideas of using a 'conditional matrix'. On the other hand, Kelle (2007) argued that modern grounded theorists often rejected the challenging use of Glaser's 'eighteen ambiguous theoretical coding families'.

This conflict subsequently encouraged others to devise their own versions of doing grounded theory based on more varied ontological and epistemological positions (Greckhamer & Koro-Ljungberg 2005, Locke 1996, Suddaby 2006), what Bryant and Charmaz (2007b, p. xi) termed the 'methodological fray'. Such differences, according to O'Neil Green et al. (2007), led to three visible and distinct traditions of grounded theory:

Emergent: A Glaserian version of grounded theory whereby the researcher takes a position where data analysis is emergent and dictates the study's direction (Glaser 1992).

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Systematic: A Straussian version of coding by using a systematic matrix (Strauss & Corbin 1998).

Constructivist: A version by Charmaz (2006) whereby the researcher and his or her existence remains central to data collection and theory development.

The proliferation of versions of grounded theory means that there remains much ambiguity about the term ‘grounded theory’. In this thesis and in the conduct of my study I have tended to follow Charmaz (2006), who differentiated between ‘product’ and ‘process’. She described grounded theory as an ‘outcome product of inquiry’ and grounded theory methods as a specific mode of analysis which consists of a set of flexible guidelines.

On the whole, witnessing these multiple versions of grounded theory methods, Greckhamer and Koro-Ljungberg (2005) were concerned about the ‘erosion of grounded theory’. Nevertheless, Mills et al. (2007) pointed out that such growing traditions are necessary for a ‘methodological spiral’ which reflects greater, growing interest among scholars who used this approach to solve their research problems. On the other hand, accepting Denzin (2007) suggestion that grounded theory is ‘not a unified framework’, but a ‘family of methods’ (Bryant & Charmaz 2007b). Many scholars (Charmaz 2006, Creswell 2007, Goulding 2002, Hood 2007) agree that the similarities or resemblances shared by all versions of grounded theory have made it a separate qualitative approach from other qualitative traditions.

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Indeed, Morse (2001) identified unique characteristics among the theories that are developed through this method. Grounded theorists have in common a focus on a research process which has a ‘set of systematic, flexible guidelines for collecting and analysing qualitative data to construct theories that are ‘grounded’ in the data themselves’ (Charmaz 2006 ). They use ‘gerunds’, meaning action and change (Glaser 1996). They identify and develop theoretical elements that are used to tie those stages and phases of the theory together. Strauss and Corbin (1998) considered those elements as a ‘core category’, whereas Glaser (1978) described as a ‘basic social process’ and ‘basic social psychological process’. Charmaz (2006, p. 181) contested the language of ‘social process’, arguing that use of grounded theory methods to produce an ‘a conceptual analysis of patterned relationships’ by which the researchers construct theories from the ‘fabric of the interactions’ (Charmaz, 2006, p. 178).

Some argue that the major limitation of grounded theory methodology is its inability to generalize its discovered theory into other settings due to the fact that is a ‘local theory’ (Cutcliffe 2005). He reasoned that it was due to grounded theory being an ‘aggregate of isolated theories of particular phenomena’, sometimes from individuals with limited experience or knowledge. However, I contend that grounded theory can contribute to developing understanding and uncover the unknown, under-researched topics, which can be explained and then used in similar settings.

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### 3.2.3 Constructive grounded theory

Charmaz, the social constructive grounded theorist, disregarded both the Glaserian' tradition of emerging theory and the Straussian version of forcing grounded theory. Rather, she contends that 'neither data nor theories are discovered' (Charmaz 2006, p. 10). She defined the grounded theory method as a 'systematic, inductive and comparative approach for conducting inquiry for the purpose of constructing theory' (Bryant & Charmaz 2007b). One of the unique features of constructivist grounded theory is that the researcher is inseparable from the research process. Charmaz (2006) criticised traditional grounded theorists as having 'intentionally blurred the sharp distinction between data collection and data analysis' whereby the role of the researcher is highly influential in constructing the theory: 'We (researchers) construct our grounded theories through our past and present involvements and interactions with people, perspectives and research practices' (Charmaz, 2006, p. 130).

According to this methodological orientation, our social world consists of 'multiple realities' that can be elicited by obtaining views of people and their common shared beliefs about social events (Charmaz 2006, Mills *et al.* 2006). Jeon (2004) argued that constructivist epistemologies view knowledge as being created through the interaction of the researcher and the researched. Accordingly, the constructivist researcher aims to elicit multiple perspectives about the study topic from his or her participants, while remaining aware of the role that he or she plays in the interpretation and representation of these in the study process (Barnsteiner 2002, Jeon 2004). Charmaz (2006) highlighted

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the shared interactions of the researchers and multiple social actors which co-constructs cultural and socially specific meanings and experiences.

By integrating constructivism within the research process, Charmaz (2006, p. 180) argued that ‘constructivism loosens the grounded theory from its objectivist foundations’. As such, constructivism ‘assumes the relativism of multiple social realities, recognises the mutual creation of knowledge by the viewer and the viewed, and aims toward interpretive understandings of subjects’ meanings’ (Charmaz 2000). Thereby, constructive grounded theory offers ‘an interpretive portrayal of the studied world, not an exact picture of it’ going beyond the position of positivist to multiple realisms (Charmaz 2006 ).

Charmaz’ view is distinct from traditional grounded theories by placing the importance of the phenomena under study that sees both data and analysis as created from shared experiences and relationships with participants (Charmaz 1994, 1995, 2000, Charmaz & Mitchell 1996). Unlike previous versions, for Charmaz (2006, p. 130), constructive approach ‘not only theorizes the interpretive work that research participants do, but also acknowledges that the resulting theory is an interpretation’.

Not surprisingly, Glaser (2002) strongly opposed the constructivist tradition and was alarmed by the ‘descriptive capture’ and inability to remove ‘researcher bias’ that would ensue with the active interpretive role of the researcher. Charmaz (2006, p. 130) contested this and suggested that the traditional objectivist approach to grounded theory

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‘erases the social context from which data emerge, the influence of the researcher and interactions between the researcher and participants’.

### **3.2.4 Adaptation and application of constructive grounded theory**

This study used a social constructivist version of grounded theory to explore meaning associated with the end of life and preferences for end of life care among older South Asians living in the UK. According to this methodological orientation, our social world consists of ‘multiple realities’ that can be elicited by obtaining views of people and their common shared beliefs about social events (Charmaz 2006 , Mills *et al.* 2006). Accordingly, the constructivist researcher aims to elicit multiple perspectives about the study topic from his or her participants, while remaining aware of the role that he or she plays in the interpretation and representation of these in the study process (Barnsteiner 2002, Jeon 2004). Therefore, by adopting a constructive paradigm, I aimed to collect multiple views about end of life from older South Asians that could be obtained from their description of their experiences, attitudes, preferences and knowledge.

Grounded theory is widely used by social scientists and has been used in many health care settings such as critical care (Williams 2005), mental health (Humberstone 2002) and maternity (Marcellus 2005). The application of grounded theory in palliative and end of life care research has been used to discover the main concerns of patients (Elgan

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*et al.* 2005, Kylma *et al.* 2001, Xie *et al.* 2006), families (Carter *et al.* 2004, Holtslander & Duggleby 2008, Mok *et al.* 2002), health professionals (Verpoort *et al.* 2004, Willard & Luker 2006) and the general population (Payne *et al.* 2008). Wilson (2000) pointed out the ability of grounded theory studies to gather insight into complex life events or dilemmas such as end of life care when death is imminent. In her study, Wilson (2000) used grounded theory to explore Canadian senior citizens views towards death and dying that identified their end of life preferences.

In line with Glaser (2002), Cutcliffe (2005) argued that doing a literature review before data collection in a grounded theory study may pollute ‘naivety and sensitivity’ of emerging findings. However, I examined the literature about South Asians’ views towards palliative care and end of life for the purpose of pragmatism. This was needed to understand preconceptions and assumptions, and in the preparation of the proposal, ethical approval application, aide-memoire, and to ensure that originality was maintained (Payne 2007).

The adoption of a grounded theory approach in this study has several benefits. Researchers choose grounded theory to a) explore little known topic areas; b) elicit experiences and preferences; or c) challenge existing or develop new theory of their participants (Payne 2007). In Chapter 2, the literature review revealed a lack of research in this area. Using grounded theory had the potential to uncover issues relating to end of life among older South Asians. Furthermore, I envisaged that using grounded theory could help in meeting the aims of this study to not only describe the views of older South Asians, but also to derive and develop theoretical explanations in relation to these

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views. Similarly Payne et al. (2008) used grounded theory for example, to understand the role of Western medicine and Chinese traditional medicine in treating older Chinese people suffering from cancer and the role it played in their end of life preferences.

Grounded theory can also be useful to explore the role of context or the environment in facilitating, hindering and influencing human interactions and intentions (Barnsteiner 2002). By understanding older South Asian perceptions about end of life, the study had the potential to illuminate how and what kind of adaptive processes these people may use to negotiate their end of life living in a country different from their homeland.

In summary, the aim of grounded theory is to generate a theory that is ‘grounded’ in and systematically derived from data (Clarke 2005). The created theory is encompassed in mutually connected concepts or categories which explain, describe, and explore shared meanings of events for people (Jeon 2004). This is possible by observing peoples’ interactions whilst engaging them in field research and interviews which are the common methods for gathering data in grounded theory (Backman & Kyngäs 1999).

### **3.3 Study design**

In this study, focus groups and semi-structured interviews were used as complementary ways of collecting qualitative data. Focus groups are described as “collective group discussions that may provide an in-depth understanding into the perceptions and points of view of people related to the research topic, while allowing



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an appreciation of the variation in experiences” (Krueger 2000). The focus group was chosen due to its ability to access and uncover people’s experiences (Kuo & Fagan 1999, Merrell *et al.* 2006) and help the researcher to clarify issues, allowing the exploration of unanticipated but potentially fruitful discussions (Seymour *et al.* 2002). Most importantly in focus groups, participants tend to express views that they might not express in other settings (Halcomb *et al.* 2007). However, various factors must contribute to the success of limitation of focus groups, including unknown (Krueger 1994) and familiar participants (Powell *et al.* 1996), dominant voices (Krueger 1994), group size (McLafferty 2004) and moderator effect (Agar & MacDonald 1995, Fern 1982).

Despite this, focus groups have been widely used to explore attitudes towards end of life (Seymour *et al.* 2002), decision-making processes (Forbes *et al.* 2000, McLafferty 2004), preferences (Steinhauser *et al.* 2001), palliative care needs (McIlfatrick 2007) and challenges to care delivery (Merrell *et al.* 2006). Increasingly, focus groups have been used to access and obtain accounts of minority ethnic groups (Greenhalgh *et al.* 1998, Payne *et al.* 2005) living in a dominant culture that may exclude their research participation (Nazroo 2003).

Semi-structured interviews were conducted in parallel to the focus groups to obtain in-depth individual accounts of end of life issues from older South Asian people. Interviews are a traditional and popular research tool for exploring meaning and perceptions and for gaining rich descriptions of the phenomena under investigation

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(Fontana & Frey 1994, Pope 2006). The choice of interviews for this study was not only for its purpose to serve as a complementary tool for focus groups, but also its value to explore meanings and perceptions in depth and on a more personal level (Murray 2003). Although a sensitive area of study, interviews have been used in palliative and end of life care research to get answers to a wide range of questions (Marilyn *et al.* 2007). Some examples include, assessing palliative care needs (Temple *et al.* 2002), end of life care experiences (McIlfatrick 2007), preferences (Fisker & Strandmark 2007), issues around care (McGrath 2007) and in evaluating care intervention outcomes (Carlson *et al.* 2007).

Different authors classify interviews according to different forms; most agree they can be classified as unstructured, semi-structured and structured (Kavanaugh & Lioness 1998). Unstructured and semi-structured interviews are more appealing to qualitative researchers than structured interviews (Silverman 1998). Semi-structured or individual in-depth interviews will allow the interviewer to delve deeply into social and individual accounts (Price 2002).

### **3.3.1 Setting**

This study was conducted in the service catchment areas of St. Joseph's Hospice in East London. This choice of East London was related to two factors. Firstly, there was an existing research partnership between St. Joseph's Hospice, East London and the

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University of Nottingham where I studied. Discussions with this hospice helped to identify study objectives that were relevant to their service. Secondly, the relatively high proportion of South Asians living in East London meant that it was a suitable location from which to recruit the sample. Greater London is a metropolitan city consisting of 32 boroughs. Almost half of the ethnic minorities (45%) living in the United Kingdom live in London, which includes more than 50 ethnic groups (ONS 2001). Asians (12.8%), followed by Black people (10%) constitute the major ethnic minority groups in London (CRE 2007). However, the Commission for Racial Equality (2007) reported that the rapidly growing population of white Eastern Europeans emigrating to the UK in recent years may change this ethnic composition in the near future.

According to the Office of National Statistics (2001), East London has one of the most ethnically diverse populations in Greater London. South Asians are one of the largest ethnic minority groups in the boroughs in East London (Newham (33%), Tower Hamlets (37%) and Hackney (9%). Compared to other regions in London, East London has a higher proportion of people with a lower socio-economic status and with higher socio-health needs (ONS 2001).

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### 3.3.2 Sampling strategy

The primary aim of any sampling method is to draw the appropriate sample from the study population (Coyne 1997, Marshall 1996). The following factors were considered as guiding principles for my sampling strategy:

- Diversity in language use, ethnicity and culture among the South Asians.
- Involving vulnerable groups such as ethnic minorities and older groups.
- Discussing highly sensitive issues.
- Accessing hidden populations.

Given my need for more flexibility, in this study I opted to use a purposive sampling to produce a range of study participants in the selected boroughs of East London. This is because, in purposive sampling, ‘the researcher actively selects the most productive sample to answer the research question’ (Marshall 1996). Community leaders of local South Asian community groups and open meetings with their older people groups played a major role in enabling to sample these participants into this study.

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### 3.3.3 Inclusion and Exclusion criteria

Box 1: Inclusion and Exclusion Criteria
<p><b>The study recruited participants who:</b></p> <ol style="list-style-type: none"><li><b>1. Self-classified their ethnic orientation as South Asian.</b></li><li><b>2. Lived in the boroughs of Tower Hamlets, Newham and Hackney.</b></li><li><b>3. Can speak Tamil, Malayalam, Telugu, Hindi, Urdu, Gujarati, Bengali and English languages.</b></li><li><b>4. Were aged 50 years and over.</b></li></ol>
<p><b>The study excluded those who:</b></p> <ol style="list-style-type: none"><li><b>1. Were bereaved within the last six months.</b></li><li><b>2. Were unable to understand and give written informed consent.</b></li></ol>

### 3.3.4 Recruitment

In this study, prospective participants were recruited through local community organisations. Studies have demonstrated that recruiting ethnic minorities can be enhanced by recruiting directly through their affiliated community associations rather than using the traditional, indirect methods, such as advertising and mail (MacEntee *et al.* 2002, Powell & Single 1996). However, Bowes and Dar (2000) argued that these organisations may act as gatekeepers to different cultural communities. In contrast, Temple *et al.* (2002) argued that using such organisations is an acceptable way to involve and ‘listen to the unheard voices’ of people in ethnic minority communities.

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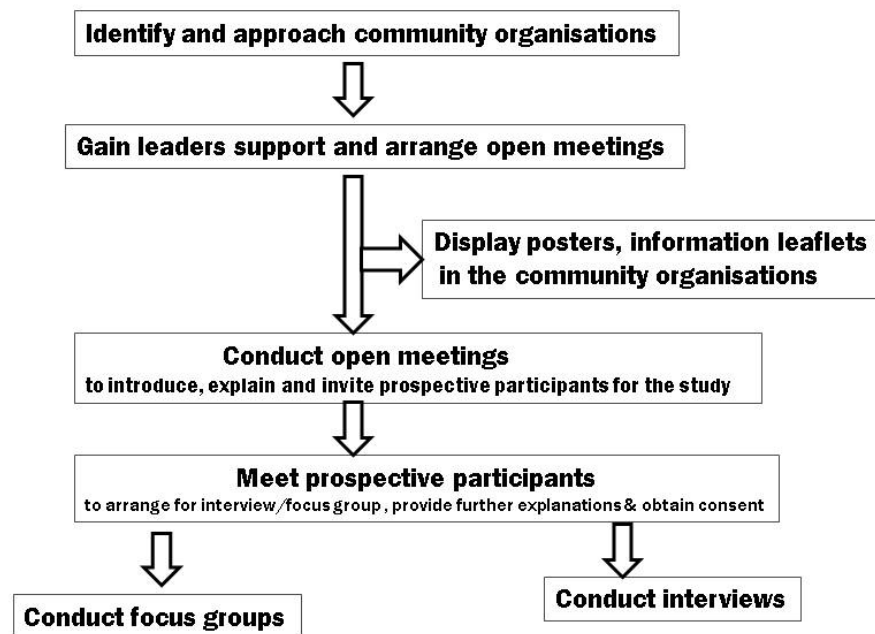
There were 11 local South Asian community organisations involved in this study. The community organisations that were approached were generally involved in supporting their members to meet their needs such as providing welfare benefits advice, health advice, exercise programmes, teaching English and celebrating their own cultural festivals. Most of them run elders' groups such as weekly luncheon clubs. These groups provide opportunities for the elders in their community to meet, talk, exchange ideas and make suggestions for future services.

I approached the community leaders of those organisations which I found through some useful websites, including [www.multikulti.org.uk](http://www.multikulti.org.uk). Initial contact varied and was either by telephone, email or letter in an attempt to arrange to meet the community group leader in person. I received some positive responses from some organisations, although many did not respond to my emails or letters. Therefore, telephone contact was generally the most successful approach in order to arrange a face-to-face meeting. During these meetings, I described my study, how I thought the leaders might be able to help, and was able to respond to any questions about the study they may have. For those who were happy to assist with recruitment to my study, I was open to any suggestions they may have had in ensuring successful recruitment. Several studies highlighted that researchers from the same ethnicity may be more likely to reach and access people who share their ethnicity (Gunaratnam 1997, Nazroo 1998, Smaje & Field 1997). Given the fact that I belong to the South Asian community, my ethnic identity appeared to affect community organisation leaders' willingness to be involved in the study both positively and negatively. Those whose ethnicity was less close to my own (for example,

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Gujarati's and Punjabi's) were less willing to be involved. The recruitment plan is described in the following Figure 1.

**Figure 1 Recruitment plan**



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### **3.3.4.1 Approaching the prospective participants**

Recruitment began by requesting community leaders to display information sheets (appendix 1), invitation cards (appendix 4), and a poster advertising an open meeting within their groups about the study. Explanatory leaflets or information sheets were produced in English, Bengali, Gujarati, Tamil, Malayalam and Urdu to reach the larger linguistic groups in East London. Open meetings were planned at the community centres with the older members of association to introduce the study and invite them to participate. However, only a few leaders displayed the leaflets and invitation cards on their notice board, and most members heard about the meeting through word of mouth or directly from the leaders themselves.

On the date specified, the introductory talk (open meeting) was delivered with the assistance of at least one contact person in each centre with the support of the translator wherever necessary. The open meetings were used to introduce the study and provide explanations to any queries potential participants may have. The open meetings lasted one to two hours. The leaders who were present at the open meeting, discussed about the participation in the study with the members. I distributed study information sheets and acceptance cards (appendix 4) I asked them to return the acceptance card to the community group office if they were willing to participate. We all three, (researcher, contact person and interpreter) spoke to the prospective participants after the open meeting to ensure that they were informed fully.



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I planned to contact or call the prospective participants who returned the study acceptance card to confirm their willingness and arrange a further meeting to discuss their potential role in the study. Although, I did not receive any completed invitation cards directly from prospective participants, instead the leader gave me a list of participants who had expressed a willingness to participate in the study when I visited the centre the following week. A few participants approached me directly and expressed their interest to participate in the study. I then spoke to these potential participants and provided more detail about the study on a one-to-one basis and gave them an information sheet. As participants could take part in either a focus group or an individual interview, or both, possible dates for focus group interviews were provided to these potential participants. These were to take place at the community hall where the relevant group met. For individual interviews, the date, time and location was arranged at the potential participant's convenience.

#### **3.3.4.2 Sample diversity**

To capture the diversity of experience and views and to reflect the demography of older South Asian people, the sampling took age, gender, language, religion, and their country of origin into account. I wished to gain views of both men and women and therefore convened two focus groups where all participants were male and three where all participants were female and had approximately equal size of male: female participants' ratio in both focus groups and interviews, for e.g., n=13 male and n=16 female participants in interviews. Furthermore, the ONS (2001) information reflected the

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selected population of largely Bangladeshi, Gujarati, Urdu, Hindi, and Tamil speaking people. However, I attempted to address this factor of diversity in South Asian languages by applying pragmatic strategies such as selecting only common languages and their countries of migration. Therefore, the sample of respondents included Bangladeshi, Punjabi, Malayalee, Urdu, Gujarati and Tamil. Table 2 describes the demographic characteristics of participants.

**Table 2 Demographic characteristics of participants**

Type of Data	Gender	Primary language of the participants	Actual language of data collection	By origin of their Country	By Religion
<b>Interviews</b> (n=29)	13 Males 16 Females	8 Bengali 4 Punjabi 4 Gujarati 9 Malayalee 2 Urdu 2 SriLankan 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
<b>Focus groups</b> (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

### 3.3.4.3 A reflection on the process of recruitment

Recruiting for research studies is time consuming, frequently undervalued in research proposals, and is particularly difficult among ethnic minorities (Halcomb *et al.* 2007,

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Wrobel 1999). Chiang et al. (2001) highlighted a need for a clear and visible recruitment strategy that would meet the critical challenges of recruiting ethnic minorities to research studies. Others have pointed out the challenges of fear of participation, the role of gate keepers such as GPs and family members, a lack of familiarity with research processes, the researching of sensitive subjects and communication barriers often make ethnic minority groups a hidden population for research (MacEntee *et al.* 2002, Temple *et al.* 2002, Wrobel 1999).

#### **3.3.4.3.1 The experience of conducting open meetings**

At times, the purpose of the open meetings was misunderstood by the community leaders. For example, in one organisation, despite explaining the study in some detail, the leader called me to hold a focus group immediately before I had addressed the open meeting.

*After that Mr. Patel introduced me in the open meeting and asked me to start the group discussion. I suddenly went back myself and looked at what to do next. I politely told him that I cannot do the group discussion with 106 people. I may need only 6-12 people in group and I also will need interviews. He said that discussing the topic with everyone will be beneficial than talking with 6-8 people (open meeting field notes with Gujarati Community Organisation).*

I politely refused and explained what the study was about and addressed the open meeting before leaving the leaflets for the potential participants to read. In some organisations, the leaders viewed an open meeting as a presentation given by the guest

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speaker to provide information about services that are available. As this was not the purpose of these meetings I attempted to ensure that the community leaders were fully briefed prior to the open meetings. With one community group, in spite of the leader's understanding, the members of the community groups failed to comprehend the purpose of the study and the open meeting failed to achieve its objectives.

*Today I went to one of the Asian elders group in Stratford. It is a male Asian group of older people. Most of them were Punjabis. When I started to talk about the topic introduction as an open talk meeting, there was a very deep silence. Then I opened up my topic, they expressed anger about local hospital services and I was not able to talk about my topic. I had a professional interpreter and a community leader with me. But even they were not able to direct the group. They said they had lost their control. There were complaints about social services and the local hospital. I and the interpreters tried to talk about the topic, but to no avail (research notes for open meeting with Asian Elders Group, Stratford).*

In this group, neither the leaders nor I was able to maintain control of the situation. The leaders suggested that group meetings would not achieve my aim. In this particular group, most of the older participants were men, and group activities were conducted by female leaders who appeared to have difficulty in being heard by the male members of the group. It also became apparent that the members of this group had not seen the information provided to the leaders. However, after I closed the meeting, a few of the members (n=4) of that community group asked me about the study and agreed to be potential participants for the study.

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#### **3.3.4.3.2 The experience of working with community leaders**

The impact of community leaders as gatekeepers in recruiting their community members is discussed in the published literature (Arean *et al.* 2003, MacEntee *et al.* 2002). In this study, maintaining the relationship with community leaders directly influenced the relationship with their members. It took approximately 14 months from my initial contact to start my data collection, during which time I continued to communicate with the leaders by updating them in relation to study progress. However, such a long time interval between the initial contact and actual data collection caused an issue in gaining support from one ethnic group. The community leader who initially supported my study was not re-elected. When I started my data collection, the new community leader was less keen to support the study and this caused great difficulty in recruiting participants from this particular group.

However, I used some other opportunities to strengthen my relationships, for example by acknowledging common religious festivals. At times, I was invited to join in day trips with their elder group. One of the leaders asked me to work voluntarily with their elder group activities for at some sessions, which the leader believed would create greater acceptance by members, however this was not practically possible at that time.

Leaders' attitudes towards hosting me as a researcher varied. Some leaders acknowledged the importance of the study in understanding the views of their members and asked for a copy of a study report when available. Many took pride in their group's

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involvement in the study. Others were happy to support somebody perceived as being a young member of their community in achieving an academic goal. Older group representatives ran luncheon clubs and the women's groups' representatives served as the 'real access facilitators' for this study. In fact, in most of the organisations, dealing directly with these peer group representatives proved more successful than through community leaders.

Participant recruitment for focus groups was highly influenced by community leaders. After three open meetings, community leaders encouraged and selected particular members to participate in the focus groups and on one occasion suggested that the focus group be conducted immediately. I politely declined and fixed a time one week after my open meeting and ascertained whether these individuals were willing to take part and stressed that they were not obliged to do so. However I needed to be flexible and acknowledge the role and influence of the leader in accessing the prospective participants.

#### **3.3.4.3.3 Challenges in recruiting participants for interviews**

Despite my efforts to provide adequate information through the open meetings, information leaflets and posters and leaflets, one of the common issues I faced was the feeling that leaders were asserting pressure on members to participate in the study. For example, when speaking to some individuals referred to me by their community leaders it became apparent that they did not have a clear understanding of the study.

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*I had waited for one Gujarati male prospective interviewee to confirm his willingness. However when he did not turn up, I informed another leader who was present at that time in the organisation. He telephoned his community leader (president of the organisation) who invited me for the open meeting. Then the president of the organisation called me from his home and said that there were three community members waiting for me in the lounge who are willing to participate for the interviews. However, when they came into the interview room and I explained about the study with my information sheet, they refused to participate. They said that they just have some problems with the local hospitals and wanted to register their complaints to me as their leader told them to do (field notes for the Gujarati Community Organisation).*

On one occasion, the leader suggested to me that their participants would run away if they realised the topic was about death. He advised me that if I needed to discuss this ‘difficult topic’ he would send the people to me and it would be up to me to ‘make use’ of them. I explained to him about the need for informed consent and declined to interview any client without giving them adequate information.

In most interviews, support from family members remained essential in recruiting potential interviewees. In particular, as a 33 year-old male, community leaders and prospective participants, particularly older women, asked me to get approval from their family members (their adult children or their husband) for them to participate in the study. For example some older women who lived with their family ensured that someone in their family was free to stay with them during the interview. A few other family members refused for their older parents to be interviewed. They said that they did not want their parents to get upset while talking about ‘unpleasant topics’.

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### **3.3.5 Ethical Considerations**

Considering the impact of exploring sensitive issues, particularly among potentially socially disadvantaged ethnic minorities (Kendall *et al.* 2007, Koenig *et al.* 2003, Seymour *et al.* 2005, Seymour & Skilbeck 2002, Sharon 2004), I had discussions with my supervisors, staff from St. Joseph's Hospice and local South Asian community leaders to discuss potential ethical issues and developed strategies to try and minimise any ethical problems that may have arisen. The fundamental ethical principles included, informed consent, discussing sensitive topics, privacy and confidentiality, similar to any research involving human subjects (WMA 2000). The formal ethical approval was obtained from the Camden & Islington Community Local Research Ethics Committee, London (Ref.08/H0722/10) (Appendix 2).

#### **3.3.5.1 Informed consent**

I provided written and verbal information, translated where necessary, about the study through open meetings, multilingual information sheets, one to one meetings and posters. These were intended to fully inform participants of the risks involved in taking part in the study in order to enable potential participants to make an informed decision (Barnes *et al.* 1998, Seymour & Skilbeck 2002) and avoid any direct pressure from the leaders being placed on potential participants. A minimum of one day to a maximum of 14 days were given for prospective participants to decide whether to be involved in the



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study. Moreover, where necessary, interpreters were used for the ease of verbal communications.

Written informed consent was obtained from all those who took part in the study to audiotape interviews and focus groups, and publish the findings. Participants were informed that they could withdraw their consent at anytime without giving any explanations and withdraw consent for any personal information to be used in the research. There is evidence that people prefer to receive from, and value the information given by, their family members (Barnes *et al.* 1998). In this study, when I gave out consent forms and information sheets, a few asked their adult children to read the information for them and sought their approval before signing a consent form.

I also made it clear that participants were not guaranteed any direct and immediate visible benefits for their participation. I informed them that their participation might be an opportunity for them to share experiences, feelings, opinions and their knowledge (Bowes & Dar 2000, DiCicco-Bloom & Crabtree 2006, Dilley 2000, Kavanaugh & Lioness 1998, Murray 2003).

In practice, I encountered several limitations to use the consent form and information sheets that challenged my aim to get ‘informed’ consent. At first most of the participants ignored the importance of reading thoroughly both consent forms and information sheet before participating in focus groups and interviews. For example, some female participants signed the consent form without reading it, in spite of my advice. Similar issues were reported by Mason and Allmark (2000); in a trial among neo-natal care

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parents, the participants regarded the information sheets as an information source to read later and instead many relied on a verbal description from the doctor. Conversely, in the focus group of Bangladeshi men, I took more than 30 minutes to explain and clarify the consent form including outcomes and conduct and the use of personal information before participants signed the consent form.

Secondly, there was some evidence that pressure was exerted from leaders for the community group members to participate in the study that threatened the principle of informed and voluntary consent. It appeared that some participants turned up for the study to participate just because their leader advised them. On other occasions, community leaders asked their members to support the study on the basis that I hailed from the same ethnic background as them. The result of this would sometimes be that after initially agreeing to take part, a participant would then refuse at a later point in the study, for example a Gujarati participant who agreed to participate for the interview subsequently refused on the grounds of health status when I turned up for his interview. From those experiences, I learned to be more vigilant by reminding the community leaders not to force their members to participate in the study. Even though community leaders felt unhappy, I politely declined ‘over-enthusiastic’ help, to avoid potential participants feeling coerced.

Some participants and their relatives understood that I was a nurse and held certain expectations as a result. For example, one participant requested information about his regular medication and its side effects. Some participants asked me to tell the local NHS hospital to provide better nursing care for the older people. However, I politely made

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clear to them my role as a researcher and the purpose of the interview. Seymour *et al.* (2002) reported in their study older participants sometimes misunderstood the role of the researcher and expected the researcher to help them with their health problems.

On another occasion, in one organisation, I found other difficulties. After I completed a focus group and a number of interviews with their community members who signed for the informed consent for their voluntary participation, the leader said her members were demanding some mandatory benefits for their participation. She claimed that this is normal as they were normally received payment for their participation in other research studies, and also she asked for rental payment for the venue. Consequently, I had to reiterate that the room rental and travel costs would be met by me, however I did not pay the participants for their contribution.

### **3.3.5.2 Discussing sensitive topics**

I agree with Seymour *et al.* (2005) and Kendall *et al.* (2007), who recognised that harm includes the psychological as well as physical effects that can result from taking part in research. As in this study, many other researchers have already reported that discussing end of life topics might cause emotional distress for participants as they recall difficult care-giving experiences or bereavement (Barnes *et al.* 1998, Kendall *et al.* 2007). Such impacts may also be expected to be especially high in this case of study among older people as study participants (Addington-Hall 2002, Kendall *et al.* 2007, Seymour & Skilbeck 2002), particularly when they believe that discussing death and dying is

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unpleasant and culturally inappropriate (Worth *et al.* 2009). Furthermore, I was a novice qualitative researcher and had no previous experience of researching sensitive topics such as end of life issues among the ethnic minorities. Therefore, this study received ongoing monitoring and mentoring from the study supervisors with an aim to conduct the interviews and focus groups with due care in a supportive, gentle and responsive way to minimise undue stress.

All of the participants were informed that interviews and focus groups would be immediately terminated, if they felt upset or unwell, or at any other time if they wished to stop the session. Two participants did become upset, but asked me to continue the interview after periods of silence and support from the family members. I further used continuous ongoing verbal consent throughout the study to confirm their willingness to continue the data collection.

Furthermore, follow-up contact for support was offered with participants' consent if they wanted this. For example, one participant disclosed her diagnosis of cancer, for which she had received treatment for the last four years, at the end of the interview. In this case, I telephoned her after the interview with her consent to ensure that there were no adverse effects of my interview; she reported that she did not feel 'anything wrong' about her participation. On another occasion, when I gave a follow-up call for a participant who cried and was upset while recounting experiences of her husband's death, she questioned the need for such a call, stating that as she was living with her family she managed herself well after her interview.

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In addition to follow-up telephone calls, I had the opportunity to meet participants again at their associations, as I regularly visited these for the eight months of data collection. Such opportunities to meet face-to-face helped me to ensure that participants had some opportunities to approach me again if there was any residual effect following participation. Other studies also suggested that these kinds of activities may be useful in reducing post interview stress (Addington-Hall 2002, McIlfatrick 2007, Seymour & Skilbeck 2002).

I previously contacted the City and East London Bereavement Services, a voluntary service who informally agreed to accept any referrals from my project. Participants were given a multilingual information leaflet that contained telephone numbers and addresses explaining the procedure for accessing those support agencies. However, no one used such services to my knowledge. Finally, while serving and sharing refreshments after the focus groups and interviews, I took the opportunity to have an informal chat to discover if anyone felt any discomfort due to participation.

### **3.3.5.3 Privacy and Confidentiality**

Privacy was assured by conducting interviews in the participants' venue of choice, for example in their home or an agreed public place such as a community hall. At community associations, I arranged for separate rooms to hold interviews. The doors were closed if the participant preferred. However, as reported earlier, in some interviews, often when I conducted the interviews and focus groups in the open

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communal areas (i.e. community halls, as preferred by the participants), I was unable to guarantee complete privacy of the conversations. In spite of this those participants insisted on continuing with the interview.

In focus groups, there is a risk of participants revealing too much information that may compromise confidentiality and privacy (Kitzinger 1995) . This is because the discussion will be heard by all the participants and the researcher does not have control over what happens to the information outside the group. Therefore participants were asked to sign the consent form, which highlighted:

- i. the potential for breaching confidentiality and privacy;
- ii. the steps taken to reduce this;
- iii. giving assurance that they would not disclose information about others following the group.

Despite everyone signing the consent forms, in practice, however, I observed some participants in the subsequent interviews reporting that the previous interviewees discussed particular topics including others' views of their community groups. Thereby, I was in need to remind the participants in the following interviews about the need to adhere confidentiality.

Data confidentiality was preserved by giving unique pseudonyms for each participant, which were used throughout the study to prevent individuals being recognized in the research documents. Personal data was stored in a separate e-folder as a file which was

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accessible only to me. Raw data were accessible only by myself and my study supervisors. Data was stored in a password-protected university computer and locked in a postgraduate research students' office until the completion of the study. Hard copies such as transcripts, field notes and audiotapes were stored in a locked filing cabinet in the same office. After completion of the study, all information related to the study will be moved into the University archive storage and stored for seven years. Any information from this study used to disseminate the outcomes, through conference, publications and public presentations is and will be anonymised to protect participant confidentiality.

In practice, while some participants asked to check that their names would be changed; before I started the interview some other participants who reported positive experiences about hospital and home care said they were happy if I used their names and even addresses. However I explained about my ethical commitment to make their names anonymous.

### **3.4 Fieldwork**

I conducted my fieldwork from May to December 2008. In total, five focus groups and 29 in-depth, semi-structured interviews were conducted. Participants were given the opportunity to participate in either one or both methods of data collection. Therefore,

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among 55 participants, there were nine focus group participants who also participated in the interviews.

### **3.4.1 Focus groups**

Due attention was given for the preparation in particular to time, language and environment for conducting the five focus groups. While the choice of language for focus groups remained with the participants, two English (with Bangladeshi and Tamil men), one Bengali and two multilingual South Indian languages (Tamil and Malayam) but mixed with English were chosen. Due to my limited linguistic skills in Bengali, I used an interpreter to conduct a focus group in that language. To prepare them for this role, I met with the interpreter on two occasions to explain the ground rules of conducting focus groups. I emphasized the depth and breadth of information they needed to draw from the participants and skills they would be required to demonstrate to encourage group discussion. These steps were expected to strengthen the working relationship and trust between the facilitators (Clegg 2003).

The focus groups lasted between 44 and 90 minutes. The most convenient time for the focus group was negotiated with the participants. Four of five focus groups were conducted before or after the luncheon programme at their community centre. The one that occurred at the home of the community leader was conducted in the late evening (9 to 11pm) at their request. In other situations, where necessary and appropriate I waited



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until the participants completed their prayers, yoga and elderly group activities, and often joined with such activities at their invitation (Strickland 1999).

Prior to the field work, I discussed with participants their choice of venue for the focus groups. Four focus groups were conducted in their community halls and one took place at the home of one of the community leaders. Such a need for flexibility and natural social atmosphere for the focus groups felt essential in this study, which indeed expected to provide a non-threatening and convey a relaxed ambience (Krueger 1994). Individual focus groups did not include men and women together. In total, three focus groups involving women (Malayalee, Bangladeshi and Gujarati) and two focus groups involving men (Bangladeshi and Tamil) were conducted.

In this study, I negotiated the choice of room arrangements with the participants. I found women in the larger groups felt comfortable sitting in small clusters with their friends. The men, on the other hand, were happy to sit in a circle. In the study by Vissandjee et al. (1998), Asian women participants felt more comfortable and confident sitting behind the table or desk when expressing their opinions, in contrast to the Western style of openness and a circular form of discussion.

I prepared and used an aide-memoire (appendix 7 & 9) as a prompt to conduct the focus groups. Since, in grounded theory studies, it is recommended the researcher needs to begin with little or no preconceptions about the phenomenon under investigation (Backman & Kyngäs 1999), my initial aide-memoires contained broader topic areas of

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investigation. Initial data subsequently informed the subsequent areas of enquiry in later focus groups (Charmaz 2006 , Green & Ingleton 2010).

### **3.4.1.1 Management of focus groups**

Often the focus groups commenced with Muslim or Hindu prayers. Each focus group began by revisiting the information sheets and consent forms. Participants were encouraged to interact and debate through the informal exchanges of ideas that would generate insights about the topic under investigation. However, to maintain the group dynamics and avoid conflicts (Freeman 2006), participants were asked to be courteous to other group members and respect the confidential nature of the group.

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 smooth transition into a discussion of sensitive topics in detail (Powell & Single 1996). Importantly, such open discussion paved the way for the participants to express their views about end of life based on their own social, family and cultural context, including the impact of growing older in a foreign country. Eventually, often such discussion challenged the purpose of the group and the content of the aide-memoire.

During the focus groups, I used several cultural cues to promote discussion. This included nodding our heads, making reassuring noises that conveyed an acceptance and sharing of their ideas, and using some South Asian proverbs to explain the topic of

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discussion. Considering the nature of one-off formal and arranged interviews and focus groups in grounded theory, Sorrell and Redmond (1995) highlighted the role of the researcher as a research instrument through which data is collected. Religious and cultural values were respected during group discussions (Halcomb *et al.* 2007), including observance of prayer times, manners and body language that was respectful of older people.

Focus groups were audio-recorded with the participants' consent. The duration of the focus groups were determined by the participants' willingness, comfort and ability to finish on time. Focus groups were drawn to a close by clearly informing group members that the session had reached an end and thanking the group for their participation. This was either prompted by the leader who signalled the time for the next luncheon club activities or participants showing signs of tiredness and starting to give limited, single word responses. Field notes were written immediately after each session to facilitate the trustworthiness of my data collection (Mills *et al.* 2006).

Furthermore, all of the focus groups ended with informing the participants about follow-up support strategies such as bereavement support, service information such as hospice and other end of life care services. Participants were given some refreshments. During this time, I was able to obtain any feedback from participants about participating in the focus group. Some of the participants had questions about the confidentiality of the data and how the data would be used. During this time, a few members who I observed were kept silent asked about whether they would be able to attend an individual interview, and

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these offers were accepted. Participants were also requested to complete the short demographic questionnaire (appendix 3).

### **3.4.1.2 The experience of conducting focus groups**

As a relatively young Asian male I felt somewhat uncomfortable in talking about death and dying to a group of older people with whom I shared a particular ethnicity. Secondly, due to my relative lack of research experience in conducting focus groups, maintaining focus together with free discussion of the subject under investigation was a real challenge. I explain these issues in detail below.

#### **3.4.1.2.1 Initiating the focus group discussion**

It was planned to open the discussion up to invite someone in the group to volunteer to talk about someone in their local community who had been ill and had recently died. However, I struggled to develop the discussion with this question. This was partly because my own cultural instincts prevented me from using such prompts. Instead I used the prompts which the participants had asked during the open meetings. For example, in the focus group with the Malayalee women, I asked the participant to repeat the question they had previously asked at the open meeting.

*MK: Good morning. My name is MK. You can talk in Malayalam, Tamil or English or any of these three languages. Aunty, can we start our discussion by asking same question that you asked me before in the open meeting?*

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*Vanaja: You said that you are doing this project and visited the local Hospice. Are the people well-looked after, or?*

*MK: Has anyone been in any hospice? Or heard about the Hospice? (Malayalee focus group transcript)*

On other occasions, I needed to slowly broach the topic around older people, their health, current situation of care, and wait for a prompt from the participants that I could use to introduce the topic of end of life. For example, with the Gujarati focus group, the discussion included the position of the older person in today's changing society, family structures and care at local hospitals and nursing homes, prior to entering into the end of life topic. However, people were more interested to talk about how as a whole family they would or have managed and trusted each other in the family during death and dying of their dying relatives.

#### **3.4.1.2.2 The challenge of maintaining group dynamics**

To maintain the group dynamics of the focus group, I explained the ground rules of group discussion, for example giving everyone in the group an opportunity to participate. However, in practice, some of the focus group members did not contribute until I brought them in to the discussion. Some women in particular were silent, felt shy, spoke under their breath and whispered with their neighbours. This was possibly because they had no confidence or they felt uncomfortable to discuss with a younger male researcher. However, I encouraged them by acknowledging their ideas, informing them that they could use their own language. I paid attention to them and waited for them to express their views.

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I attempted to use the influence of the community leaders to move into new topics and to talk about subjects in a way that would suggest to other members of the group that it was safe to do so. For example, in the Gujarati women's group, the leader (Jayanthi) pulled the participants into the topic when their discussions went off course.

*MK: Thank you for accepting my invitation. Could you please tell me your name - whatever name ... you want to be called in this discussion? And why you are interested in coming today? Can we start from my left side?*

*Chandra: My name is Chandra but I don't know anything I am looking after by my children and my life is just like as child.*

*Jayanthi: You know, sorry, sometimes I go with elderly people ... I am one of the representatives in the group of older people in local hospital. Sometimes I go to the hospital; I saw many people were suffering with stroke (focus group with Gujarati Women).*

Nevertheless, the social hierarchy and position of community leaders within the South Asian community influenced the group dynamics during the focus groups(Huer & Saenz 2003, Strickland 1999). For example, a focus group that included Tamil-speaking religious leaders became the leader of the group and 'directed' the participants to talk. Similarly, the participants showed great respect for the leader and did not express any views against them and waited for the leader to give them an opportunity to talk. It felt like a series of interviews rather than a group discussion. Therefore I struggled in my role as a focus group facilitator or a researcher.

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*MK: Good evening. Thank you for accepting my invitation. Could you please introduce everyone and say where you are from?*

*Ebi: My name is Ebi, I am from Sri Lanka. To my left, his name is Michael. He is from Singapore and he comes originally from India. But he is settled in the UK. In my right, Mr Jose he is from Nagarcovil. I am ready to share my thoughts about this topic.*

*[after long conversation from Ebi, he continued]*

*Ebi: You can stop or maybe you can ask me some questions. And you want to add anything Jose or Michel?*

*Jose: I think whatever he said is true (focus group with Tamil religious leaders).*

#### **3.4.1.2.3 Use of an interpreter**

An interpreter was used to help with one focus group where participants wished to speak in Bengali, a language that I do not speak. This was a focus group of Bangladeshi women, wherein the community centre coordinator acted as the interpreter. The interpreter was a woman, similar in age to most of the participants in the group, and familiar with the experiences discussed by the group participants. As noted by others, this was likely to have caused the least ‘disruption’ to the running of the group (Freed 1988, Hudson 2003, Riessman 1987, Westermeyer 1990). However, it is not possible to exclude the possibility that the role of an interpreter ‘filters’ data through the act of interpretation.

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*MK: Have any one heard about hospice?*

*(Interpreter laughed and started to talk with the participants in Bengali.)*

*Interpreter (Halima): They said that they did not hear about that. Then I explained about hospice being a place like a hospital but smaller where people in the last two or three months of their life are cared for. But (pointing to one of the participant) she said that her brother-in-law has used the hospice (focus group transcript with Bangladeshi women).*

A similar issue of ‘impartiality of the interpreter’ was also noted in the study by Murray & Wynne (2001) of South Asian women where the researchers suspected that not all the information was being translated back to them. They argued for the need to understand the views of the interpreter so these could, if necessary, be disentangled from those of the study participants thereby making the role of the interpreter in the research process transparent. When I conducted an interview with the interpreter who was also an older Bangladeshi older woman, such impartiality was become evident. Furthermore, I also observed that in order to protect some values about her culture and community, the interpreter used selective interpretation. In her interview, she came up with her own opinion about hospice and compared with her ideas with the focus groups participants:

*Halima: When you had focus group on that day, the women are talking about hospice as a Jamkar. I shocked when I heard that word, how they choose the word.*

*MK: Jamkar?*

*Halima: Means the last place or slaughter house. I was looking and started to laugh on that that Lady, because I know what they mean. Because they thought it is a last stage.*

*MK: Is that view of community about Hospice?*

*Halima: They are not their views. Because they don't know the word (interview transcript with Halima, 64 years, Bengali woman).*



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Because of this, I sent the audio file for transcription to another local Bengali speaking health professional along with used paid transcriber. The transcript revealed discrepancies in the way participant views were being translated back to me at the time of the focus group(Freed 1988, Kapborg & Bertero 2002).

### **3.4.2 Interview process**

In total, 29 semi-structured interviews were conducted with the aim of exploring a deeper understanding of individual attitudes, preferences and experiences towards end of life (DiCicco-Bloom & Crabtree 2006, Fontana & Frey 1994). The interview process included three phases: preparation, conduct of the interview and the ending the interviews.

#### **3.4.2.1 Preparation**

Interviews were conducted at a time convenient to the participants. Price (2002) recommended that the researcher needs to have the flexibility to expect and manage unexpected upheavals during the interview process such as change in the focus, direction, duration and sequence of discussion. Some people were interviewed when they were attending a community group activity in their community organisations, for example, part of the luncheon programme activity. Participants' religious and ethnic preferences were respected. Participants were invited for interview outside of prayer

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time, and religious days such as the Hindu festivals of Navarathri and Diwali, and the Islamic festival of Eid-Mubarak. Muslim prayer times and auspicious Hindu days were avoided.

The participants' choice of venue was respected and included their homes and the community centres. Most of the interviews (n=23) were conducted at the home of the participant, with the remaining six in community centres. The physical environments for these latter interviews were arranged in such a way to maximise comfort and privacy. For interviews based at home, I called by telephone on the morning of the appointment to confirm the interviewee was happy to proceed with the study. In order to ensure that I was speaking to the correct person, I employed following steps:

- a) asking an opening question, such as: "am I speaking to Mr X?" to clarify identity;
- b) clarifying that they are able to speak for a few moments in private about the study;
- c) If it is an inconvenient time, I scheduled an appointment to telephone again, or where appropriate, arrange to visit the person at home.

Where possible and acceptable to the participant I tried to arrange the appointment during daylight (particularly for female participants) and office hours.

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### **3.4.2.2 Conducting the interviews**

Interviews were started after revisiting the information sheets and obtaining the consent. Initially, for the first three interviews, I followed the interview topic guide (see appendix 8) that was primarily informed by the earlier focus groups and also informed by my preliminary literature review (Calvin 2004, Payne 2007). I used open questions to invite participants to describe their perspectives about the topic of investigation. Interviewees were encouraged, if they felt comfortable to do so, to describe their personal experiences; these served as a guide for the participants to talk freely about the issues on the topic (Price 2002). The interviews lasted between 35 and 116 minutes.

Each interview was analysed concurrently by which the core issues were derived that informed subsequent interviews (Calvin 2004, Charmaz 2006, Green & Ingleton 2010). Nevertheless, I stopped my data collection after three focus groups and 17 interviews, and developed a new aide-memoire (Appendix 9) to proceed. Towards the end of the fieldwork phase, I found a few interviews (at least the last three interviews) generated issues more similarly that had arisen in previous interviews and realised that I reached theoretical saturation of my data (Charmaz 2006). Hence I discontinued further interviews.

### **3.4.2.3 Ending the interviews**

Interviews were closed with thanking the participants for their contribution. This was signalled by participants giving single-word answers, observing tiredness after longer

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hours, and participants informing me about other appointments. Some participants requested more information about local palliative and end of life services which I gave as much as I could. While I offered an opportunity for the interviewee to contribute anything further before the end, some participants also asked about confidentiality and I attempted to reassure them. With their consent for those I felt might need further support (three individuals); I asked if I could make a follow-up telephone call within a week of the interview. Furthermore, I also gave contact details for East London bereavement support services.

#### **3.4.2.4 Reflective accounts of conducting interviews**

I found that the individual interviews were useful in involving people from ethnic minority groups, especially those who do not often use community organisations and who did not want to participate in focus groups. For example, some participants who remained silent during the focus group approached me after the groups to share their experiences, and this was an opportunity to invite them to be interviewed individually. Moreover individual interviews allowed for a different perspective that I believed enhanced the quality of gathered data for this study (McCallin 2003). Some interview participants commented that the interview had given an opportunity for them to share their story as immigrants to the UK.

##### **3.4.2.4.1 Being an insider**

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On many occasions, being an ‘insider’ helped this study. This included accessing the participants, and understanding the cross-cultural context of interactions and meanings and the impact of using various sensitive words and topics during the interviews. More particularly, my multilingual skills supported the interviews in at least four South Asian languages. On the other hand, I also faced the tension between performing my role as a researcher and my position as a South Asian among my own community members.

For example, on many occasions I felt the pressure of expectation to share my personal biography with participants. I considered these questions arose partly because participants identified with me due to a shared ethnicity, and partly because they were showing an interest in a younger adult who hailed from their own ethnic background. Furthermore, on one occasion, I was unable to say ‘no’ to the participant while she offered a night supper, as I felt that refusing the dinner could initiate mistrust and seem disrespectful. A similar issue was highlighted in a study by Deianira and Sam (2006), whereby ‘cultural insider’ researchers faced challenges with their qualitative interview participants. However, I developed strategies to encourage rapport such as ‘without being false’ to ‘move-up’ and ‘move across’ the class, gender, and social positions (Deianira & Sam 2006).

#### **3.4.2.4.2 Relationship with interviewer-participant**

I found at times that the relationship with the participants aided the interviews in exploring and getting deep into the topic of investigation. In this study, I referred to some participants using terms that described relationships such as *aunty* (meant older female family friend), *uncle* (means older male family friend), father and mother.

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Although, initially I felt uncomfortable to use such words, being an insider I found that this was the expected way that a younger person should refer to their elder. On the other hand participants also used words with the same level of relationship, particularly while they shared some of their more sensitive experiences. For example, a Malayalee woman at her interview referred to me as *enda ponnu mone*, meaning ‘my dear son’.

### **3.4.2.5 Reflective accounts on the use of focus groups and interviews**

It was initially planned to conduct the study in two phases, with the initial focus groups informing the content of the subsequent individual interviews. In practice, when I conducted the first three focus groups, I was unable to recruit any more participants for focus groups in the following two months. Furthermore, from my initial experience of focus groups, I noted that some participants were less than comfortable in talking in a group setting, and sometimes the groups were ‘hijacked’ by the more vocal and influential members of the community from where they came from. At this stage, I expended more energy in recruiting to and conducting individual interviews.

Furthermore, interviews conducted in participants’ homes offered me the opportunity to observe their living context, thereby giving me a meaningful interpretation of the data that I collected. Moreover, many interview participants also reported that they felt more confident and free to share their whole accounts in the interviews than in the focus

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groups. However, I conducted two further focus groups that had been pre-arranged and these were useful in exploring some of the issues that arose in the individual interviews.

#### **3.4.2.6 Language of the interview and focus groups**

As South Asians have more than one language, participants were given the flexibility to speak any of the seven South Asian languages (Tamil, Telugu, Gujarati, Malayalam, Hindi, Bengali, and Urdu) and in English in the focus groups and interviews. I was able to speak four South Asian languages including four in the inclusion criteria (Tamil, Telugu, Malayalam and Hindi). I used an interpreter to support my data collection for the languages that I was not familiar with. In practice, the data were collected in following languages: (table 3)

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**Table 3 Languages used for data collection**

<b>Language</b>	<b>Focus groups</b>	<b>Interview</b>
<b>Only in English</b>	<b>2</b>	<b>8</b>
<b>Their own language</b>	<b>1</b>	<b>6</b>
<b>Used both English and their own language</b>	<b>2</b>	<b>15</b>

In this study, most of the interviews and the focus groups were conducted in participants second language (i.e. in English), or in English mixed with the participant's own language. Existing research has shown the positive benefits of this approach, particularly when researching sensitive topics. For example, Marshall and While (1994) suggested the use of a second language, which they claimed can minimise the problems associated with using multiple interpreters and enhance the 'accuracy and value of the data'.

Westermeyer (1990) and Nicassio *et al.* (1986), however, reported that when participants used a second language, not only was it time-consuming and laborious, it



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often resulted in impoverished accounts. Murray and Wynne (2001) cautioned that ‘unless the participant is fully proficient in speaking English’ (p158), using English as a language of interview will impact on the quality of data gathered.

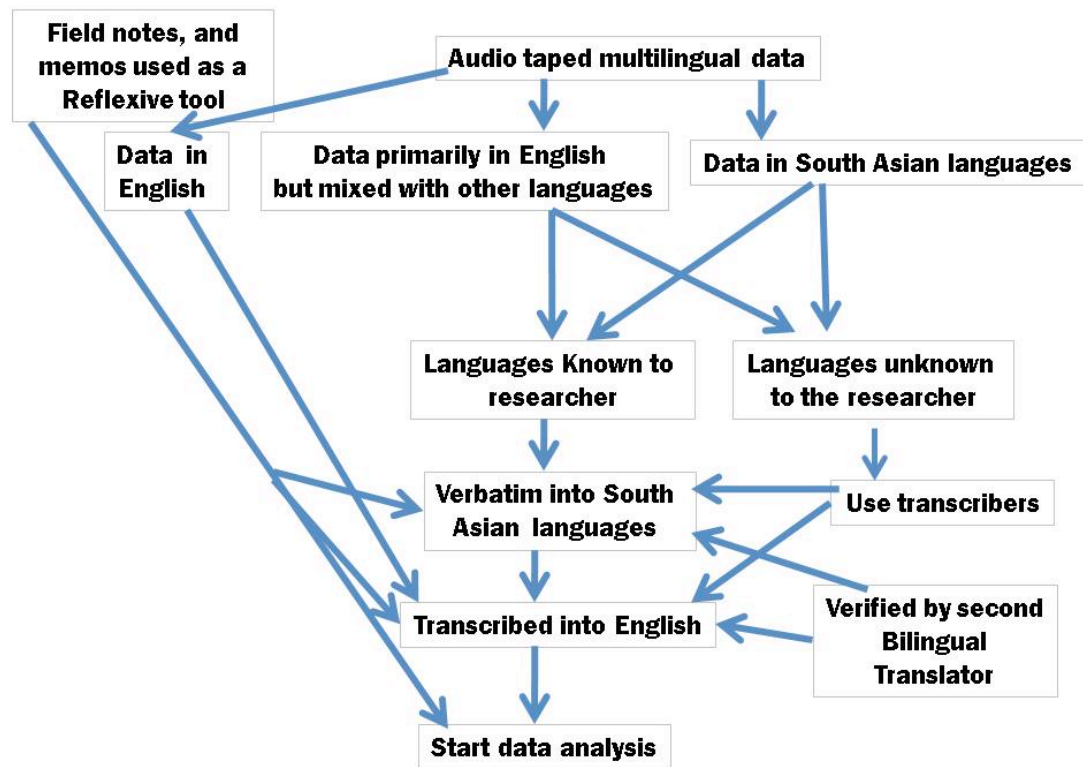
Nevertheless, since I gave participants the flexibility to use any language, most of them chose to be interviewed in their second language, English. This was possibly because participants could have had gained some proficiency in speaking in English language given the length of time they had lived in the UK, and felt an element of pride in providing an interview in English.

### **3.5 Transcription**

The management of multilingual textual data was processed using a model of translation and transcription proposed by Twin (1997), as illustrated in Figure two. The data from the participants who spoke in English was transcribed ad verbatim in English. I transcribed the audio tapes with South Asian languages initially into the language they were spoken in, and then into English. The audio recording of the language I was not familiar with, for example the Bangladeshi focus group, was sent to a paid transcriber. To maintain the transparency of the transcription process, the transcripts’ were verified by a second translator who was working as a nurse and verified with my memo notes.

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**Figure 2 Translation process**



In practice, most of the interviews and focus groups were not conducted in one language but included a number of languages that participants slipped in and out of. Participants often used broken and incomplete English sentences. For example, the focus group with Gujarati women highlights the transcription issues:

*MK: Could you please tell me about older people and their health status at local community?*

*Sreeja: Is I said can we not look after... not feeling anything... is not feeling*

*Jayanthi: Family is a busy like*

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*Sita: Someone...any child... any body*

*Mohana: All family is not same*

*Sita: Not feeling everybody* (Excerpt from Focus group with Gujarati women)

Nevertheless, since I was an ‘insider’ interviewer and also researcher to analyse the data, I was able to understand the meaning of such broken sentences. My similar ethnic background also helped me to understand the directions of the conversations, the respondents’ intentions and the meaning of some of their expressions. The following excerpt describes how the above focus group data was further transcribed without altering meaning of the participants words (Avis *et al.* 2007).

*MK: Could you please tell me about older people and their health status at local community?*

*Sreeja: We are not going to be looked after by our family members at last days. Nowadays people never think about older people.*

*Jayanthi: But, our family members are also busy*

*Sita: No, at least someone in the family can look after us.*

*Mohana: Yes. But every family is not same; some do look after older people at their last days*

*Sita: No not everyone feels the same to look after their older parents at their last days* (excerpt from focus group with Gujarati women).

Words were spoken in a highly contextualised manner. For example, one participant used the word ‘abuse’ when he actually meant to indicate his mistrust of health services.

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Furthermore, as participants often resisted using words such as ‘death’ and ‘dying’, they often used lengthy indirect words and made non-verbal signs, including putting their hands over their face when recounting unpleasant experiences. Similarly, I too responded by posing questions and drawing on prompts by slipping in and out of different languages in keeping with the expectations of the participants. However, these needed to be translated in order to make the transcript both readable and analysable.

The transcription was done in two stages. At first, the audio-taped data that had been transcribed as a ‘raw data transcript’ often remained unreadable and un-analysable. In the second stage, the raw transcript underwent further ‘polishing’ to make readable and analysable transcripts. However, due consideration was given to maintain the originality of the data.

### **3.5.1 Stage 1: Making a raw data transcript**

Audio files were listened to carefully before I started the transcription. However, this raw data contained broken sentences, deep cultural meanings, lot of hidden, very small sentences and lost words. Therefore, the audiotapes were listened to at least twice to grasp a sense of the interview and keep my mind alert to cultural cues, the nature of language and the tone at various points of the interviews. Further repeated listening before actual transcription helped to familiarise me with the participants’ words and communication styles.

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The transcription was conducted at a slow speed. Following the transcribing process I listened to the audio files again while checking the accuracy of the paragraph-level transcription. During this time, I compared the re-transcribed data against audio files and noted down the errors and non-verbal responses. Finally, field notes and memos about the interview process were included in the transcript.

### **3.5.2 Stage 2: Making the transcripts readable and analysable**

The raw transcripts often contained incomplete sentences and both the researcher and participants' use of grammar and syntax sometimes made initial transcripts incomprehensible. Consequently, I needed to take some steps to make the data not only readable, but also analysable and quotable for the reason of transparency. Hence, I alone transcribed the contents of the interview. However, in an attempt to maintain the desired level of transparency, I remained aware of the fact that I should not insert my own words to make the transcript readable, as I felt that would have developed ambiguity over the trustworthiness of the data. Therefore, I used the following strategies:

- Bracketing any additional words to complete sentences.
- Using footnotes to indicate cultural meanings.
- Linking with my memos to support inserted words.

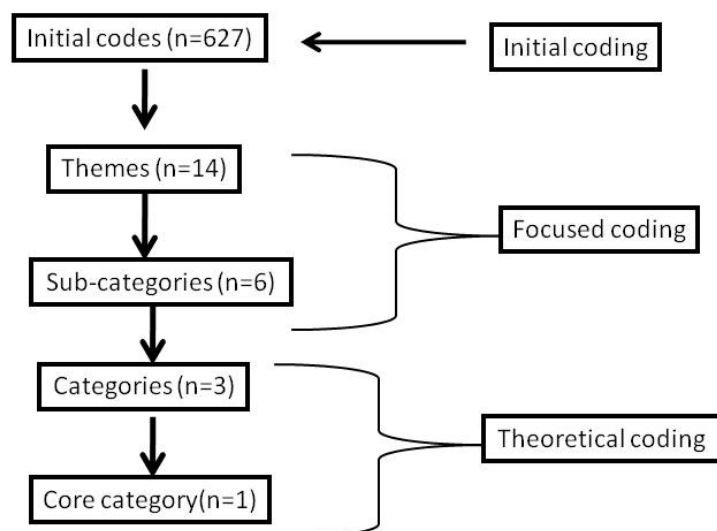
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### 3.6 Data analysis

Figure three describes the process of data analysis. As this study is rooted methodologically in constructivist grounded theory, the central focus for data analysis process conformed to the ‘set of flexible principles and practices’ described by Charmaz (2006). Therefore, the transcripts underwent three steps for the purpose of analysis:

- i. Constructing initial codes using line-by-line coding.
- ii. Constructing themes, sub-categories and categories by focused coding.
- iii. Constructing a core category by using theoretical coding.

**Figure 3 Development of core category**



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### 3.6.1 Constructing initial codes

I entered all my transcripts into NVivo software version 8. Having some basic understanding about ‘codes’, which Charmaz (2006) described as ‘attaching labels to segment of data that depict what each segment is about’, I started coding the transcripts using the NVivo software (Burnard 1994, Webb 1999). However I always tried to ask four questions while coding as suggested by Charmaz (2006):

- What is this data a study of?
- What does the data suggest/pronounce?
- From whose point of view?
- What theoretical category does this specific datum indicate?

Charmaz (2006) further suggested that ‘through coding, you define what is happening in the data and begin to grapple with what it means’. Following this set of flexible constructivistic principles, I started constructing the codes by using both my own abstract words (conceptual coding) and participants’ words (in-vivo coding). Therefore my initial codes neither emerged (Glaser 1978) nor were forced (Strauss & Corbin 1998), but ‘constructed’ between researcher and participant.

I also used ‘free flow coding’ which Charmaz (2006) recommended to help to move quickly through the data though remaining close to the data. This helped me construct a number of codes from a particular segment to reflect all the possible theoretical

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directions. Based on the above principles, I conducted the line-line coding by carefully reading every line and segment of the data. An example of such coding is presented in box 2.

**Box 2: Example for initial coding**

Initial codes	Transcript
Accepting the importance of discussing about end of life. Importance of awareness Accepting that death is inevitable event for everyone. Discussing with family will make them uncomfortable. Claiming that no suitable place for her community people to be cared at their end of life. Portraying that difference of understanding between others "No suitable place for South Asians" Illustrating the reasons as "the way of thinking" as difference "There is not that sort of privacy" home is comfortable for the dying people not for others	MK: How do you think about discussing this kind of topic? Dolly: No. it is important to discuss such topics to make awareness for the people. Because everybody knows that we will go one day. We don't know which way we go.. if we can plan for hand if we gets time to sit with our family and tell them. Then family also will feel confident to send them to comfortable place to care. But our case that ...especially Asian subcontinent people... there is no very suitable place for them. Usually.. I saw the African or white people sent their people to hospice in last stages couple of weeks or for couple of months. But our people think that that is not suitable place for us...there is not that sort of privacy... there is not that... the way of thinking everything... like habits, religious way. People feel more comfortable at home. But home is comfortable for them, but not for the other people who are living and doing jobs for them.

However, there is always the risk when coding in this way that the synthesising ability of the researcher will lead to an overwhelming number of codes. When I completed my initial coding, I had constructed 627 initial codes.



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### **3.6.2 Constructing themes, sub-categories and categories**

When dealing with a large number of codes, Charmaz (2006) has recommended that the constructivist researcher use a ‘focused coding technique’. With this technique the more significant and frequently recurring codes inform conceptual categories. I used the constant comparison method where I compared code to code, by which I grouped a total of 627 initial codes into 14 themes. Where codes could theoretically be placed within more than one theme, a decision was made on the basis of its most natural fit into the thematic structure. Following this, with the use of pen and paper the 14 themes were then reduced into six groups, referred to as ‘sub- categories’ in the hierarchical structure. From those six sub-categories, three categories were then created: (i) home; (ii) family; and (iii) trust. A process of checking that the lower level codes were relevant to the higher level of categories was undertaken. For example, appendix 10 describes the process undertaken to develop the themes, sub-categories and categories from codes produced from N-Vivo for the first core category ‘Home’.

On reflection, there was a constant tension throughout the process of data analysis between a desire to follow the process logically and methodically, and the temptation to construct more abstract categories too early in the process. This method of constructing categories was a way of seeking an answer to my research questions, rather than exhibiting the whole complexity of the interpretive paradigm. Moreover, I felt my initial categories remained as mechanical outcomes of ‘N-Vivo software assisted data

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analysis’, which often missed the interpretation necessary to capture the voices of the participants.

In particular, I struggled with the large number of 627 codes. However, having undergone what is known as the “immersing” effect of transcription (Burnard 1994) I was able not to lose sight of the essence of each interview and focus group in the deconstruction of the data into isolated codes. While constructing codes, I instinctively viewed codes as the potential member of a broader theme and sub-category that had yet to be fully articulated. Careful coding of the data also familiarised me with the data at a micro level and I was sensitive to the recurrence of data which again helped form broader and robust groupings later in the analytical process.

### **3.6.3 Constructing the core category**

From the three categories, I used the process of ‘theoretical coding’ to identify the core category or the theory (Charmaz 2006). This was done through a constant comparison of the three categories. In practice, I was in the process of identifying and specifying ‘possible relationships’ between those categories I constructed through my focused coding (Charmaz 2006). This endeavour resulted in constructing the ‘theory of continuity and reconstruction’ as a core category. Indeed, Charmaz (2006) suggested that the theory is a product of the researcher’s thoughtful intellectual effort of grouping,

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grasping and organising in the manner of the interactions between interview and interviewer.

### **3.6.4 Memo writing**

Memo writing is highly regarded and valued in grounded theory. Charmaz (2006, p, 72) emphasised memo writing is a ‘crucial method in grounded theory because it prompts you to analyse your data and codes early in the research process’. During the initial data collection, though I had written field notes and formal notes about my early findings for each participant, I did not really understand the value of memos until I struggled to construct my codes during my initial coding. In fact my initial memo writing gave me the direction of the data and initiated early data analysis. Furthermore, my ongoing memo writing during data analysis assisted greatly in identifying and constructing the higher level categories. In addition, when I had derived my early 627 initial codes, I engaged in a process of mind mapping. Such mental visualization of memo helped me to arrive eventually at the core category.

## **3.7 Summary**

This chapter had described the design and implementation of a grounded theory study of end of life issues among older South Asian participants living in East London. Using

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constructive grounded theory, I conducted five focus groups and 29 interviews. Community organisations played a pivotal role in recruiting a potentially ‘hidden’ population. Multilingual data was transcribed and analysed. Three categories were identified through a process of coding and categorising and constructing the core category. These categories, home, family and trust, are presented in detail in the following three findings chapters: four, five and six.

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## CHAPTER 4

# Home

This chapter focuses on the study findings about participants' attitudes, beliefs and expectations towards the meaning of 'home' during end of life. My data analysis revealed two patterns of meaning: 'home as a haven', and 'reconsidering the homeland'. The first sub-category, 'home as a haven', describes participants' accounts of how their home is a physical place in which it is possible to perform various cultural and religious rituals. The second sub-category, 'reconsidering the homeland', captures participants' perceptions of returning to their 'homeland'- the country from which they emigrated during end of their lives. Table 4 presents the sub-categories and themes that this chapter covers.

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**Table 4 Sub-categories and themes relating to meaning of home during end of life**

<b>Category</b>	<b>Sub-categories</b>	<b>Themes</b>
<b>Home</b>	<b>Home as a Haven</b>	<b>A religious place</b>
		<b>Finding safety and comfort</b>
	<b>Reconsidering the Homeland</b>	<b>Returning home</b>
		<b>The increasing importance of culture at the end of life</b>
		<b>Laying down new roots</b>

## **4.1 Home as a haven**

Most of the participants claimed that having a place to call home and which they could retreat to, and feel comfortable and safe in, was an important concept, not only during their daily lives, but also when someone was approaching the end of their life. Most notably, participants reported that home provides space for religious practices and cultural rituals at and around the time of death. Furthermore, they reported that home gives an opportunity for the dying individuals 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

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providing care, and in turn provide a private space and a sense of security, so that those who were dying could do so peacefully.

#### **4.1.1 Home as a religious place**

From a total of 55 participants, 53 of them self-categorised themselves into one of the common South Asian religions, namely Hinduism, Islam, Sikhism and Christianity (see table 2 in chapter 3). Many of these individuals specifically reported a preference of home as the preferred location of death, as they perceived it as providing them with a space to perform important religious duties at and around the time of death. For example, Khan talked about the religious practices undertaken towards the end of people's lives. He believed these were necessary components of a peaceful death for older South Asian Muslims. Khan was a Pakistani Muslim Imam who visited families both at home and in hospital to say prayers at the time of death. When asked what was meant by dying in peace, he explained that there were two important elements concerning care towards the end of life: religious practices and being surrounded by family during the final days of life. He argued that it was the family's responsibility to ensure that the dying person departed peacefully in their own religious way:

*We feel that one should have their last breath in peace. I mean reading the Quran, family, friends, everyone is there. Praying that everything is Allah, like this [points hands towards the sky in a praying position]. These are the*

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*emotions that everyone feels when their loved one is going. He lived for the family; he should at least not be left alone while he is dying. But this won't happen if we die in the hospital. That's why people always wanted to die at home* (Khan, Pakistani male aged 62).

Khan echoed one of the main reasons that many participants said they preferred to die at their home was because it provided the opportunity to be with their family. Similarly, Kesavan argued that dying around the family at home is essential for South Asian Hindu people to ensure the peaceful departure of the dying person's soul. He was a Hindu Punjabi man who was living with his wife. His only son was living in another city in the UK. He argued that even though dying people might be unable to see things around them, their soul would roam around the house and feel comforted by and be aware of the support provided by family members:

*It is much better to die at home. Because, though your vision may die, your soul doesn't. Your soul roams, and looks around, which gives you comfort. Why do you sit next to a dying person and pray? It gives comfort. You can feel that atmosphere, the affection and the need to belong* (Kesavan, Punjabi male aged 72).

Kesavan described how, according to Hindus, at the time of death, the soul lingers around relatives, the home, the body and the person's materialistic possessions. He explained how Hindus do prayers, hymns, devotional songs, and perform religious *pujas* at home, to create a divine atmosphere which is believed to support the peaceful



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departure of the soul. If these are not done, Hindus believe that the soul leaves the body without peace and comfort and will not be liberated from the cycle of birth-rebirth and attain *moksha*. In fact, Hindus prefer the body to be burned, which means that the soul does not feel the relationship with the body anymore, and returns to the heaven.

Some study participants perceived that such rituals were mainly for the purposes of family rather than the person who is dying. For example, some people described how rituals were done not so much for the soul to rest in peace, but so that the family would know that they had fulfilled their responsibility. It was perceived that if these responsibilities were not completed the restless soul of the dead person would bring loss and harm to the rest of the family. Thus Kanda, for example, reported that dying at home not only offers a sense of completion for the dying person, who is enabled to complete their familial responsibilities, but also helps the family to feel a similar sense of completion, as they could complete their spousal and filial responsibilities by providing personal care at home for their dying relatives. Kanda was a Gujarati woman who was living with her son in East London. She explained that home not only helps the family to offer the prayers for the dying relatives, it also helps them show their gratitude to the dying person by providing personal care during their last days of life:

*For my parents and my husband, for as long as they were still alive, I used to give them water. That were their end of life wishes, like cleaning their face, giving them water to drink and being with them until their last breath (Kanda, Indian Gujarati woman aged 62 ).*

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In contrast, Gujala perceived that it was often difficult for the family to be present or available at the time of dying, since many older people live alone and their adult children lived and worked elsewhere. Gujala was an Indian Malayalee woman who was living with her husband who had multiple health problems. Her daughter and son lived in different cities of the UK, but they often visited their parents. When asked about dying at home, Gujala opposed dying at home and argued that hospital would be more suitable in her particular case, as there was no one easily available to care for her and her husband at home. For Gujala, familial religious practices at home were not seen as a possibility and she saw them as less of concern for her and her husband since she was not living with her extended family:

*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 (Gujala, Indian Malayalee woman aged 68).*

Gujala highlighted the important issue of living alone as an older couple; this was one of the main barriers participants perceived to care and death at home. In fact, in this study, among the 29 people who were individually interviewed, 18 of them reported living alone. In addition, similar to Gujala, there were five older South Asian participants who reported that they lived with their spouse and that their children lived away. Many of these people stated that there was no-one available at home to care for them. For many generations, it has been a tradition for South Asians to live as part of an extended family and to share caring responsibilities for a dying relative. However, being in the UK meant

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that living with extended families was impractical for many, and as Gujara argued, in these situations religious practices seemed to assume less significance.

Some participants described an element of compromise in which the perceived value of religious practices and the practicalities of living alone were balanced. For example, Mariyanayaki reported that she hoped that someone would be available to pray at her bedside during her last days of life; ideally one of her children, but if not another person from the community. Mariyanayaki was an Indian Malayalee Christian, living on her own in her house. Her daughter and son were living in other cities around the UK:

*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).*

Importantly, Mariyanayaki demonstrated how people would adapt to a new situation of social living whereby children live away, which is very different from living in South Asia. This was achieved by adopting flexibility in their interpretation of religious practices at the end of their lives. She indicated that as her larger family are not nearby,

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at least someone in her community would be expected to pray for her, and the priest would be called to lead the prayers to enable a peaceful departure.

However, among the Muslim participants, dying at home was perceived as an alternative to dying at Mecca. For example, Amir was a Pakistani Muslim Imam living with his family in East London. He explained that the ideal religious place for dying and death was Mecca, where Prophet Mohamed had been born. However, if this is not possible, Amir stated that the dying person should be facing the east in his home, the *qibla* towards Mecca and the Holy Mosque, the *Ka'ba* (believed by Muslims to be the first place of worship on earth and the most important site of Abrahamic and Islamic worship). In addition, he mentioned that dying on Friday is considered to be an auspicious death among Muslims, as well as dying during the month of Ramadan:

*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).*

Furthermore, Amir described one of the reasons for their preference to die among their family members at home was that Muslims believed that their God would make a judgement based on how many of his relatives and friends felt sad and cried about the dying person. The moral principle behind their wish to be around family was to request forgiveness for any harmful acts. Muslims believe that this would purify the body and

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mind of the dying person. He reported that these rituals were practised among South Asian Muslims, as prescribed by the Quran:

*If someone comes and tells me that my loved one got cancer and is dying soon, as an imam I would advise them to recite our holy book. In his last days, he should do the good things to purify himself. If you take any money or property from others, return it to them and apologise to them. He will also prefer religious things. So, whether hospital or home, we should continue to do the religious things. So that is the base on which he will survive beyond that period*  
(Amir, Pakistani male aged 58).

Amir challenged the perception gained from other participants that the presence of the family at the time of dying and death was primarily for the good of the family rather than the individual. Rather, he said that the presence of the family would help the dying person to discuss how best he could complete his family responsibilities and unfinished business. Amir believed that this would help a person to be judged positively by God and to attain heavenly life.

The religious importance of dying at home was echoed by other Muslim participants and those from other religions. Four other Muslim participants described how dying at home with the family in attendance would enable forgiveness. For example, Fathima was a Bangladeshi woman who was living with her husband and two daughters in East London. She said that:

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*In the Muslim religion, after death, before the body leaves our home, when the priest is there, he will ask their wife or husband of the dead person for forgiveness in all the things he has done. The body can't be removed from the home until everything has been forgiven. That is Muslim religion. This is our custom. It is like when the person leaves this world, he should not owe anything. And also, my last wish is to see my grandson, and nephew. Even really small things are important in these situations. I think people need time to do these things. I need to tell my family that I love them (Fathima, Bangladeshi woman, aged 65).*

Fathima reported that forgiveness would help the dying Muslim attain heavenly life after his death. Importantly, she highlighted that forgiveness, the declaration of faith, and pronouncing the name of God are paramount for dying Muslim people, irrespective of place of death. Similarly, Hindu participants explained that dying at home would allow them to practice their religious rituals. For example, Rajeswari reported that dying at home provides space which facilitates ritual practices. These, such as giving sips of holy water to the dying person, and chanting from holy books are considered an element of good care. Rajeswari explained that South Asian Hindu families read or chant from their holy book, the *Bhagavad Gita*. This is because Hindus believe that their Holy Gita describes that whatever a person thinks of at the final moment when he leaves the body, this is what they will attain. Rajeswari perceived that there would not be any opportunities for the family to perform those rituals in a hospital:

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*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).

Rajeswari explained that it is a Hindu custom to give sips of water to the dying person by relatives. The water is treated as holy water, and where possible, water is brought from the Holy Rivers of India, like the *Ganga*, *Yamuna* and *Saraswathi*. It is believed that this water purifies the body and mind of the dying person and cleans their sins. Sometimes people also give cows' milk instead of water, since in Hinduism the cow is revered as a source of food and symbol of life. However, if someone dies in a hospital, Rajeswari argued that there are fewer possibilities for the family to practice such rituals.

For some participants, dying at home would enable the person to have their personal possessions around them. For example, Vanaja reported that Hindus keep idols or pictures of their favourite gods around the dying person, so that the person can see them and pray to them. Vanaja was an Indian Malayalee Hindu woman who was living with her husband while her two daughters married and had moved to other cities in the UK. She said that she would wish to keep an icon of her Lord Krishna, the Hindu god of incarnation, with her until her death. Vanaja described one ritual practice where she prays to a Hindu god which, she believes will provide her with comfort at the end of her life:

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*Look I have Lord Krishna in my home. I always feel happy to be with my god. Like this statue was with me for the last 40 years, even I brought this from Singapore. Every day, I used to pray, like 'oh God please give me strength to serve others. For any of my concerns, I used to feel that I am close to Him, and I want to pray to Him until my death (Vanaja, Indian Malayalee woman aged 65).*

In contrast, a few participants, like Gujala, opposed the idea of dying at home. She perceived that having the personal possessions of the person who died and being the room where they died would make it difficult for the family to subsequently use the same home. Gujala was an Indian Malayalee woman living with her husband. She claimed that family might not wish to stay and live in the same home where their loved ones died. Furthermore, she argued that family would find it a difficult experience to see their relative die:

*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).*



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Gujala challenged the concept of home as a ‘comfortable place’ for the family as well for the dying person. This concept of home as a place of comfort is discussed in detail in the following paragraphs.

### **4.1.2 Finding safety and comfort**

Alongside the perception that home can create a religious atmosphere, most of the study participants reported that home would provide a comfortable physical environment for the dying person. The 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. On the other hand, some participants also perceived that care at home in the UK may bring more difficulties than comfort for their family.

Six participants perceived that dying at home provides privacy during dying and death for both the family and for the dying person. For example, Kamruz explained that such privacy at home provides comfortable environment in which a peaceful death could occur. In contrast, he claimed that such privacy would be less likely to occur in hospital. Kamruz was a school teacher, who was living with his immediate family in East London. He explained that dying in a ‘so crowded hospital is dangerous’ and that he would prefer to die at home in a quiet and private place:

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*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).*

In contrast, later in his interview, Kamruz argued that with no extended families to provide support, and his perception that there was no home-based health care system in Britain, home was not a suitable place for end of life care. Kamruz stated that dying at home would only be possible back in his homeland where there was the availability of extended families, space, time and social commitment:

*If there are provisions at own home which there are not in Britain? In Bangladesh, yes, they will be cared for relatives. There are mostly joint families. Even if they are poor, doctors and other professionals would come to visit the patients at home. That happens as a matter of course normal cases in Bangladesh (Kamruz, Bangladeshi male aged 58).*

Here, Kamruz observed that the health care system in Bangladesh is designed around a culture in which home is the traditional place of for end of life care, and he believed that in Bangladesh health professionals would do home visits to support the family caring for the dying person. In addition, he exemplified that most South Asians have inadequate knowledge of what is available in the UK to help families provide end of life care, and saw this as a reason that some would be put off the thought of home as a place of dying and death.

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In contrast, though home was generally perceived as a comfort for the dying person, a few participants perceived that home was not a suitable environment in which to provide such care. Vasantha, for example argued that older people who were ill would be better cared for at hospital than at home. She was a Punjabi woman who was living with her son as a joint family. She said that:

*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).*

Vasantha reflects here the feelings among many participants towards home as the best place to be at the end of life, while simultaneously arguing that providing care to a dying person at home would be difficult for most families. This highlights the need for health professionals' support if families are to be successful in providing care at home.

Similarly, Rajendran highlighted the importance of support by health care professionals to make it possible for dying and death to occur at home. He argued that hospitals were better placed to provide specialist care that a dying person would need:

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*Compared with home, the hospital is a better place. At home, they are only one or two people to give care which is definitely difficult, unless specialized people can come and help them to do that. It is very, very complicated for the rest of the family to stay awake, there are specialist people who look after and concentrate on caring for older patients (Rajendran, Indian Malayalee male aged 65).*

There were two factors highlighted by Rajendran that he perceived may make people prefer to die in hospital. Firstly, he argued it would be burdensome for the family to manage a dying person at home. Secondly, he argued that often families perceived that hospitals could provide better care for dying people.

Similarly, four other participants argued that it was difficult to locate care of the dying at home. In the focus groups with Gujarati women, a number of participants reported their view that their existing facilities at home would not support the care of dying relatives at home. For example, Jayanthi reported that nursing support, special toilet arrangements, wheelchairs and hoists were needed to help the family make their home environment suitable as place of care for relatives who were dying:

*You know, sometimes they need to get one nurse and they need toilet facilities, wheelchairs, this and that. So many things people want and need. In the last hours of life, some people cannot walk to the toilet anymore, and some people*

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*are so heavy. It is very hard to give cope to the family. So if they can get help its very nice* (Jayanthi, aged 68, Gujarati woman in Focus group with Gujarati older women).

Another participant, Sreeja, reported using the cases of her mother-in-law as an example where it had been necessary to place her mother-in-law in a care home because of a need for special equipment. She argued that this was a better option, which resulted in less suffering for her mother-in-law:

*At times, take my example, for my mother-in-law, in my husband's family; there are four brothers like my husband. But we cannot take care of her, because there are no facilities at our home. My home is empty. She needs a hoist; but sometimes even we don't want her to suffer by caring for her at home. So we have to put her in care at a special home* (Sreeja, aged 62, Gujarati woman in focus group with Gujarati older women).

On the other hand, Halima claimed in her interview that the risk of dying alone in places other than home would mean that the death was 'bad'. Halima was a Bangladeshi woman who was living with her husband and unmarried son. She highlighted the importance of the family psychologically supporting the dying person. However, she said that this would not happen when no one was there to 'hold her hands' and to reassure her:

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*Halima: So people want their family together during their last couple of days, and friends. Even I also expect. I will die one day and nobody cries for me. I cannot believe that [laughs].*

*MK: Could you tell me more about when you said when you die nobody will cry for me?*

*Halima: Yes, nobody will hold my hands. I can think. I will go. Nobody will see me in that time and I will not be able to see my family and my friends (Halima, Bangladeshi woman aged 64).*

Halima explained that she hoped that at the time of her death, she would be at home with family and friends able to visit her, hold her hands during the final hours, remember her qualities and crying for her departure. These are traditional ways of mourning that she perceived would bring her comfort. Conversely, Shohail, a Muslim participant in the Bangladeshi focus group, argued that irrespective of the place, a calm and clean environment was essential for a comfortable and peaceful death. Indeed, in contrast with Hindus, among South Asian Muslim communities, crying loudly would be seen as taboo during dying and death. They are expected to stay calm, 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).*

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Six participants reported that cultural factors existed that would work against an older people staying at their own home in their last days. Chandru for example declared that despite his preference to stay at home; there was no one available to care for him there. Chandru was a Punjabi man who has been living on his own in East London, since his wife died 15 years ago. His two daughters live in other cities in the UK but visit him often, and sometimes stay for a weekend. However, he then said that such preferences are threatened by the practicalities of dying at home. Although the daughters have made it clear that they would want him to stay with their respective families, he said that he would prefer not to depend on them. He further stated that it was not a common practice in South Asian communities that older people to be cared by the family of their daughter and son-in-law's family:

*MK: Where do people normally prefer to be cared for and die during their last days?*

*Chandru: That's still, if I am going to die, If I can, I want to be at home. But still I can see that I cannot live at home on my own and my daughter cannot look after. But still I don't want to go to hospital, otherwise if there is a choice available; I will go to an older people's home (Chandru, Punjabi male aged 74).*

One issue that participants consistently reported was their recall of experiences of their homeland culture and the practices surrounding death and dying there. Malar for example, reported that the support from extended families commonly available in their country of origin allowed people to die at home, but this was often not available in the

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UK. In so doing, she described how her mother had been cared for by the extended family and how this had maintained the good name of the family in the village. She perceived that such traditions would be unworkable here in the UK, because of a lack of adequate space or extended family. Malar was Indian Malayalee woman who lived on her own in East London with her two daughters living in other UK cities. She said that:

*Malar: Back in India, we hired a special nurse for four years for my mother and cared for her until she died. But we cannot do these things here.*

*MK: Could you tell me about you in this issue?*

*Malar: I don't want to be in that situation. And we don't have space here. Everyone in my family joined together and took care of our mum. Because our family has a good name in our village. So we gave one special room and took care of my mum (Malar, Indian Malayalee woman aged 68).*

Some participants reported similarly that caring at home would be more feasible back in their home country than in the UK. Thus Syam highlighted various issues around making home a comfortable place for dying and death in the UK compared to his homeland. He argued that restrictions including lack of extended families, young children who also struggle to manage their own day to day commitments, the time-consuming nature of care, and lack of space would encumber the home as a place of care in the UK:



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*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).*

Similarly, Chitra argued that being cared for at home in the UK would not be possible for her, because it would threaten her daughter's employment. Chitra was an Indian Malayalee woman who lives alone; her daughter lives in the same city with her own family:

*No. I don't want to be cared for like that when I have a long-term illness, and it is not suitable for this country. How can I go to my daughter's home, how will she go for a job? (Chitra, Indian Malayalee woman aged 67).*

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## 4.2 Reconsidering the homeland

As reported earlier, almost all of the participants in this study were first-generation South Asians who still held vivid memories about their homeland. These older participants had emigrated from South Asian countries such as India, Pakistan, Bangladesh and Sri Lanka, and although, they had physically left their homeland, most claimed that they still had a substantial relationship with it. In particular, most of them reported that they still had economic and social ties with their homeland.

Many of the participants stated that they often travelled to their homeland for various social purposes. These purposes included attending the important celebrations of their extended family, taking part in religious festivals, travelling to complete traditional family customs, visiting their immediate and other family relatives, and to visit holy places in their homeland. Some of them also reported that they still had their own ancestral properties in their homeland which encouraged them to return to their countries of origin. Participants further reported that when they got older, and their formal responsibilities became more limited in the UK, for example when they retired, they visited for longer periods and a few returned to live in their homeland.

Importantly, participants reported that the subject of their homeland was important in relation to end of life care. Findings revealed three patterns of attitudes in relation to homeland towards the end of life: ‘returning home’, ‘the increasing importance of culture at the end of life’, and ‘laying down new roots’.

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### 4.2.1 Returning home

Returning to their country of origin at the end of their life was for some a heartfelt and idealistic preference. Kamruz claimed that dying in his homeland would provide a comfortable end of life for him. He stated that though he accepted his dual identity as British and Bangladeshi, when it comes to death, he would prefer to die in his homeland. He was a Bangladeshi Muslim and worked as a school teacher in East London. He had emigrated from Bangladesh at the age of 23, and he now lived with his children in East London. However, he regularly visited his parents and other immediate family members who still resided in Bangladesh. In his interview, he claimed that his preference to die back in his ‘own Bangladeshi soil’ would provide him a peaceful death. When asked his opinion about people going back to their country to die, he answered that:

*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.*

*MK: Could you tell me why?*

*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).*

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Another participant named Ramesh voiced a similar view concerning the value of dying in his home country. He described how some people have an emotional relationship with their homeland, referring to it as the ‘mother land’. He was a Gujarati businessman living with his wife in East London; his daughters were married and living in other cities across the UK. When I approached him to arrange a convenient time for conducting an interview, he scheduled six weeks later to accommodate his journey to India to attend a family wedding. In his subsequent interview, he said that some people still have a desire to return to their country of origin, since they prefer to die in their homeland:

*Some people might want to go back home. Because, that is their homeland.*

*That’s what they say. This is not our homeland; it is our fatherland [laughs]*

*(Ramesh, Gujarati male aged 72).*

A female Bangladeshi participant, Jameela, argued that the preference to die in their homeland clearly relied on the decision of one’s adult children, as it involves a significant financial cost. However, she reported that it was common practice in local Bangladeshi communities to send their older relatives back to the homeland for the last days of their lives. Jameela was a Bangladeshi woman who had recently retired as a teacher. She was separated from her husband, and she was living with her son in East London. She said that she visited Bangladesh almost every year for the last 25 years, since her parents and extended family reside there. She stated that because she is retired, she would now perhaps visit more often and stay for longer periods of time in her homeland than previous years:

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*Jameela: Some people they send their father and mother back to Bangladesh. They keep them for the rest of their life. 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.*

*MK: So why do they like to go back?*

*Jameela: 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).*

Jameela reported how the family has an obligation to decide whether they consider their homeland as a 'home' at end of their life. She said that one of the reasons underlying preferences to return to a homeland was because of important childhood memories, many of which involved witnessing traditional end of life practices such as being around family and relatives, traditional cultural rituals and religious practices.

On the other hand, Halima suggested that the attitude of second-generation South Asians might be different, and that they may prefer to be cared for by older relatives in the UK. She stated that her son, who was born and brought up in the UK, would have a different attitude towards preparing for the end of his parents' lives. When asked her personal preference concerning returning to her homeland for the end of her life, she said that her son would prefer for her to remain in the UK during her last days:

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*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).*

#### **4.2.2 Laying down new roots**

While some participants held attitudes towards homeland that suggested it was the preferred place to die, others argued against the culture of returning to the homeland, instead associating the meaning of 'home' with where their family was living. In the Indian Malayalee women's focus group, for example, participants argued that their homeland was the place where their adult children have settled. They indeed saw no necessity for such a return, because their children, who have a moral obligation to provide end of life care, remained settled in the UK. Furthermore, they reported that there was 'no-one' in their homeland to care for them, as they had lost their ties with their original social community, which under normal circumstances would be expected to provide such care. For example, Kamala and Mariyanayaki claimed that home is where one's children live, not necessarily one's original homeland. They suggested that people who had settled in the UK with their children would not be as eager to return to their homeland at the end of their lives, and would instead prefer to receive care in their country of residence:

*MK: What do you think about people who prefer to go back home?*

*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?*

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*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).

The above focus group respondents demonstrated various elements that influenced the concept of reconsidering homeland for their end of life. These included having their immediate family settled in the UK and having no-one to care for them back in their homeland. As the first generation likely to experience dying in the new country, there was a need to believe that their adult children would decide about the best place in which to die.

Similarly, another participant Kalian challenged the idea of home as a homeland by portraying how older South Asians have lost their relationship with their extended families in their homeland which makes returning back to the homeland pointless. She was an Indian Malayalee woman living in her own house. Her daughter and younger son were living in other cities in the UK, whereas her elder son lived not far from her in East London;

*I won't go, because my children are here. In case I fall ill and die, the children are here. I won't go to India; we should return, if we have either elder or younger family members back home. Otherwise, we should have our parents. But no-one is there. Sometimes if they say only 5 months, we might only live for another 5 months. So who is there to look after us?* (Kalyani, Indian Malayalee Woman aged 62).

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From her explanation, it was evident that all of her children had settled in the UK, and rather than returning to India, she would rely on them for care towards the end of her life. Furthermore, she claimed that when her close family was no longer living back in their homeland, it would be unfeasible to return, particularly when the timing of death was uncertain. In contrast, Rajendran portrayed the prevailing tensions about place of death and meaning of homeland in their last days of life, particularly if their immediate family were scattered throughout the world. Rajendran was an Indian Malayalee man who was living with his wife in East London. Her son and daughter were living in the USA.

*Individuals feel the way they want to end their last days, and that also depends on their family connections. For example, someone first generations may have one child who might be in the USA. In another case, someone might have four children and live around him them? So his situation is different. There are lots of different situations, and we cannot say that this is what all we thinking (Rajendran, Indian Malayalee male aged 65).*

Many of the Gujarati participants who had come to the UK and were involved mainly in businesses reported that they have large extended families in the UK. In the focus group with Gujarati women, participants strongly challenged the view of dying in their homeland as an ideal, as voiced by the previous respondent, Rajendran. They reported how they have established their own social network of families, friends and community and that in this sense, their homeland is here in the UK, where they are surrounded by their families. Interestingly, they defined living in East London as ‘home’, as they have



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spent the whole of their lives there. Moreover, these participants reported that returning to the so-called homeland would be an emotional rather than a practical decision:

*Sreeja: No, I don't agree with going back to our country to die. This is our home, and all our friends are here.*

*Archana: We have spent our entire life here, so we don't need to go back to India.*

*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).*

The above respondents clearly demonstrated that their level of attachment to their homeland depended on whether they were married or have lived life on their own. Although they would be classified as first generation migrants, most of these participants migrated with their parents when they were children. Therefore, they might not share 'childhood memories' like previous migrants. This would indeed make them more reluctant to return to their homeland. However, they reported that they still had an emotional attachment with their homeland culture of care during death and dying. On the other hand, participants reported that their children, who were second generation South Asians, challenged their older parents about their intention to return to their homeland and the requirement for post-mortem rituals to be performed there. Instead they felt it was possible to conduct such rituals for their older parents here in the UK.

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### **4.2.3 The increasing importance of culture at the end of life**

Some participants believed that their ethnic culture played an increasingly important role in their lives as they moved towards the end of their lives. They claimed that although they did not necessarily wish to receive care at the end of their lives in their countries of origin, they still wished for certain religious rituals to be observed at and following their death. The participants reported the perception of 'home' as more than homeland and family. They claimed that home signified culture rather than a physical place. They highlighted the importance of carrying their culture through generations, and how it was essential in terms of preserving their ethnic identity. However, there was dilemma among the participants in relation to returning to their homeland. While some participants reported that people would prefer to send their bodies or ashes back to their homeland for their end of life rituals, others argued that such rituals would be done here in the UK.

In the focus group with Gujarati women, one of the participants, Jayanthi, argued that people need to follow their own cultural norms in order to not lose their own culture. She described how people did not need to go to their homeland for pre-death rituals, since these were possible to do in the UK, and then it would be possible also to return ashes to the home country for funerary rites. She believed that this would possibly preserve their culture at the end of their life, according to their religion. Furthermore,

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she claimed that older generations need to practice and teach the younger generations about such rituals:

*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. 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.*

*Archana: Yes I am here.*

*Selvi: New generations are thinking differently, and not like our older generations. Because they were born in this country.*

*Vimala: They have a lot of freedom, it is not good (focus group with Gujarati women).*

Most of the Bangladeshi participants that were interviewed were Muslim, and preferred to return back to their homeland to live the final days of their lives in the traditional way. However, most Indian Gujarati's, Tamil and Indian Malayalee participants who were Hindus and Christians reported that they would be able to practice their own traditional end of life rituals in the UK. For example, in the Gujarati focus group, people reported that they would be able to practice the same end of life rituals that they

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practised in their home country in the UK, except spreading their ashes in the Holy Rivers of India.

In South Asian Hindu culture, people are commonly cremated and have their ashes thrown in the Holy Rivers, which is believed to purify their sins and permit them to join with God. In South India, there are other Holy Rivers where people also spread their ashes. Sivasakthi, an Indian Malayalee Hindu, said that while he was happy to die in the UK, he would like to be cremated so that his ashes can be spread into the Holy River *Barathapuzla* in Kerala, in southern India. He stated that in his view, the homeland was a place where families could participate in rituals:

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

In India, the choices of cremation and burial are personal ones. For example, Hindus tend to prefer cremation while Muslims and Christians prefer to be buried. Hindus believe that cremation will help their soul to detach from its physical relation to the body, so that it can return to the divine court. Furthermore, the principle behind such cremations is to enable the ashes to be sprinkled into the Holy Rivers. However, some ethnic groups among Hindus also prefer to be buried. Similarly, Archana wanted to be cremated in the UK so that her ashes could be spread into the Holy Rivers in India. Archana was a Gujarati woman who was living in East London in supported accommodation as she did not want to live with her daughter who was living with her

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fiancée. She explained that having a large family as a support system makes people less worried about the end of their lives:

*But in our community, most of them live as a big family. Especially in bereavement, sons and son-in-law take care of the family. I think that's why people don't want to talk about such things. You know, I told my daughters that I wanted to be cremated and have my ashes sent to India (Archana, Gujarati woman aged 74).*

Archana believed that the nature of living as part of an extended family among South Asian communities usually provides support for the family in terms of performing death-related rituals. Indeed, she reported that having a large family helps to facilitate the bereavement process for the family. She said normally the men at home take the responsibility to perform all the rituals. However, she reported that she has had discussions with her daughters about her funeral arrangements. She said that she would prefer to be cremated, and her wish was to have her ashes sent back to India for after-death rituals.

In contrast to cremation, participants also reported that some people preferred to be buried in their homeland. Mariyanayaki reported how she took the body of her husband back to India and buried him there to honour her husband's preference. However, when asked about her preference over burial, she hesitantly expressed that though she would prefer to be buried next to her husband, it is generally up to the family to decide:

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*MK: What is your preference?*

*Mariyanayaki: I cannot say it like that. So, let them do as they wish. We don't know where I am going to die ... like sometime I might die back home, while I am visiting. But if they want to take my body and bury it next to my husband's, let them do so. I have done what he told me. But it's their money. They can do what they want with me. Even if I provide money for this, they will only do whatever it is that they decide (Mariyanayaki, Indian Malayalee woman aged 68).*

Similarly, Malar claimed that she would not be able to make any decision concerning the end of her life, and that it would be 'up to her children' to decide. She said that returning back to India would be a 'big wish' which indeed suggested that cost, time and family support were all involved, as well as a commitment to fulfil her preferences. Instead, she decided not to express any wishes in relation to the end of her life:

*MK: What about you? Do you wish to go to India?*

*Malar: Yet, I did not tell anyone about such things. But it is up to my children to make that decision; since I don't have any big wish or plans (Malar, Indian Malayalee woman aged 68).*

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Vanaja argued that a dead body would not receive a ‘fine finish’ in one’s homeland. She preferred the funeral process in the UK, and claimed they showed due respect for the body, whereas in India, she claimed that the dead body was not treated with due respect:

*No I don't plan on going back to India permanently. You know we can have a very good funeral over here. But is not the case in India. I like the way they respect the dead body a lot [in the UK], regardless of whether it's a man or child. Normally in India, when people die, they don't take care of the body. But we saw the funeral process here, where they show a lot of respect for the dead body, which has been in this world for a long period of time, and deserves a fine ending (Vanaja, Indian Malayalee woman aged 65).*

## 4.3 Summary

This chapter has reported the findings in relation to the meaning of home at the end of life among older South Asians living in East London. For many generations, these people have grown up in a culture that viewed home as a place where people can freely engage in their traditional practices at and around the time of death. In addition, they work at maintaining their cultural heritage without the pressures of having to conform to

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the outside world. Nevertheless, living away from their traditional home environments challenges the participants' perspectives on the meaning of home, especially when faced with death. However, existing realities in the immigrants' new country of residence make them aware of various barriers and burdens that could potentially hinder their traditional meaning of home during the end of their life. Nevertheless, their intention is to maintain the traditional, religious and cultural values surrounding end of life rituals; as such, participants reported that they always intend to balance such burdens and barriers.



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## CHAPTER 5

# Family

This chapter examines primarily how participants reported their experiences of family care giving at the end of life. In focus groups and interviews participants reported these experiences either in relation to their own family members (n=23), or in relation to their relatives and friends (n=25) (see the table 5).

**Table 5 Reported experiences of providing end of life care**

Type of data	Total		Direct experience giving end of life care	Experiences of close friends and relatives
Interviews	29	Men (13)	3	6
		Women (16)	9	8
Focus groups	35 participants from 5 focus groups	Men (12)	2	5
		Women (23)	9	6
Total	64 (including 9 participants in interviews and focus groups)	Men (25)	5	11
		Women (39)	18	14
		Total	23	25

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Data analysis revealed that family care giving at end of life within South Asian communities remains a complex phenomenon, often due to inherited socio-cultural values. This chapter shows how participants reported two of those predominant values: ‘honour within family’ and the value placed on ‘extended family and social networks’. The first section deals with ‘honour within the family’, and findings are reported relating to two predominant themes: firstly, the experiences of providing end of life ‘care within marriage’; and secondly, the expectations of ‘filial responsibility’ in the provision of such care at the end of life. In the second section I present findings in relation to how the extended family and the wider community are considered key in supporting the dying person and his or her immediate family. Table 6 summarises sub-categories and themes related to this chapter.

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**Table 6 Sub-categories and themes relating to meaning of family during end of life**

<b>Category</b>	<b>Sub-categories</b>	<b>Themes</b>
<b>Family</b>	<b>Honour within the family</b>	<b>Caring within the marriage</b>
		<b>Filial responsibility</b>
	<b>Extended family and social networks</b>	<b>The extended family</b>
		<b>The wider community</b>

## **5.1 Honour within the family**

Almost all of the study participants were first-generation South Asian immigrants living in East London. They still held vivid memories of how their families had honoured and revered older relatives while growing up in their home country. Some had memories of these relatives being cared for at their home towards the end of life. Thus, most participants believed that caring within the family for dying older relatives was an honour and an important tradition which expected to remain an essential aspect of their family life.

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Participants reported that older spouses, particularly when they lacked an extended family and their adult children live away for the purposes of employment, become the main carers for their husbands or wives. Despite the fact that they often faced difficulties with their own health problems, and with language and communication difficulties inhibiting engagement with health and social care agencies, they reported that provision of end of life care was considered as a core aspect of ‘caring within marriage’. In a similar way, it was perceived that caring for elderly parents by adult children was an essential demonstration of ‘filial responsibility’.

### **5.1.1 Caring within marriage**

Among the participants it was reported that older spouses often acted as primary family carers for their dying relatives. The reason for this was often circumstantial, as adult children were no longer living with their parents or were busy leading their own lives. Most notably, participants perceived that it was an aspect of the traditional role of married women to be committed to the care of their spouse, in spite of their own health problems. Leena, for example, explained how she was committed to caring for her husband at the end of his life despite her own health problems, which included severe joint pain. Following her and her husband’s immigration to the UK, her two sons were refused a visa and remained living in India although her daughter lived in another city in the UK. Since the funeral rituals in the South Asian culture needed to be performed by male family members, she said that she upheld her promise to care for her husband until she sent her husband’s body back to India to be ‘handed over’ to her sons:

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*Leena: I didn't care about my health. After my husband death only, I have started taking care of my health. I used to take medications and care him, I didn't care about health.*

*MK: What are your health problems?*

*Leena: I have diabetes, arthritis, cholesterol and all the problems. I have all the problems, but when my husband was ill, I had strong mind for care him in better way I had. Until I took his body back to India and handed over to my children, then I started to think about my health. I never took care of my health for myself (Leena, Indian Malayalee woman aged 71).*

One of the reasons for such dedication to providing family care for their spouses at the end of their lives was reported by the group of older Indian Malayalee women as 'common tradition'. During this focus group, when one participant, Aswathy, explained about how she cared for her husband at home, other participants agreed that it is a 'love to care at home' and a 'tradition'. Aswathy said her family felt satisfied by seeing how her husband appreciated the family care provided for him, in particular how the family gave him his favourite homemade food and he was able to meet his own friends within the community:

*Aswathy: As soon we heard that, we made discharge and we took him back to home. We gave him the food which he likes, he was quite happy. He is also in Thursday luncheon club for older people in our community group. He wanted to see his friends on Thursday they visited with all food that they cooked he enjoyed the meal that was a last meal and on Friday he had big stroke and died.*

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*Vanaja: We are the same, we like to bring home*

*Bobby: we don't like to send to hospice and other things especially when he was dying*

*Shankari: We don't like to send to hospice, we want to care him in our home*

*Leena: We love our husband, so we love to take care of him at his last days. It is a tradition (focus group with Indian Malayalee women).*

The focus group participants' views above reflect that providing family care at the end of life is not only a matter of tradition, but also of social prestige. Participants viewed families who adhered to traditional practices and responsibilities about care giving as highly respected and valued.

On the other hand, as shown in table 5, only five male participants in focus groups and interviews reported that they had been involved in the care of their older spouses or relatives at the end of life. However, while not involved directly in care-giving, others reported that they were always there to ensure that the last days of life were comfortable. In particular, they reported being involved in discussions about decision making and organising aspects of care. For example, Ramalingam reported how he looked after his wife in the last days of her life. He was a Sri Lankan Tamil Man who was living with his son in East London. His two sons were currently living in East London as asylum seekers from political conflict in their home country. Ramalingam moved to East London after his wife died as no one was available in Sri Lanka to care for him in his old age. He reported that he stayed in Sri Lanka itself to care for his wife who had

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chronic illness and was present during her last days of life. He reported how he had not moved from Sri Lanka to be with his son in the UK because of the need to care for his wife and his commitment to keep his promise to his wife. He claimed that he provided the ‘most comfortable’ final days for his wife:

*At the tail end of life, she died in the age of 62. It is about eight years back. Her both kidneys and liver have been affected. I had given her all treatment and the best of comfort in Colombo with help of the most qualified doctors. But doctors said anytime. They did not tell me about the position of the liver and the kidneys. Had I known it, I would have taken her into Apollo Hospitals, in India, and I would have tried to save her life, but anyway it was nothing but fate. Doctors given me the opinion that she was in her last days of her life and it was not best decision to send to India to save her. Anyway that is off course that was long story she passed off at the age of 62 (Ramalingam, Sri Lankan Tamil male aged 78).*

Ramalingam emphasised the value of spousal relationships in regards to care and decision making concerning death and dying. This perhaps reflected the fact that in South Asian families, spousal relationships are a significant factor in terms of providing mutual care, particularly when old age sets in, and when the children are residing elsewhere. Moreover, Ramalingam also underlined the importance of gender in South Asian families during decisions involving death and dying. Usually, husbands were expected to organise and provide the best possible care for their wives, and in return, the wives were normally expected to provide basic comfortable care, and negotiate with

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their children in order to ensure that their husbands received the best possible care during their last days.

Family care giving was not only considered an opportunity for the family to respect elders at their end of life; it was also regarded as an opportunity for the person at his end of life to care for his family. For example, Malar explained that though her husband preferred to be cared for by his family, he wanted his wife to take some rest from her caring responsibilities. Malar was an Indian Malayalee woman who was living on her own in East London with her two daughters living in other UK cities. However, she reported that although her husband was admitted to hospital during his last days, she could not refrain from caring for him in hospital. She stated that she had her own health problems, and also she was the only a carer available on a day-to-day basis to support her husband, which made her extremely tired, and she felt constantly exhausted while caring. She reported that despite being close to the end of his life, her husband asked her to stay at home to take some rest but she refused.

*I cannot stay at home at 9 am, I should be at hospital. Sometimes my husband asked me to go and take rest at home. But I cannot. Even when he was about to die he asked me, it is 2pm now go and take rest at home. But I did not; as I know something is going to happen (Malar, Indian Malayalee woman, aged 68).*

Malar suggested that caring within marriage, even at the end of life, was characterised by reciprocity, whereby those coming to the end of their life were acutely aware of the carer burden placed on their husband or wife and did what they could to ensure they



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were given a chance to rest during the period when they were in the role of ‘carer’. She highlighted a strong South Asian family tradition that encourages mutual dependence and family solidarity among its members. This occurs not just horizontally within marriage but vertically between generations. Younger members of the family are expected to respect and provide comfort at the end of the life of older relatives. In turn, the older family members were expected to follow the moral principle of reciprocal responsibility. Thus older people in South Asian society are traditionally expected to be wise enough to solve problems, make decisions, predict, caution and protect the family as well as act as a buffer to safeguard the family. In addition, they are expected to sacrifice their own needs in order for the family to prosper if required. In this study, participants reported that the person at his end of life not only received care from the family, but also maintained his or her responsibility to care the family during such stressful events.

A similar view about mutual caring was exemplified by the participant Aswathy. She lived alone with her husband before he died, since both her daughters had previously relocated away from London following their marriages. She described how her husband cared for her despite being at the end stage of his life. She discussed how he constantly urged her to go home, as he knew that she did not like being at the hospital while he was admitted.

*At 10 o'clock they said they are going to admit and going to do further test and all. You know, 10 o'clock he was unconscious. You know, we have been in the hospital from the 3 or 4 o'clock, I think he knew that. Only he kept saying is*

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*going home, go home, go and eat something, go and eat something. That was he's telling me. He is saying go home go home, that's only kept saying* (Aswathy, Indian Malayalee woman aged 68).

In addition to spousal responsibility, some participants, such as Kanda, reported how family support is an essential factor in providing family care. Kanda was a Gujarati woman living with her son in East London. She reported that when doctors told her and her family of the poor prognosis of her husband, her family took a joint decision to take him back to their home for his remaining days. She stated that all her family were happy to care for her husband at home and happy to support her as his main carer. She reported that her daughters who were living in Leicester came and stayed with the family in London to support each other while caring for their father at his last days of life. Thereby, she said that she was able to respect her husband's wish to be cared for by his own family.

*Kanda: He was in hospital for three weeks. They arranged everything. After three weeks, we asked the doctor can we take home and doctor said 'if you can cope, you can take', then I said 'yes, I can', and doctor said 'ok, you can take, if you cannot we will help you'. Then every day they ask me and they ring me. The nurse comes every day to look after, to see my husband and every day they talk to me. In one week, social worker came twice and they sit with husband. I have to do my shopping, banking and they helped me. I was doing everything. I was so happy with that.*

*MK: Who took the decision to bring home?*

*Kanda: My husband, me and my both sons*

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*MK: Did your husband agree with your decision?*

*Kanda: He said that I want to come home he say I want to die home we are pleased my son my daughter everybody was pleased (Kanda, Gujarati woman aged 62).*

Conversely, a few participants argued that as family were able to provide only limited support for their parents, most of the care burden fell on the older spouse. Malar claimed that at times, such respect may become a burden when adult children live away, either in Britain or abroad. She explained that she needed to be healthy enough to care for her husband, as other members of the family were unlikely to be available locally. She was a housewife with many health problems during the time she cared for her husband. In her situation, she and her husband had decided to live alone as they did not want to be a burden for their children in their old age. Therefore, to demonstrate her care and respect for her husband in his last days, she decided to care for him by herself as she did not want to ‘trouble’ her children’s day to day life.

*MK: How did you feel while you cared your husband at his last days?*

*Malar: I never had any problem to care. I had only one wish to be healthy enough to care my husband at his last days. I did not think, about myself. Because, I know that I need to take care. If I fall into sick, who cares my husband? My daughter and son in law were in need to go to work. They can only come in the evening. Someone should be there always to care him.*

*MK: How did your family support?*

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*Malar: They brought me back to home from hospital every day. They did not able to stay as they have 2 children to look after. So, I decided and never gave that trouble to them (Malar, Indian Malayalee woman aged 68).*

Furthermore, she indirectly raised the issue of gender in end of life care. Of her family of two sons and one daughter, only her daughter lived in the UK, but she was living a few miles away in London. She explained that another reason for her decision to provide the care herself is that in South Asian culture, people tended to expect to be cared for at the son's home rather than at the daughter's (or indeed, rather than in their own homes). Therefore, she decided to care for her husband at their own home rather than moving to her daughter and son-in-law's home. However, she did receive some limited support from her daughter and son-in-law, such as taking her to hospital and supporting her in making decisions, although the personal and day-to-day care was mainly her own responsibility.

### **5.1.2 Filial responsibility**

In common, most participants trusted their adult children to take responsibility for providing peace and comfort when they reached their last days of life. Such trust was perceived as a filial responsibility of adult children, and was considered as an important inherited custom. However, they also recognised that there were various barriers faced by their children that may have impeded them from fulfilling those filial duties. Some of

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these barriers meant that while care at home was considered an ‘ideal’, participants accepted the reality of needing care provision from other places.

Many participants believed that issues related to dying and death were the responsibility of their adult children. Selvanayakam said that older people should be cared for by their children in the children’s home towards the end of life. He was an Indian Christian priest who worked with local Tamil-speaking community in East London, by providing religious services. He also visited older people in their homes and in hospitals to perform prayers when they were dying:

*By and large, people live with their families and expect their loved ones, their children to look after them until the very end. If it is impossible for the children to look after their parents, they would not mind being admitted to hospital. But these old people would wait for the day when they can return to their place, a place we call home. In most cases, this would be their own children’s home (Selvanayakam, aged 62, Indian Tamil male in focus Group with Tamil speaking older community).*

Selvanayakam described various traditional and cultural realities that are embedded in older South Asian people’s lives. He stated that older South Asian people most commonly expect to live with their adult children, especially during their last days of life, when they often accept the need to be admitted to hospital since they appreciate the difficulty their family may experience in caring for them. However, he claimed that in

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these circumstances, older people will ‘wait for the day’ to return to their family’s home for the last hours or days of their lives.

Such a view was echoed by others and was not specific to particular ethnic groups within the sample. A Bangladeshi participant, Karim, believed that the family is traditionally obliged to care for their older relatives at home towards the end of life. Karim was a Muslim who was living with part of his extended family. He reported that any South Asian from the local Bangladeshi Muslim community preferred to care for the dying person at home if they were given a poor prognosis:

*Yes. Any South Asian who is Bengali Muslim is very, very keen to care for a dying person. They want to take the patient home if the prognosis of that gentleman determines that he is going to die that day, or the next day. The family will decide to take the person home to care (Karim, Bangladeshi male aged 64).*

However, such views were sometimes tempered by what may be considered the reality of the situation. Jameela claimed that although such expectations of filial duties were an obligation and tradition, whether they could be carried out often depended on family circumstances. Jameela was a retired teacher who lived with her son. She explained that the culture of caring for the older relatives is how people are ‘brought up’ in South Asian families and she perceived that most South Asian people accepted their duty to care for their older relatives at home:

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*It is accepted. But sometimes it all depends on the family. But feeling a sense of responsibility to look after the older is how we have been brought up by our parents. If my parents became ill, I would look after them. I have seen most of families do this (Jameela, Bangladeshi woman aged 62).*

Jameela explained that expectations about the care of older relatives at home were the ‘way they think and learn’, however she highlighted that there were a number of tensions prevailing among South Asian communities in relation to expectations and strong family values by stating that it ‘depends on the family’.

Kanthasamy echoed similar views. He perceived that although there are advantages of providing care at home, the family commitments of one’s adult children might be a barrier to home care. Kanthasamy was a Sri Lankan Tamil man living with his wife. His only daughter worked in another area of London. He argued that some families considered it burdensome to provide care for a dying relative at home. He reasoned that adult children have their own family pressures that include caring for their own children, and earning their livelihood. He felt such commitments would not allow them to provide adequate time, attention and care for a dying older person at home. When asked about his views of caring for a dying person at home, he answered as follows:

*Kanthasamy: There are advantages, but it is not a burden. I know they look at it as a burden*

*MK: Why is it viewed as a burden?*

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*Kanthasamy: They have more commitments. They need to look after their children, and they have their own family pressures to deal with. They haven't got much time. Those are the pros and cons. They are neglecting children to look after a dying one. So, how can they afford to take care of a dying person? If you do take care of an older person who is dying, he needs a lot of attention and care (Kanthasamy, Sri Lankan Tamil male aged 68).*

Although Kanthasamy agreed that dying at home meant that they would be surrounded by their family, he argued that families could not always afford to provide care in light of their own commitments. He highlighted that the cultural value of caring for dying people at home was becoming diluted or becoming 'unaffordable', as there were other mounting family pressures to deal with. His views highlighted a question about the extent to which second-generation South Asians consider their older people as their own family, beyond their immediate nuclear family of partner and children.

However, most participants claimed that caring for the dying person at home could be disturbing to members of the family. Sivasakthi was an Indian Malayalee man living with his 62 year-old wife, and since his immediate family were living far away from them, he reported that care at home was not possible. He stated being cared for at the home of his children would disturb his family member's daily lives:

*Yes. It is same for me. My daughter is in other city and my son lives in another city. They are both doing business. I don't want to disturb them. However, they still love us. At the same time, they need to live their own lives. So I don't want*



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*to waste their time. No, it is not a waste. But I don't want them to be disturbed. We did a lot in our life for the community, and friends. But the children are leading a busy life. So I don't want to disturb them* (Sivasakthi, Indian Malayalee male aged 75).

Similarly, a number of participants wondered whether their adult children would be able to fulfil the filial expectations held by their parents when they were often out all day working. Bilalji, who was living with his son and daughter-in-law, reported that both had fulltime jobs. He said that he was supporting his son by taking care of his grandchildren while they both went to work. He claimed that family support is important when caring for older family members toward the end of their lives, and believed that family members should stop work where necessary to stay at home and care for their parents.

*Bilalji: That's when we need to keep them at home. If we know for sure that the person only has 3, 30, or 45 days left, then, we need to care for them properly, to be there at their side, and if it is possible, also stop work in the meantime.*

*MK: Do you mean that family members need to stop their work?*

*Bilalji: Yes, at least one family member must be available to provide care. I don't want them to leave the provision of care to just anybody. The family must be there. Then the dying person feels happy, the patient who is ill is happy, and the family will also be happy. The dying person needs to be fed from their own family members, at least a cup of tea, soup, little bit water, anything or from time to time, they need to be given medicine. We need to have family members with us. That is a time I feel satisfied for*

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*what I have done for them throughout my life. So, we need to provide care (Bilalji, Gujarati male aged 72).*

However, later in the interview, Bilalji appeared to contradict some of these views suggesting that such a position does not always withstand close scrutiny. He realised that there may be conflicting interests between his own personal preferences for family care at the end of his own life and the wider responsibilities of his children who lead demanding lives. However, he continued to claim that dying at home ‘according to the family’ would benefit them in the traditional sense of enabling them to complete their filial responsibility. He explained that people would ‘in their hearts’ rather not leave their older relatives to ‘alone’ in other places of care at the end of their lives:

*No. Sometimes we don't want to die in the hospital. According to the family, we need to be at home. But circumstances are like that. We want them to go on with their work, because they can't just stop what they are doing. In which case, we need to be placed in a hospital or older home. So there is nothing we can do. In our hearts, we don't want to leave them alone (Bilalji, Gujarati male aged 72).*

The above statement illustrates a dilemma commonly voiced by the participants in relation to managing end of life care. Fulfilling the wish to be cared for by their family at home was a desire that was often associated with complications and family burdens. Acknowledging the realities of life in a ‘new’ country and amidst changing family structures meant that attitudes were often being reconstructed. Thus, some participants

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reported that they believed that hospitals and other health services would be useful in terms of providing care that could complement rather than replace family care. This was perceived as a means of creating a balance between family burdens and traditional responsibilities. Ananthi, a Bangladeshi woman, while she did not hold particular end of life preferences, felt that she would be prepared to hand over decisions to her family at a critical point when the implications of where she would be cared for would be felt more by her family than herself:

*I cannot think that way, because I don't know how I will die. So I cannot think. However, in my last days, as long as I am not a burden to my family, I would like to stay with them. Then if I am still conscious, I would ask them if they were unable to cope with me, to send me to hospital or wherever they think is suitable. So it is their decision (Ananthi, Bangladeshi woman, aged 62).*

Ananthi explained that one of the elements of a good end of life was not to make her family suffer by caring for her at home. She said that she would like to be at home and cared by her family 'as long as she was not a burden'. Importantly, Ananthi illustrated the wish to create a balance between family burden and obligation at the end of their lives. She explained that she would prefer to stay at home in order to facilitate her traditional obligation in terms of receiving care, and the family's obligation of providing care. However, she said that she could envisage circumstances in which she would prefer to die in hospital in an attempt to fulfil her own obligation of not making her family suffer.

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Similarly, some of the participants argued that on the one hand, the family would be seen as ‘shameful’ among South Asian communities if they did not complete their filial responsibility to care for dying relatives at home, but they themselves evidenced increasing acceptance of the pragmatic necessity of alternative solutions. Kanthasamy claimed that current life in Britain sometimes meant that even if people agreed with traditional views about filial responsibility, it can often be difficult to deliver this because of environmental and geographic constraints, and the changing structure of the family. He described that the traditional view of responsibilities relating to care can become problematic when living in a country other than one’s homeland:

*People expect that their family will look after them. That is the way they think, because we looked after our parents, and also, putting my mother somewhere else would be seen as a shameful act. But we also think about practical problems. We don’t have extended family anymore. I cannot expect my daughter to look after me by taking weeks of leave, and asking her to take a year out to look after me, is not very practical, or fair on her. It is a combination of everything. But still, it is the last option, and if I am dying I want to stay with my family for my last days (Kanthasamy, Sri Lankan Tamil male aged 68).*

Kanthasamy highlighted the two competing perspectives which were common. Firstly, he reported that family would feel ashamed to let their older relatives be cared for and die in places other than home, and that they wished to care for them as a demonstration of filial responsibility. However he also highlighted that many older people prefer to be

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cared for in places other than home, since they appreciated the practical difficulties of providing care for a dying person. He argued that the lack of an extended family together with living in a culture where it was the norm for women to be in paid employment made dying at home almost impossible. However, by referring to care by the family as a 'last option', he suggested that the family could and should act as a safety net to provide the care that formal services may be unable or unwilling to provide.

Similarly, Bulbinthar explained that in addition to the feeling of shame, people would feel guilty if they left their older parents to die alone in other places of care. Bulbinthar was an Indian Punjabi man. He was living with his wife and he cared for his mother-in-law during the last stages of her life at home. He argued that his family was ready to care for her mother in law at home, if adequate support from the health professionals was given. He argued that leaving older relatives to die in other places would mean that they would be dying alone without being surrounded by their family:

*But the thing is, in care, the person himself and family will have a guilty conscious of leaving the person to die alone. So that is not an ideal home*  
(Bulbinthar, Punjabi male aged 74).

It is notable that the end of life care provided by family members is an important factor which gives them a sense of completion in exercising their responsibility. As mentioned above, he acknowledged that it is a reciprocal honour for both family members to feel satisfied, and for the person at the end of their life to feel valued for contributing to their

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family during their lifetime. However, later in his interview, he said that he transferred his mother-in-law to a hospital, as his family was unable to cope during the last hours of her life:

*But for the family, it will be very, very difficult. They got more commitments. They got children and family pressure. They haven't got much time. That is the pros and cons; they are neglecting children to look after the dying one. So how they can afford to do? Rather if you do care older person who die, he needs lot of attention, lot of care. And some might be...like their wife or husband...mentally lot of stress. So both way...as long as dignity is preserved for dying, her prayers is maintained, her faith is maintained and her body is maintained. Because they don't know what the person is going through ... they don't have knowledge about how to manage them. But affection overrules us (Bulbinthar, Punjabi male aged 74).*

Despite this argument, most of the participants argued that filial responsibility was a marker of respect and a repayment to older relatives for the contribution they had on their lives. For example, Mariyanayaki argued that children have a filial responsibility to care for their older parents during the end of their lives. She was an Indian Malayalee woman living alone in her own house. Her two sons were living in other areas of London. She said that one of her sons was living within a reachable distance, and was supporting her to live alone. However, she said that she would rather not stay with her son, as she felt she was becoming a burden for her children. Indeed she mentioned that

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she believed her children would take her back to their home, if the care she received from hospital was deemed inadequate:

*We worked hard to provide them with an education, comfort, and passports. These are some of the reasons why they have succeeded in life. They enjoy all the comfort and benefits of being here because their father migrated from India. So, it is their responsibility to care for their parents. Only people who don't look after their parents will send them to homes. But if you don't care about your parents, your children won't care for you in the future. However, you live today as healthy and wealthy. Eventually, you will be just like us at our age. So everyone has their own responsibility to take care of their parents* (Mariyanayaki, Indian Malayalee woman aged 68).

However, later in her interview, there was more ambivalence as she reported that she would prefer to be cared for elsewhere if her family felt burdened when providing care to her in the last stages of life. It seems to be that she was clearly aware of the issues associated with living in an urban environment like East London which, while often allowing emigrants to secure a better life, was to some extent incompatible with traditional expectations.

*If something happens, my children will take care of me, if they do not care for me properly, it is bad for them also. So at a time like that, how can we be sent somewhere for care other than being kept at home. In case I agreed to go to other places for the sake of my children. But if they are not taking care of me*

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*properly, then my children will take me back* (Mariyanayaki, Indian Malayalee woman aged 68).

In the circumstances in which she needed to be cared for away from home, she believed her children would fulfil their responsibilities to her by monitoring the care that she was given and taking her back into their own care if it was unsatisfactory. Similarly, other participants, including Vasantha, argued that such tensions over their filial duty versus family burdens meant that people struggled morally to decide whether care for their parents should occur in other places rather than at home. She claimed that such contradictions concerning filial responsibility made people ‘think twice’ before ‘sending’ their parents to receive care in hospices, although families were often unable to ‘afford’ the burden of caring. Indeed she perceived various costs of caring for the dying person at home including the lack of extended family, lack of time, lack of physical facilities for caring at home, and distance from children. When asked about her views on hospices, Vasantha said that:

*It is not. It is not. People think twice about sending their father or mother to hospices. I have seen many people that use to come and visit hospices, but it is very difficult to leave our mother in a hospice. At the same time, they cannot afford to care for them. But we tell them, if you cannot look after at home, why shouldn't you use such hospice services?* (Vasantha, Punjabi woman aged 64).



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## **5.2 Extended family and social networks**

Participants often drew attention to the issues around living alone, with most of their extended family living at a great distance from them, often in other countries. The changing nature of traditional family structures, the language barriers faced by participants, and the prospect and realities of confronting death in a new and unfamiliar social environment greatly influenced the end of life care context for older South Asians living in East London. In fact, many of them highlighted that where family members live some considerable distance away, it remained uncertain as to whether their desire of having family to care for them during their last days would be satisfied. However, findings revealed that apart from their immediate family, their relatives, friends and community groups often played an important part in caring them during their last days.

### **5.2.1 The extended family**

Most participants reported that their relatives and their extended family members were involved in providing end of life care for their dying older relatives. Halima explained how her relatives helped her to take care of her husband during his last days of life. She was a Bangladeshi woman who was living with her unmarried son. She described how her relatives were ‘part of the family’ and explained that they took part in important decisions at this time and extensively supported her son. Although they were living

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away from her, she said that they took their time and stayed with her son to support him in caring for her husband:

*MK: So your relatives also involved that decision?*

*Halima: You know, my relatives, there are part of my family. So, they help my son to take decision. They called us and said us that he may not come back and if you want any electric shock or life machine, we can try. Then my son said that let me think and I will ring my cousin and I will tell. Then my nephew came from Bradford and she was counselling my son. She said that because uncle is not in good health and he has severe diabetes and sometimes breath was also weak, so trust Allah. If he come back, it is our luck, if not let him go (Halima, Bangladeshi woman aged 64).*

Similarly, some of the participants explained how their relatives not only supported family members to make decisions, but they were also there for the family to provide support during those stressful events. Aswathy said that her brother-in-law from the USA had come and stayed with the family. She said that although he needed to go, she asked him to stay to support her, since she only has daughters and ‘no men in the house’.

*Only thing we know that he was breathing, he died on 30<sup>th</sup> of December, Monday. But on Sunday, my brother-in-law has to go back to USA. I said that ‘Look, there is no men in the house, why cannot you stay back another week? If nothing happens in this week, otherwise you can go. So wait for a week. Then*

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*Sunday night about 3 o'clock he died. The doctor said six weeks to three months; he died within six weeks (Aswathy, Indian Malayalee woman aged 68).*

A few participants reported how they had approached their relatives who were health professionals to support them in providing care. Kanda explained how her medically qualified relatives supported her greatly in taking decisions around care during last days of life. She said that the family followed their relatives' advice in taking care of her husband.

*They asked if he gets bad heart attack, they want to know whether we want to do resuscitation. His brother is a doctor and he told us 'don't allow (to resuscitate); if he comes out from resuscitation, he is going to have other problem like his rib bones will get fractured. So we wrote no resuscitation (Kanda, Gujarati woman aged 62).*

## **5.2.2The wider community**

Living together as one community was reported as typical in South Asian culture, and these study participants made reference to their homeland in reflecting on this issue. Back in their homeland, community is synonymous with the extended family, and community members and relatives tend to live in the same geographical area and support each other. Living in East London, South Asians faced being separated from a

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social system which gave them safety, security, regular and often instant support. However, study participants had sought opportunities to find ways of connecting to their traditional values and reconstructing some aspects of the social networks with which they were familiar. For example, I observed how people who had immigrated to East London tended to live in close geographical proximity to others from their homelands. I observed pockets of South Asian populations in and around East London, such as Indian Malayalee, Bangladeshis, Gujarati's and Sri Lankan Tamils. Community organisations also offered opportunities such as elders' clubs for social networking which helped individuals maintain a sense of ethnic identity, belonging and cultural continuity, as well as strengthening their adjustment and adaptation to life in older age in the UK.

People attending the elders' clubs appeared to make strong connections and friendships with other older members, and relied on their friends for support in old age and towards the end of life. In particular, where the sons and daughters were living outside the UK, the members of this social network often remained the only source of support. Shankari was a Indian Malayalee woman, both of whose sons lived abroad. She said that since her sons were unable to come and support her husband during his last days, her friends remained highly supportive. She said that her friends in the community centres used to visit every day and support her:

*Shankari: My husband he never say like that Friday night, I thought myself to tell him but after that I stop it, our elder son not here, in Singapore, then he said tell him to come and see him, then I phoned after five minutes, he could not come before two months. He came and his family came for holiday after two months, after my husband died, he came.*

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*MK: did you receive any other support for you to care your husband during his last days?*

*Shankari: My friends, they talk with me, that was more than enough. They used to see every day, which is good support, health services they never give anything (Shankari, Indian Malayalee woman aged 68).*

Similarly, another reality is that while people of advanced years are living without extended family, and their children often reside in other UK cities or in other countries, they often receive support from their neighbours who live around in the provision of end of life care. Chitra explained that her friends who live near to her were very supportive when her husband was dying. Chitra was an Indian Malayalee woman and her daughter was living within the same city. However, as living in the daughter's home is unusual in South Asian culture (see above); she cared for her husband by herself in her own home. Nevertheless, she said that as she was unable to speak English well, she was entirely dependent on her friends who supported her, to the extent of calling an ambulance and dealing with health professionals.

*Even though, as I told that I was only the person who cares my husband, but I don't have language. I call my friends and they helped me a lot. In sudden, he gets chest pain at midnight, I call my friends, and they come and call ambulance and take him to hospital. They did help me a lot (Chitra, Indian Malayalee woman aged 67).*

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In contrast, one participant, Vasantha, an Indian Punjabi woman who was working in one of the Asian community groups for older people, felt that there were often occasions when families failed to observe what she felt were their responsibilities in terms of caring for sick and dying relatives. She explained that one of the community group members who was at the end of life was not visited by his brother. Partially in response to that, the community took the responsibility to care for him.

*He has been in home for fifteen years, shunted from one home to another, because his mother died and father died he got stroke so he gone to care home. I invited his brother; he is only person from his family left. I asked him to come and see him, after all he is brother. You don't bring anything. I will give you travel expenses, finally he agreed. But he didn't turn up. This poor man has died. In funeral his brother said he got backache (Vasantha, Punjabi woman aged 64 years).*

Other participants reported that a clear distinction between 'family support' and 'community support' was not always possible, or desirable. Aswathy explained how the family facilitated her husband's wish to be around the community during his last days. She reported that as her husband wished to see his other members of his community, they often visited to spend time and share meals.

*As soon we heard that he is not going to live longer, we discharged him and we took him home. He likes some Indian foods. We gave those foods at home and he was quite happy. He was also in this Thursday elder's luncheon club in our*

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*Indian Malayalee association. He became very close to everyone, like Girija's husband. He said that he wants to see everyone at that luncheon club. So everyone came and saw him on that Thursday, they came with all food what they cooked and he enjoyed the meal with them that was a last meal, then Friday he had big stroke (Aswathy, Indian Malayalee woman aged 68).*

Aswathy highlighted that such community belongingness provided cultural continuity and a sense of social wellbeing for the dying person. Furthermore, this demonstrated how people at the end of life felt respected and valued when their community members supported them at the end of life.

## **5.3 Summary**

This chapter has reported on the importance of 'family' in providing care needed at the end of life for older South Asians living in the East London. Participants held strong traditional values rooted in their own cultures, which influenced how end of life care was conceptualised and addressed. This occasionally created tensions, given that they were now living in a different social context. Spousal care giving and filial responsibility were the two dominant themes drawn from their discussion of family care giving. Additionally, participants reported that older people at the end of life were often supported by existing, though sometimes limited, social networks within South Asian communities. This included their own family members, friends and relatives, and

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members of their local community. Hence, the findings of this chapter suggest that meaning of the family at end of life is used to authenticate best possible, yet, traditional end of life care for these older South Asians.



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## CHAPTER 6

# Trust

In this chapter, I report the study findings that relate primarily to the attitudes and beliefs participants expressed towards the discussion of death and dying and decision making. Most of the participants reported that they 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. Instead, they reported that they trusted that their family would discuss their needs with health care professionals when the time comes, and take any decisions required on their behalf.

Trust is a category of focus in this chapter, and results from two sub-categories: ‘avoidance of discussion’ about death and dying; and ‘locus of authority’ in decision making. The first sub-category on avoidance of discussion relates to the relative absence of discussions around death and dying among participants. The second sub-category on locus of authority in decision making relates to beliefs and experiences about delegation of decision making to family members. Table 7 shows the subcategories and themes related to discussions and decisions related to end of life.

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**Table 7 Sub-categories and themes relating to end of life discussions and decision making**

<b>Category</b>	<b>Sub-categories</b>	<b>Themes</b>
<b>Trust</b>	<b>Avoidance of discussion about death and dying</b>	<b>Avoidance as a cultural norm</b>
		<b>Avoidance as protection</b>
	<b>Locus of authority</b>	<b>Deferring to the next generation</b>
		<b>The hierarchy of decision making</b>
		<b>Outside experts</b>

## **6.1 Avoidance of discussion about death and dying**

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. Data analysis revealed two barriers: avoidance as a cultural norm, and avoidance as protection. I explore these below.

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### **6.1.1 Avoidance as a cultural norm**

Most of the participants explicitly reported that discussing death and dying, including related decisions, was risky, particularly when one was healthy. In fact, I observed that many participants appeared to smile and laugh at times during the interviews. In one of the focus groups, when I entered the meeting room, the participants called me an ‘ambassador of death’ and laughed loudly. It is likely that participants perceived that a researcher from the same ethnic (South Asian) background was expected to be aware of such norms in relation to conversing about death and dying, and act accordingly. Not doing so led to the expression of humour.

Furthermore, the fact that I was younger than the participants may have created an additional reluctance among them to talk about such things with me. In addition, being a male researcher, when interviewing older women participants, both I and the participants found that asking such questions to older women was culturally inappropriate. In fact some of the participants even referred to me as their ‘own son’, which in turn made me ambivalent in using any direct words related to death and dying. As a consequence, as on many occasions, I used indirect terms, including ‘end of life’ which I believed to be a less sensitive phrase than using ‘death and dying’.

One of the participants, a man called Kamruz, exemplified the perception of such absence about discussions related to death and dying among Bangladeshi communities. Kamruz was a school teacher who was living with his extended family in East London.

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In his interview, he talked about some of his preferences about end of life care. This included dying at home, receiving care in a hospice and sending his body back to Bangladesh. However, when I asked whether he would be likely to talk about such things, he said that it would be ‘highly unusual’ for his community to have such discussions or to make 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).

Kamruz’s words: ‘we don’t plan for death’ and that it is ‘highly unusual to talk about death’ reflected the wider issues expressed by many other participants relating to beliefs and attitudes towards discussion and decision making in death and dying among South Asian communities. In another instance, Prakash, a Gujarati man who was living with his son as part of an extended family, claimed that he ‘never thought’ about discussions involving death and dying, as he believed that his family would ‘know what to do’ and would do what they could for him during his time of death and dying. He stated that:

*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).

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Prakash perhaps thought that living with an extended family naturally facilitated the role of decision making. Furthermore, his belief that ‘they know what to do’ meant that formal discussions concerning death and dying were insignificant. In addition, he clearly indicated that pre-planning is unnecessary, since any decisions will depend on ‘family circumstances’.

Other participants stated that generally in South Asian families children would avoid discussing death and dying, or involving older relatives in any such discussions. For example, Simrita, a Punjabi woman who lived with her son’s family, claimed that it was unusual to ask older people about their own end of life care decisions. She said that the family would come forward to take their responsibility, and make any necessary decisions on behalf of their older relatives, and thus shelter their older relatives to avoid distressing them from topics perceived to be unpleasant:

*I don’t think people ask where you die. I think the family makes that decision*  
(Simrita, Punjabi woman aged 72).

A few participants had contrasting views. For example, Malar reported that although she would trust children as decision makers, she expected these decisions to be based on her preferences, which she would share with her children when she became terminally ill. Malar was an Indian Malayalee woman who was living alone at home after the death of her husband. However, she said that she would prefer to go and stay at her son’s home when she was too ill to live alone. Her two children lived in the same city and often visited her to offer support:

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*MK: Have you spoken these decisions to any one?*

*Malar: No. I never spoke [laughs]. I used to keep it in my heart. I did not tell my daughter. Yesterday, I gave some money to them and told them to keep the money, and if anything happens to me, they should use that money.*

*MK: So, you made some decisions?*

*Malar: No. I did not. I have my children with me to decide. When the stage comes, I will tell them about my preferences. When I go to their house, I will tell them that I want to go back to India and die, like my husband (Malar, Indian Malayalee woman aged 68).*

Later in her interview Malar reported that she would ‘tell’ her children what her plan for death and dying is, ‘if they ask’ her. She perceived that having done this, the children would then make the decisions that may be necessary:

*If they ask me, I will tell them what my plan is. Then they will take decisions*  
*(Malar, Indian Malayalee woman aged 68).*

Importantly, her words ‘if they ask me’ clearly denote that she perceived that her participation in decision making involving her death and dying would be limited. This is because she expected that South Asian families usually avoid the inclusion of dying relatives in the decision making process.

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However, Kanjana claimed that another reason for such a reluctance to discuss aspects relating death and dying was because people would wait for their ‘time’ to discuss it with her family. Kanjana was a Bangladeshi Muslim woman. She moved to the UK when she married her husband who had settled there. At the time of the interview, she was living with her husband and two daughters in East London. She said that she needed to be supported for her daily communication, either by her daughter or her husband, as she had very limited proficiency in English. During the interview, she mentioned various preferences relating to her death and dying:

*MK: You said that you want to be kept at home when you are dying. Did you ever think at anytime if such decisions needed to be discussed with someone?*

*Kanjana: When the time comes, I will. My daughter told me that I shouldn't think about it yet. When you start thinking about it, you get very sick. We don't know when, or what will happen to us (Kanjana, Bangladeshi woman aged 58).*

Kanjana 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 nature of death, and family preferences for not engaging in any decision-making discussions. In addition, she reported how she expected that discussing death and dying would bring illness and death forward. Importantly, she described how her family asked her not to ‘think about it yet’ in relation to her death and dying, possibly when she attempted to discuss it. She later communicated that she perceived that such family restrictions were helpful to her in the sense that they avoided causing distress through the discussion of unpleasant topics, and helped her keep a positive attitude.

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Ramalingam argued that positive thinking in late life (with the hope of living longer) may act as a barrier to thinking about one's own death and dying. Ramalingam was a retired Sri Lankan teacher living with his son in East London. He taught English for the local Tamil-speaking community as a voluntary job. He claimed that initiating discussions and making decisions usually takes place within the family when the health of older individuals deteriorates towards the final stages of their life. Interestingly, he acknowledged his own preferences in relation to the last days of his life, which included his preference of dying at hospital and the use of life prolonging treatments. However, until his 'ripened stage', he preferred not to hold such related discussions with his family:

*MK: 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).*

Ramalingam pointed out that age and health status would remain factors that influence his preference to participate in end of life discussions and decision making.



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Furthermore, he highlighted that not only the culture of avoiding discussion, but also a denial to accept death at old age would also impede such discussions.

Similarly, Neela demonstrated that denial to accept death at an old age would be another factor linked to avoidance of discussions. Neela is an Indian Malayalee woman living on her own. However, her daughter comes over from Australia, and stays with her for more than six months every year. Neela refused to talk about death in her interview, as she believed that no-one wanted to die. Instead, she claimed that she trusted that her children would ‘carry out everything’ for her:

*MK: 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.*

*MK: If not, what will happen?*

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

*MK: Is it belief or expectations?*

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

### **6.1.2 Avoidance as protection**

My data analysis revealed that a barrier to discussions about death and dying was the perceived need among participants to avoid any early discussions featuring the subjects, as it would 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

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and discouraging topics. In addition, some participants reported that avoidance was enforced because of language barriers.

For example, Baseema indicated that discussions around death and dying with her family were difficult to initiate. Baseema was a Bangladeshi woman living with her son and husband. Her husband was chronically ill. Baseema said that she has had opportunities to discuss with her son what would happen as she approached the end of life because her husband has been admitted several times to hospital. However, she reported that her son refused to discuss these issues with her, and encouraged her to think positively:

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

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

*MK: 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).*

Another participant, Archana, took a positive stance towards the idea of planning and talking about end of life issues, however said that she could not discuss any of these issues with her daughter at the moment because of the risk of upsetting her, as she was soon to be married. She was a Gujarati woman living in a flat, which was supported housing provided by the local council. Her husband died four years after her marriage.

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However, she did not remarry; as she said that remarriage for women was not accepted in her community. She had lived with her brother's family when her daughter was young. Later she moved out and lived alone with her daughter. However, at the time of the interview, she said that as her daughter was living with her fiancé and she was now living alone:

*MK: 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*

*MK: Ok?*

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

Indeed, her statement reflected earlier findings related to the culture of regarding discussions on death and dying as a taboo subject within the family. Importantly, she mentioned that such discussions would certainly be avoided during the occurrence of any auspicious or religious events at home. Indeed, she reflected the customs in Hindu culture whereby people would prefer not to use words related to death and dying at home. If anyone in the family used such words accidentally or purposefully, people would advise them to eat sugar or some sweets to keep their mouth free from bitterness.

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Furthermore, in South Asian families, some people would also avoid attending funerals when the family has planned weddings in the forthcoming year.

Some participants talked about how they generally avoided talking about death and dying with their families. For example, Rajendran was an Indian Malayalee man who was retired from his council job, and living with his extended family. He argued that early discussions within their family would be unproductive, as his children would refuse and ‘not listen’ if he initiated any discussion about his death and dying. Rajendran said that instead he preferred to discuss these issues with his friends or people in his 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.*

*MK: 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.*

*MK: Have you ever discussed anything?*

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

Rajendran explicitly highlighted that his family would resist thinking negatively and refuse to engage in any conversations in relation to death and dying. He expressed the strong opinion that ‘thinking positively’ was clearly linked with avoiding thoughts about death and dying.

In contrast, some participants claimed that practical difficulties were the reasons for avoidance. Chitra reported that language difficulties prevented her and her husband from being involved in any discussions or decisions with doctors about end of life care when her husband was ill. She assumed instead that the doctors had discussed with her children any decisions that needed to be made during the last days of her husband’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).

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## 6.2 Locus of Authority

As reported earlier, most of the older participants in this study reported that their family were expected to play a crucial role in discussions and decisions related to their death and dying. However, the changing pattern of their social living arrangements, including living alone and the lack of availability of the extended family, posed various challenges for such locus of authority in decision making. In this section, I report such locus of authority in decision making in the following three sections: ‘deferring to the next generation’, ‘hierarchy of decision making’; and ‘outside experts’.

### 6.2.1 Deferring to the next generation

There was a general consensus that children were essential in leading any discussions and also in making decisions for their older dying relatives among the study participants. Rajendran strongly argued that children would be the decision makers for older relatives in South Asian families. He claimed that for every older parent in South Asian families, their children were expected to lead in any discussions and decisions related to end of their life.

*MK: So you mean that the family will be involved in the decision?*

*Rajendran: Yes, I think for all elderly parents, their children eventually will play a part definitely, definitely (Rajendran, Indian Malayalee man, aged 65).*

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Rajendran demonstrated that people in their old age presumed that their authority in decision making concerning death and dying will be dealt by their children. He perhaps reflected the earlier findings in chapter two on ‘family’, wherein it was reported that children were expected to assume filial responsibility. In contrast, later in the interview, Rajendran argued that he would prefer to make his own decision. However, he said that such a decision would be shared with his children, who he believed were ‘more knowledgeable’ than him:

*The final decision will be mine. But it won't be 100%, because I may not be the more knowledgeable person. There might be somebody else in the house, maybe my children* (Rajendran, Indian Malayalee male aged 65).

Similarly, Prakash claimed that children would be more appropriate decision makers, as they were considered to be better educated than their older relatives. Prakash was a Gujarati man who immigrated to the UK as a manual worker, and worked in a local factory. He was living with his wife and son as part of an extended family. In his interview, he pointed out that his religion prescribed that children would need to take responsibility to care for their older parents, including making decisions on behalf of them. Moreover, he highlighted that as these older people were ‘not educated well enough’, they would need to depend on their children to make the decisions. In fact, he also believed that his advanced age would impede him in making decisions concerning death and dying:

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*We cannot think for ourselves. So we rely on our children to decide. At the end, they must understand that we are depending on them. Our religion also tells them to care for their parents. And also, we are not educated enough to make decisions. I am unable to make any decisions myself because I am already 76. I cannot think like my children (Prakash, Gujarati male aged 76).*

Prakash's comments perhaps reflected on wider issues related to migration history to the UK among South Asians, in relation to their level of education and language skills. Like many other participants who immigrated to the UK, Prakash was a Gujarati who has limited language proficiency in English. Entering a manual job with long hours, men like Prakash held onto their memories of cultural practices while working in factories, with minimal exposure to and knowledge of British social culture and the National Health Service (NHS). On the other hand, their children who were born and raised in their host country's culture, immersed in British life, are expected to be better informed of prevailing health facilities, as Prakash observed. This is the basis of many participants' belief that their children would be expected make better decisions than themselves.

Rita, a Indian Malayalee woman living alone, similarly reported that she had no control over her children's decisions, as they would make the necessary decisions about her burial based on their own circumstances:

*I cannot say just like that. So let them do as they wish. Because we don't know where I am going to die, maybe it will happen when I go back home to visit.*



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*But if they want to take my body and bury it next to my husband's, then let them. I have done what he told me. But it is their money; they can do what they best see fit for me. Even if I put money aside for this, they will only do whatever it is, they choosing to do* (Rita, Indian Malayalee woman aged 67).

Importantly, Rita highlighted that even though she had her own preferences, she would need to depend on her children to make the choice, as they were the ones who could implement such decisions. In turn, she believed that since her family already knew what her preferences were, they would do the best they could for her during the last days of her life. Indeed her words, 'let them do as they wish' and 'they will only do whatever it is they choose to', clearly demonstrated that any decisions involving death and dying are family-centred. This in turn seems to illustrate certain fatalistic attitudes over their issues concerning death and dying, as Rita claimed that she could not decide on her death and final days own by herself, even if she 'put money aside for this', and said resignedly: 'so let them do as they wish'.

Another participant, Chitra, reported that her children had 'already prepared' for what will be needed for her last days. Chitra was Indian Malayalee woman who lived on her own; her children lived away from her, although they visited frequently. She argued that having any discussion or to make decisions would be unnecessary for older people. She perhaps believed that children were there to make right decisions for their parents:

*So before, we thought that they had already prepared everything for us. So we didn't have to tell them anything. That is my opinion. If they are able to think*

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*and do most of the things before we can, then we should leave it to them. That way, we believe in our minds that they are there for us* (Chitra, Indian Malayalee woman aged 67).

On the other hand, while participants reported that children were the decision makers in the family, some expected that their children would consider including their views in the decision-making process. For example, Gujala, an Indian Malayalee woman who was living with her husband, argued that her children would consult her before they made any decisions concerning the end of her life. When she was asked about who was likely to make decisions at the time of death, she answered that she believed that children were key in making decisions concerning such matters:

*MK: Who makes the decisions on receiving care during the end of your life?*

*Gujala: Only my children will decide. They ask us, but they decide* (Gujala, Indian Malayalee woman aged 68).

Indeed, her description demonstrated how the family would respond to any decisions in relation to dying older relatives in South Asian families. At times, as Gujala described, children were expected to discuss any decisions with their older relatives. However, she claimed that the outcomes of the discussions would depend on the family members, rather than their older relatives. Children in South Asian families are traditionally expected to respect their elders' knowledge, experience and wisdom, before making any

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decisions. However, in relation to death and dying, such involvement would be as limited as possible, so as not to distress any of the dying relatives.

### **6.2.2 Hierarchy of decision making**

Several participants reported that they expected to be involved in a hierarchy of decision making during their last days of life. Notably, most suggested that men in the family would generally be the main decision makers. Kanjana explained that the eldest male relative would be the leader of the family, and would also make decisions about issues related to death and dying for their older relatives. Kanjana was a Bangladeshi woman living with her husband and daughter. She explained that her husband, followed by her children, would be the decision makers for her last days. Furthermore, she mentioned that women in South Asian culture traditionally defer to the decisions of a man; before marriage their fathers would decide for them, followed by their husbands and sons after marriage:

*The eldest one in a family will decide. In my parents' family, the eldest is my dad. But in my own family, here in London, if my husband got sick, our children would then make the decisions for me* (Kanjana, Bangladeshi woman aged 58).

Kanjana explained the hierarchy of decision making among South Asian families. Though she explained that elder family members were responsible for making decisions

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in her culture, she also illustrated a certain male dominance in such decision making. Indeed, such cultural notions of the elders as decision makers were inherited through generations of the cultural epics of *Ramayana* and *Mahabharata*. In those ancient Hindu epics, it was prescribed that the eldest son would be the next leader of the family after his father. The Quran similarly affirms that men ‘are the protectors and maintainers of women’ (4:34), and all South Asian cultures and religions are permeated with deep-rooted patriarchal identities and concepts. In experience, Ramalingam legitimated such hierarchy who described how he made his best of his efforts to ensure the best possible care for his wife during her last days which was described in chapter 4 (page no 188).

When the husband died, the elder son would become a decision maker in the family, as described by another participant, Rita. Rita was an Indian Malayalee woman living on her own. Her son was residing in the same city, and her daughter was living in another city in the UK. In the event of her death, she said that her eldest son would be called by the doctor, who would be responsible for any decision making within her family:

*If anything happens the doctor will call the eldest family member. But the decision needs to be taken in unity. The daughter will call the eldest son, and they will join together to make their decision* (Rita, Indian Malayalee woman aged 67).

Indeed Rita demonstrated that even though her daughter would serve her in tending to her personal care needs during her last days, she would invite her eldest brother to make

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any necessary decisions for her mother. However, Rita also expected that her children would ‘join together’ to make any decisions involving her death and her final days.

Another participant, Simrita, explicitly portrayed the imperative role of men in decision making during death and the final days of their older parents. She was a Punjabi woman living with her son. When she described the last days of her mother, she said that, as a daughter, she would not be able to make any decisions for her mother. She argued that she could have decided for her mother, since she had cared for her during her last days, and knew her preferences. However, she said that she was required to relinquish those decision-making ‘rights’ due to the fact that ‘brothers are brothers’ in her culture:

*I would have really fulfilled her wishes, all sort of wishes. She was my mother and always talked to me from the heart. I would tell her everything in my life. I wouldn't go out for her wishes, if they kept her on a machine. I don't know what my brother would say. Because you know, brothers are brothers. They stay behind, we work hard, but they want all the credit for themselves, which is ok, it is their right, you know. But I could have said let her go, I will pray for her (Simrita, Punjabi woman aged 72).*

Simrita observed the influence of gender, particularly in relation to male dominance in decision making, during the last days of her older relatives. The fact that she affirmed ‘it is their [men's] rights’, and ‘brothers are brothers’, indicates that people from South Asian communities perceived that men would play a decisive role during the last days of their older relatives. However, she additionally stated in the above response that ‘we

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work hard’ and ‘they take credit’, which demonstrates her pessimistic views concerning role and the social status of women in South Asian families.

Conversely, such culturally bound rights for the eldest son being the main decision maker for older relatives were challenged by Kanda. Kanda was a Gujarati woman living with her son as part of an extended family. Her husband has been dead for two years. Her two daughters live in other cities across the UK. Although she supported the view that family needed to be included in the decision making process, she claimed that she would prefer to choose someone in her family who she would feel comfortable discussing taking decisions concerning her death and her final days with. She explained:

*Kanda: Yeah, I think I should to be including my family*

*MK: So, family in a sense ... who you want to be included?*

*Kanda: No, I cannot involve everyone. I want to tell my eldest or youngest sons, or my daughter. Whoever I feel at ease with discussing such things* (Kanda, Gujarati woman aged 62).

Additionally, Shankari presented another challenge to the traditional concept of the eldest son as a decision maker while living in the East London. Shankari is an Indian Malayalee woman living on her own in East London. Her sons both live in Singapore. During her late husband’s last days, she said that both of her sons were unable to come and undertake their perceived responsibility, making decisions for their father.

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Therefore, Shankari claimed that it was necessary for her to take all the decisions in her husband's last days:

*Our eldest son was not here in the UK. He was in Singapore with his family. My husband wanted him to come and see him. Then I phoned him, but he said he would not be able to come. Because he and his family were just been in the UK for their holidays two months ago. So he said that he would not be able to come. He came to UK only two months after my husband died (Shankari, Indian Malayalee woman aged 68).*

Shankari demonstrated that when responsible children were unavailable to support their older relatives in decision making, the difficulty of the decision making was left to their older spouse. Furthermore, she observed that children who migrated elsewhere for the betterment of their lives would clearly challenge their expected role in decision making, and also in supporting their older parents. Importantly, Shankari indicated that in such situations, spouses were required to make decisions on their own for their partner.

Similarly, Archana mentioned that when there were no men in the family, neither a father nor sons, the daughters would be decision makers for their older parents. However, she reported that her daughter would seek support from men from their extended family to make decisions. Archana, a Gujarati woman, was living on her own ever since her only daughter was living with her fiancée. Nevertheless, she lives in East London, the same part of the city as her mother. Although her daughter invited her to live with her, she refused and said that older parents would rather not stay with their

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married daughters in South Asian culture. When asked about who would make decisions concerning her death and final days, she answered:

*No, my daughter makes all the decisions. My daughter would always ask my brother, and he would say to her do this, and do that. He supports us all the time. My brother and my nephew are very good* (Archana, Gujarati woman aged 64).

Indeed, although there were no men in the immediate family, Archana demonstrated that the culture of male dominancy within South Asian families would also influence the decisions made during the end of one's life. She observed that it was not only men from the immediate family who played a vital role, but also men in the extended family would be needed in order for the women to make decisions. This is particularly the case when there is absence of such men within the immediate family, women would be required to depend on the men in the extended family to support them in making decisions.

In experience, Aswathy authenticated similar gender issues in terms of decision making. Aswathy was an Indian Malayalee woman who was living on her own in East London. During the last days of her life, her husband was cared for at her home, and eventually died in hospital. Her two daughters are married and have settled in the north of England. During his last days, she mentioned that they both stayed with her to support her in caring for her husband. She reported that since she only had daughters, in an attempt to gain support from men, she asked her brother-in-law to come from the USA and stay with her family during the last days of her husband's life. She explained how she



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depended on her brother-in-law to make all the necessary decisions concerning the last days of her husband's life.

*And the doctor saw us, and told us that he had massive heart attack, do you want us to try and resuscitate him? Because we need to know your decision. So they wanted to know our answer. And I didn't want to give them permission to do it. So I rang my brother-in-law, and he said that on no account, should I allow them to perform resuscitation on him, because his condition was going to worsen. So don't do it. You know, what we did, we didn't tell that to the doctors. So on the file; they had resuscitation with a question mark next to it, because we didn't give them the answer. We left it like that. And they didn't ask us second time, so we left it (Aswathy, Indian Malayalee woman aged 68).*

Later in her interview she said that she asked her brother-in-law to stay longer with her family as she had 'no men in the house':

*He died on the 30<sup>th</sup> of December, Monday. On Sunday, my brother-in-law has to go back to the USA. I said to him, 'Look, there are no men in the house. Why can't you stay here for another week? If nothing happens during that week, then you can go. But otherwise wait for one more week (Aswathy, Indian Malayalee woman aged 68).*

Indeed Aswathy's statement indicates that there appears to be a natural dependency on men to support the family in making decisions. Furthermore she implicitly reflected that

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in South Asian culture, men were always considered to make the right decisions, and their presence in general gave a sense of moral strength to the family. On the other hand, Aswathy also demonstrated that she trusted her brother-in-law, and viewed him as an older man, who was wiser and more experienced than her daughters in relation to providing support for her decision making.

On the other hand, few of them reported their preference for their wife to take decisions. Sivasakthi mentioned that his wife would make the decisions towards the end of his life. However, he expected that his children would support her in making such decisions. He was an Indian Malayalee man who was living with his wife. His children were living in various other cities around the UK. When I asked about his preferences in regards to his last days, he said that he did not have any particular desires, and would rather have his wife make decisions in the event of his death and the days leading up to it.

*MK: How do you want to be cared for during your last days?*

*Sivasakthi: I have no particular wishes. In my case, my wife will make the decisions. I have my son and daughter, and they will make a decision (Sivasakthi, Indian Malayalee male aged 75).*

Sivasakthi reflected the significance of spousal relationships in terms of making decisions around the time of death and final days. He indicated that when children live away from their older parents, spouses would be expected to be the main decision

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makers, because they live together. Furthermore, he illustrated some gender-based practices in decision making among South Asian families. He evidenced for example, that in South Asian families, in situations when wives often seek support from their children to make decisions, husbands make their own decisions for their wives, either with or without consulting their children.

Sreeja experienced this when her husband was in his last days in hospital; her children were initially given the choice and/or responsibility for her to make the decisions for him. Sreeja was a Gujarati woman living in East London on her own, while her children live in other cities around the UK. Her husband, who had dementia, died in a local hospital in East London. During his last days, when doctors asked his children to decide on life saving treatments, they said that it would be up to their mother to make the appropriate decisions for her husband. She said that she decided to refuse any life-saving treatments, as he had suffered long enough from various multiple diseases:

MK: *Was he put on a ventilator?*

*Sreeja: No. When they called me and asked for that, I said no ... don't do it. Because, he had already lost everything. He had diabetes, memory loss and suffered a lot in his life. I didn't want to add to his suffering by doing that, and also he wouldn't have been able to tell anyone how much he was suffering. My dear son, how can I tell them to end*

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*his life, instead of putting him on a ventilator? So it was me who told them not to do that. They called my children too. But they said it was up to their mother to decide. I told them not to do it (Sreeja, Gujarati woman aged 68).*

Sreeja demonstrated that her children had decided to respect the views of their mother in relation to the decision surrounding the death and final days of her husband. Moreover, they decided that her mother would have more rights to decide for her husband, since she was the one who cared for him during his last days. In addition, the children lived in other cities in the UK. Implicitly, it seems that her children might have decided to respect the spousal relationship in the decision-making process.

### **6.2.3 Outside experts**

Participants in this study most commonly reported that they trust the medical professionals because of their expertise and skills in any decision-making discussions around their death and dying. In fact, a few of them claimed that it was essential for them to discuss decisions about their death and dying with the medical professionals, in order to make viable decisions. However, some of them argued that medical professionals were expected to defer to family members, as they are the perceived decision makers for their dying older relatives in South Asian families. On the other hand, other participants claimed that they would prefer to discuss these matters with medical professionals themselves, as it would help them make their own decisions.

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Throughout both focus groups and interviews, I used the word ‘health professionals’, by which I intended to explore the participants’ views on all health professionals, including nurses. However, participants perceived my prompts on health professionals to mean doctors.

Most of the participants generally agreed that getting advice from health professionals was highly regarded as positive input for the family, in order to make better decisions. Ramalingam claimed that trusting medical professionals was logical, because they were ‘appropriate and qualified persons’. When asked with whom he preferred to discuss his preferences related to death and dying, he said:

*Doctors are the qualified persons to look after patients. He will be the appropriate person to know what is necessary and the nature of treatment I should receive. The facilities are available in the hospital for the doctor to decide. Otherwise, if one doctor can't come to a decision, he can get support from other doctors and they can decide together. So, two minds are better than one (Ramalingam, Sri Lankan male aged 78).*

Ramalingam’s attitude suggest that, in general, people tend to accept medical supremacy and doctors’ right ‘to look after the patients’ in any health-related discussions and decisions. He further illustrated that medical professionals have the advantage to access to facilities and professional support to make better decisions for the patients. He perhaps reflected the South Asian perception that doctors revered and almost god-like, because they have the ability to save people’s lives which might be stemming from the

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fact that the science of medicine was always liked to spirituality and religion in South Asian civilisation.

On the other hand, later in the interview, Ramalingam reported that the perceived positive role of health professionals in decision making was not necessarily applicable in discussions around death and dying. He argued that it would be unusual for medical professionals to discuss death and dying issues with older people, who always believed that their treatments would save lives. He claimed that such discussions would discourage older people and cause emotional distress. He said that he would expect doctors to discuss such things with the family rather than with himself. He stated that:

*Most probably, the health professionals would not dare to ask these questions to the person who is getting the treatment. Because this will affect his psychology, because he thinks that his doctors' treatment would make him better. And also, you cannot expect the medical personnel to discuss these things with my relatives who are dying. But if the doctor comes out with that kind of discussion, certainly I will discuss it with him. But as I told you earlier, not every doctor will discuss such issues if I am well. He might when you are in that situation of death and dying. Anyway, he will not discuss it with me, but with person concerned for example with my family members (Ramalingam, Sri Lankan male aged 78).*

His illustration demonstrated that positive beliefs around health professionals would make expect them to discuss treatments to save the life, rather than death and dying. He

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perhaps reflected the practice in South Asian countries whereby medical professionals would usually reassure dying people, but discuss the terminal nature of patients' conditions with their families. He also reported that his family would resist medical professionals discussing death-related topics with him. If at all, however, they prefer to discuss it with the concerned person, then, he reported that people would listen to them in order to respect the doctors, rather to oblige their decisions.

In experience, Neela echoed similar positive perceptions about health professionals, while demonstrating how such role perceptions made her take decisions against the recommendations of the medical professionals for her mother. Neela was a retired teacher who cared for her mother in her home during the last days of her life. When she was illustrating her experience of caring for her mother, she explained that whenever her mother got acutely ill, she would admit her to the hospital. During the last days of her life, the doctors recommended withdrawing the treatment for her mother, as continuing it would lead only to a poor quality of life. Neela said that she refused to accept their decision and continued to treat her at home. She claimed that hospitals were expected to 'make the people healthy, not let them die':

*MK: You said this when the doctor said it was not wise to give treatment*

*Neela: Yes*

*MK: But you took the decision to continue the treatment. Could you tell me more?*

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*Neela: Yes, we had a meeting with the doctor and nurse and all. It was decided that they should stop the treatment for my mum. I was shocked*

*MK: Do you know why doctors took such a decision?*

*Neela: Because, they said if we continue the treatment for my mother, she will end up with a poor, very poor quality of life. You know. But, we want the hospital to make her healthy not let her die (Neela, Indian Malayalee woman aged 74).*

Indeed, Neela claimed that people see hospitals and health professionals as curative roles that save lives. However, on occasion, when they make recommendations against such positive beliefs, as Neela demonstrated, people will mistrust them. Usually, in such situations, South Asian people would intend to explore other opportunities, including alternative medicines and doing religious customs to save the life of their dying relative. In essence, such efforts are not only attempted by the people to save the life, but also to demonstrate their filial responsibilities in caring for their dying relatives.

Similarly, Rajendran reported that he would refuse to accept any medical decisions if he considered them to be negative. In such a situation, he argued that ‘other ways of treatments’ would save his life. In fact he claimed that ‘English medicines were not the ultimate medicine to cure’. He demonstrated his trust in alternative medicine as his choice, if the medical professionals declared a poor prognosis.

*Again, when such situations arise when the GP is going to tell you, ‘look all these treatments have failed and you only have another three or four months’, I*



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*am not writing myself off. Because there may be other available treatments. But maybe medically, there is nothing else. But then maybe the family will come up with a suggestion of other treatments. Because English medicine is not the ultimate medicine to cure. For example Chinese people have lived until they are 110 with their own medicines. Indians lived longer without these English medicines for 100 years. So, English medicines are not the only treatments. There are other ways. I mean like, if my children say 'yes dad, I want you to go and receive Chinese treatment if that can help you', then I will say 'yes'. Yes I will go for that (Rajendran, Indian Malayalee male aged 65).*

Although his response could be interpreted as a denial to accept his poor prognosis; he perhaps reflected wider beliefs and practices among South Asian communities where people often tend to shift their trust from the hospitals to complementary therapies and indigenous health systems, such as *Ayurveda*, *Siddha* and *homeopathy*. These indigenously developed medical systems in South Asian countries would normally be portrayed as a narrow alternative for the existing Western medical system, named the 'English system' by South Asians.

Some participants reported that the culture of trusting medical professionals discussed above was not often practised, particularly when the family has had a strong dedication to fulfil the preferences of their dying relatives. Jayanthi reported that her family refused medical advice and they decided against the medical decisions. She was a Gujarati woman living on her own in East London, whose husband had died in hospital four years previously. She narrated that during the last days of his life, doctors advised her to

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accept the medical decision to take him to the hospice, but she said that she refused and brought him back home to fulfil his wish to die at home.

*Then they wanted to put him in a hospice. That's when the hospice thing came. They told us that they were going to move him to a hospice. But my husband always wanted to come home. So I said no we can't put him in a hospice. We told them that we didn't want to move him to a hospice for a simple reason; if he had been actually bedridden or something like that; we would have accepted the hospice. But we didn't want to do it because he always wanted to come home. So, we brought him home (Jayanthi, Gujarati woman aged 64).*

In fact, another participant, Bulbinthar, observed that a culture that trusted medical expertise potentially excluded family preferences. Bulbinthar was a Punjabi man, who converted to Christianity after he moved to London, and was living with his wife. During his interview, he talked about the last days of his mother-in-law, who died in a hospital. He reported that because he was a male person, he had been excluded from staying with his mother-in-law during her last hours of her life. Thus, his wife stayed with her and 'left it to the doctors to decide' for her mother. However, he claimed that 'if the chance' had been given to the family to decide, they might have brought her mother back to their home to care for her.

*MK: So your wife took the decision to have life supporting devices such as a ventilator?*

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*Bulbinthar: No. Everything was the doctors' decision. She left it to the doctors to decide. I didn't know of anything. But if the chance would have been given to me to decide, she would have brought her back home (Bulbinthar, Punjabi male aged 74).*

Indeed, Bulbinthar's comment demonstrates how the culture to respect medical professionals could act as a barrier for people to express their own preferences. Later in his interview, however, Bulbinthar argued that any family-centred discussions and decisions would be less 'guaranteed' if health professionals or third-parties were not involved. He claimed that the significance of health professionals was essential as it would be more 'effective' than family decisions. When further asked about his preference to talk to health professionals about his death and dying decisions, he agreed and explained:

*Yes. Any discussions within the family of this nature cannot be guaranteed to be effective. Except if a third party is involved. Family can only make decisions either under affection or as a consequence of grief. So, involving either a health professional or a third party would be fair, and they should be (Bulbinthar, Punjabi male aged 74).*

Instead, he reaffirmed that the mediation of decision making by health professionals would be a better option. Moreover, he continued his argument by saying that decisions made by the family members may be influenced by their emotions. Thereby, he argued that the family would need to discuss such decisions with health professionals, if such discussions need to be 'guaranteed'.

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It was found that most of the older participants preferred the health professionals to consult with their family members regarding any discussions related to their death and dying, and asked to exclude themselves from discussions. Chandru claimed that it would be appropriate for the health professionals to discuss such issues with family rather than involving the dying older people. Chandru is a Punjabi man living in his own house and his daughters were living in another city in the UK. His wife died six years ago. Though his children were living in other cities in the UK, he said that health professionals would need to consult them in relation to his decisions around death and dying. He argued that even if he was prepared to discuss it with the doctors, his family would not agree to such discussions:

*MK: If the health professional wants to ask you about your end of life care decisions, are you ready to discuss them with him?*

*Chandru: I might. My situation is different. My children are grown and live away from me. So when you are on your own, if the doctor comes up with this one, I can always say what my wishes are. Yes. I don't mind discussing them. But they would have to discuss it with my children and also my next of kin too, because they may not agree with my decisions. So that's the problem (Chandru, Punjabi male aged 74).*

Chandru felt that individual discussions with health professionals would not only cause distress for the older people, but also strain their relationships with their families. However, he mentioned that if a medical professional preferred to discuss any issues

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related to the end of his life with him, he would participate in such a discussion. His words ‘in my situation’ and ‘living on your own’ demonstrate that such participation would be out of respect to the health professional. Furthermore, those words would also indicate that discussions involving death and dying were presumed to be the responsibility of the family rather than the individual. Usually in South Asian families, older people are respected for their wisdom, knowledge and experience; avoiding distress from such discussions would also be considered as respecting older people during the end of their lives. However, Chandru considered that living alone in the UK, without any immediate family support, strongly induced older people to have such discussions with health professionals, overriding cultural mores.

Similarly, Chitra echoed that having such an individual discussion with health professionals would upset their family and cause distress. Chitra was an Indian Malayalee woman living with her son. She explained that her family would be disappointed if she had had an individual discussion. She said that her family would feel offended if she discussed it without them. To avoid such distress for the family, she claimed that it would be much better for the health professionals to discuss these matters with the family first rather than with the older person:

*Because if something happens, I have done wrong, if they come to know only after everything has happened they may want to do differently, and then they may get upset. They may ask why she did things this way, or why she didn't discuss it with me, and all of those sorts of things. Otherwise, just tell them, it's easier (Chitra, Indian Malayalee woman aged 67).*

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Chitra underlined the importance of family in end of life discussions and how they would usually expect health professionals to discuss matters with them rather than with the dying people themselves. In fact, Chitra reported that if any of her plans or discussions with health professionals would be contrary to the other family members', this would greatly offend the family's integrity.

In contrast to trusting medical expertise and trusting their family to discuss and decide with health professionals, seven participants reported that they would prefer it if the health professionals discussed it with themselves than with their family. Baseema stated that a discussion between the family and health professionals would only fulfil the preference of the family members rather than their dying relatives.

*I will because I want to have my own decision, and because women's are women's. If I found out that I would not live longer than a couple more days, I would want to stay at home. But if I am unconscious, I don't know. I don't know whether I will be unconscious or not at that time. If I am conscious, then I will see how well the family are coping with me. I don't want to kill them with my own problems. I am about to leave and lead a quality life. So I will not torture them. I feel the emotion, that emotion is torture for other people (Baseema, Bangladeshi woman aged 64).*

She argued that she would make her own decisions, because 'women's are women's', with their preferences and decisions. She described the benefits of taking individual

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decisions, which would help her to assess and decide the ability of her family in coping with her burdens.

## **6.3 Summary**

The concept of ‘trust’ as the category discussed in this chapter was explored by reporting how participants relied on their family and significant others to help them to avoid any discussions related death and dying. In particular, they felt it was inappropriate to be discussed with them directly because it would distress their family; was perceived as disrespectful; and could act as an inauspicious precipitator of illness and death. Many participants reported such avoidance as a cultural norm to which people adhere. As well as protecting older people from discussing such unpleasant topics, avoidance of discussing death and dying was thought to encourage optimism during old age. Moreover, they reported that decisions related to their death and dying would possibly be discussed only at the time of their death and during their last days.

Trust was also explored in terms of the locus of authority in decision making related to death and dying. Older participants expected that their family members would lead any decision making during death and dying. They believed that deferring to the next generation would absolve themselves of responsibility to lead any discussions, and lead to better decisions being made by younger and more informed relatives and kin.

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Findings also presented their belief in and practices of a perceived hierarchy of decision making, one culturally rooted and generally observed. However, many reported the role of outside experts, the health professionals, in end of life decision making. Findings demonstrated that health professionals were revered figures, whom the participants would trust for their medical knowledge and role during their death and dying, although there was a widespread perception that it was not the role of professionals to discuss death with patients themselves, but with their families.



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## CHAPTER 7

# Discussion

This chapter describes the methodological strengths and limitations of the study and reviews the key findings of the study in relation to existing literature. In so doing, it sets out a theoretical framework of ‘continuity and reconstruction’ which explains how participants made efforts to adhere to important social and cultural values relating to death and dying, while rebuilding and adapting those values as they accepted the challenges of living in an emigrant society. This framework encompasses the categories of ‘home’; ‘family’ and ‘trust’ at end of life which emerged from the analysis of data.

### 7.1 Overview of the study

Interview data from 55 older South Asian people living in selected boroughs of East London were gained by using five focus groups and 29 semi-structured interviews. Most participants were able and willing to discuss their attitudes and share their experiences of the topic under discussion. However, the data were limited in scope for two reasons. Firstly, I was a novice qualitative interviewer with no previous experience of researching such sensitive topics; and secondly, most of the participants had never before had experience of discussing their own death and dying, and sometimes considered this culturally inappropriate. Nevertheless, the data provided some valuable

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insights. Table 8 describes the summary of categories and sub-categories arrived at from the data analysis.

**Table 8 Salient categories and sub-categories of this study**

<b>Core -category</b>	<b>Categories</b>	<b>Sub categories</b>
<b>Continuity and reconstruction</b>	<b>Home</b>	<b>Home as a Haven</b>
		<b>Reconsidering the Homeland</b>
	<b>Family</b>	<b>Honour within the family</b>
		<b>Extended family and social networks</b>
	<b>Trust</b>	<b>Avoidance of discussion about death and dying</b>
		<b>Locus of authority</b>

A theory of ‘continuity and reconstruction’ is posited here as a core category that captures perspectives on death and dying perspectives among older South Asian participants living in East London; it provides an understanding of how participants balanced attempts at maintaining traditional values with the necessary adaptation or reconstruction of these to their circumstances of living in East London. In this thesis, this theory of continuity and reconstruction is explored in three ways.

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Firstly, the theory of continuity and reconstruction is explored through participants' accounts of home during the last days of life. Particular attention is given to their attitudes, beliefs and expectations towards the meaning of home as a religious and comfortable place at the end of their lives. Secondly, the theory is explored with regard to family, in terms of how families are bound to care for their dying relatives at end of life. Findings also revealed the importance of considerable support from social networks in family care giving at end of life. Finally, the theory is explored in terms of participants' understandings of the role of trust in family, medical professionals and wider social networks and the responsibilities of the latter to lead any discussions related to illness and to make decisions related to the death and dying of older people.

From these findings, this chapter posits two key conclusions. Firstly, while keeping their vivid memories of home, homeland and family at end of life, older South Asians were repositioning their values regarding their death and dying in the new social context (living in the East London). The second key conclusion that this study suggests is that existing stereotyped assumptions about home as a place of death, family care, and autonomy-focused models of decision making approaches may have limited application for wider South Asian communities. These conclusions will be considered in relation to current literature in this chapter. The validity of these findings is clearly dependent on the methodological strengths and limitations of this study, which are discussed in the following paragraphs.

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## **7.2 Methodological strengths: Does being an ‘insider’ benefit this study?**

This study’s strengths include its being a multilingual, multicultural and multi-religious one. Importantly, this study benefited from using an ‘insider’ approach. Existing literature was highly positive about the strengths of having an insider as a researcher at the heart of cross-cultural studies (Deianira & Sam 2006, Gunaratnam 2003, Nichols-Casebolt A & Spakes 1995). However, previous studies on death and dying have clearly demonstrated issues with researching ethnic minorities in end of life studies (Gunaratnam 2003, Hughes *et al.* 2005). For example, Seymour *et al.*’s (2007) study on Chinese participants narrated how Western researchers struggled to enter ‘inauspicious territory’, though they found that their fears were partially unfounded as respondents actually showed high turnout and active participation. On the other hand, such ‘unfounded fears’ reportedly restricted them from using the vignette approach. Furthermore, studies focused on South Asians have often used interviewers from South Asian communities, but then rely on analysis conducted by researchers from other communities (Bowes & Wilkinson 2003, Owens & Randhawa 2004, Seymour *et al.* 2007). Some researchers have pointed to several benefits of using insider interpreters who act as ‘cultural brokers’ (Jenny Hsin-Chun *et al.* 2008). Hence, this study benefitted from the researcher being a socio-cultural insider who framed, analysed, interpreted and reported the whole study.

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My ethnic background is that of a young adult who has recently migrated from South Asia (India). Culture in the Indian subcontinent is closely bound with religion (which influences dietary choices, dress, family arrangements, and occupation, as well as traditional religious practices, to a much greater practical extent than commonly observed in the West or elsewhere). Although I belong to the Hindu religion (the largest religion of the Indian subcontinent), I am familiar with other common religions in the area, namely Islam, Buddhism and Christianity, which are widely practised in India. The plurality and coexistence of major (and minor) religions in India enables a broad understanding of interfaith issues and common understanding. I come from the south of India, in which all Hindus, Muslims and Christians live closely together and have stronger neighbourhood networks than elsewhere in India or indeed most of the world.

Furthermore, being an insider, I perceived myself as a research instrument, which added several strengths to this study. This is, I believe, a particularly valuable strength, as this was a study of a particularly sensitive topic. Firstly, I was able to navigate cultural boundaries in terms of using words, dress, language, place, time and relationship with the respondents. For example, being able to sense subtle nuances in the meaning of the participants' words, I intermittently stopped the interviews to check the willingness of interviewees to continue before resumption. Besides, I did not use many direct words in relation to death and dying, as I understood that people would feel embarrassed to hear such words from a person from outside their home. Instead I used the indirect words in those languages which I felt comfortable to use. By this, I believed that participants were able to understand and were willing to contribute to my research aims. Murray and Wynne (2001) emphasized the need for interpreters as they could 'access the thoughts,

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feelings and experiences’, while they live in a ‘different and dominant culture’. Moreover, being an insider, I was able to sense the meaning and power of family relationships, which strengthened my study and rendered it more flexible, enabling research potential to be maximised (e.g. by obtaining permission from other household members whose permission I deemed it culturally appropriate to ascertain before proceeding to interview their older relatives).

As a male researcher I needed to appreciate gender as well as cultural barriers. These considerations included keeping a physical distance from the female respondents, sitting in an opposite chair, accepting drinks if offered (to show respect), getting permission from their husband’s or adult children, and at times accommodating their children or their friends during the interviews (which made them feel safe and comfortable). On the other hand, with older male respondents, I expressed more deference in terms of words and manners (such as standing until they sat or I was asked to sit), using cultural relationship words like ‘uncle’ and respecting their age. Furthermore, I was able to sense the cultural meaning of unsaid words or silence, and behave accordingly. Additionally, I was able to sense during most of the interviews cultural indicators of their willingness or dissatisfaction to continue their participation.

Being a multilingual researcher who can speak and understand four of the eight South Asian languages used by people who took part in the study (Tamil, Telugu, Malayalam, Hindi and English) added additional strengths to this study. I cannot speak or understand Urdu, Bangladeshi and Gujarati, although there are close parallels between these languages enabling some degree of comprehension, as with Roman languages of

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Europe. In reality, although I gave the option to participants to talk in any language that they wished, most used English (albeit mixed with words from their first languages). The resulting transcripts were thus ‘pidgin’ and not ‘monolingual’ English, including words and phrases from other languages. Methodologically, my multilingual flexibility helped the respondents to use any language they preferred at times when they did not find suitable words in English; they used their own language to explain. In other words, my multilingual knowledge strengthened this study by enabling the inclusion of a variety of people, from those fully fluent in English to those who spoke only their mother tongue. However, I depended on an interpreter for one focus group, which was conducted in Bengali.

Significantly, given the well-known difficulties in recruiting ethnic minorities, particularly for faith groups, this study accessed these ‘hard to reach’ groups both for research and for sensitive topics of research and I was able to recruit a relatively large sample, with a total of 55 older South Asians participants. My sample included a diverse range of South Asian communities (Indians, Pakistanis, Sri Lankans and Bangladeshis). Additionally, the ethnic composition of the study sample correlated to the ethnic diversity of the selected boroughs (Indians 12%, Bangladeshis 9%, and Pakistanis 8%). In addition, I accessed the participants from six different cultural traditions (Tamil, Malayalam, Bangladeshi, Sikhs, Gujarati and Pakistani South Asians), which I believed would capture a representative sample, at least in terms of ethnicity, of the South Asian communities living in East London.

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The majority of studies of Asian people have involved only north Indians, Gujarati's (Smith *et al.* 2003), Punjabis and Sikh Muslims (Worth *et al.* 2009), Bangladeshis (Bush *et al.* 2003, Greenhalgh *et al.* 1998, Merrell *et al.* 2006, Somerville 2001, Spruyt 1999), or North Indian Hindus (Deshpande *et al.* 2005, Firth 1999, 2005, Laungani 1999, Sheikh *et al.* 2003). The study reported here included Indian Malayalee's, including those who migrated from colonial Singapore, and Sri Lankan Tamil-speaking refugees.

In addition, this study included people from various contexts; men and woman, housewives, religious leaders, community leaders, community group members, community group volunteers, retired teachers and asylum seekers. I also included respondents from various living arrangements, such as those living on their own, with their extended families, with their spouse, those with limited support and also people with extensive social support from their family and relatives. Arguably, by being an insider, I was able to enhance the diversity of the study sample.

## **7.3 Methodological limitations**

### **7.3.1 Researcher-centred limitations**

Exploring such a sensitive topic by an inexperienced qualitative interviewer was a crucial limitation of the study. This obviously impacted on the quality and richness of the data. For example, when I used the aide-mémoire, participants sometimes



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misunderstood the questions or I found difficulty in translating them into a suitable language, and struggled to express face-to-face certain concepts to participants. This resulted in the occasional perception (on reflection and in discussion with my supervisors) that I attempted to force answers from participants by use of my set of prompts in the aide-mémoire. In addition, participants had no prior experience of participating in research, except for six Bangladeshi women. This resulted in either limited expressions of respondents' views, or description beyond the scope of my questions. In effect, my aide-mémoire was of limited usefulness, and I gradually learnt to mostly listen and await elaboration of participants' initial responses.

My 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. For example, four Tamil Christian priests and two Muslim imams who participated in the study influenced the data from their religious perspectives. In addition, five community leaders participated. I believe such dominant voices had an impact in my findings and this study should be interpreted in the light of the potential impact of these dominant voices, which as well as clouding some implications of the outcomes, may also yield some colour and flavour of the mindsets and psychological milieu of general South Asian patients.

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### 7.3.2 English as a second language

One definite methodological limitation to be considered while interpreting the findings of this study is the issue of my own proficiency in the English language. This issue was reflected throughout the research process, especially during data collection, analysing the data and writing up. During the data collection, at least for my initial interviews, I found it difficult to adhere to the role of qualitative interviewer. As English is my second language, while interviewing I often used Indian English (*Hinglish*) (Coughlan 2006), commonly used by people from South Asian backgrounds when conversing among themselves in English.

I observed however during my transcription that being a researcher with English as a second language, my spoken English was often unclear; I was more concerned with conveying questions in a culturally sensitive way. This resulted in too much of ‘me’ in some of the interview transcripts. A qualitative researcher should use more listening and give more time to the participants (Murray 2003, Russell 1999). However, in effect, this technique worked as an ice breaker and gave an opportunity to create mutual trust; however, while transcribing I found that respondents sometimes appeared to misunderstand the question or prompt, a reflection of my English obscuring the meaning of my questions. An alternative explanation may be that when I used alternative words with similar meaning in their language I may also have confused my respondents. These issues may have influenced the quality of the data collected.

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### **7.3.3 Identity and Gender**

My ethnic subgroup identity influenced the data content and quality. As I come from a particular ethnic subgroup, South Asian Tamil, I observed some participants from other South Asian subgroups distanced themselves from me. Such distance was evident both in the level of involvement and depth of information that was given during the interview, particularly people from Bangladeshi, Gujarati and Pakistani backgrounds. I supposed that they did not feel as comfortable in discussing the issues with me as some other subgroups with which I was identified more closely. For example, often Punjabis and Muslims explained broadly or checked my awareness about some issues before they talked about them. On the other hand, respondents with whom I identified often tended to give a comprehensive answer in a condensed language. At times, they stopped before detailing the events and said ‘as you know’. This is possibly because as I came from the same ethnicity, respondents expected me to have a clear understanding and thus they did not need to explain details. Such assumptions might have restricted or obscured the depth and breadth of data reflected in my findings.

Furthermore, my age and gender would have had some influence on the data I collected. As reported earlier, being younger than the participants, culturally they did not feel completely free to discuss sensitive subjects with me in the interviews and focus groups. In addition, gender was another factor important in considering the process by which my

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data was generated. Being male, I felt some women participants were reluctant and reticent during the interviews.

### **7.3.4 Recruitment issues**

Although the community leaders provided the access that made this study possible, this gave rise to methodological issues. Although all participants gave consent to study participation, they may have been ‘chosen’ by the community leaders and so their consent was constrained. Additionally, I sensed that some participants felt some degree of obligation to give an interview as I came from the same ethnic group, and they did not want to be viewed as unsupportive and unaccommodating to me.

Furthermore, while conducting one-to-one interviews, some participants invited their family members, friends and community leaders to be with them, who then also volunteered to take part in the study. When I explained confidentiality and privacy issues, respondents said that they would feel comfortable if they stayed with their friends while giving the interview, which I accepted. This is possibly because people felt that friends would support them while discussing the issues, particularly when recalling their memories about the death of a close friend or relative. Alternatively, they also might have felt less vulnerable being with a friend at the interview, as I was a stranger, and a young adult. This may have been a particular issue among those participants who lived alone. One respondent with an extended family asked her daughter and daughter

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in-law to stay with her. Sometimes, these ‘extra people’ helped me to explain my questions to the participants.

On the other hand, the presence of others at the interviews raised two particular methodological issues. Firstly, they interrupted the flow of the conversation with respondents and made attempts to influence the participants’ response. For example, they sometimes gave some specific answers for my open questions in the interview and asked the participants to choose from those answers. Secondly, when I interviewed the leaders and older friends later, they often concurred with the answers of friends, perhaps not wishing to differ, or having been conditioned to think along the same lines. I believe such interpretations also had an impact on data quality.

## **7.4 The theory of continuity and reconstruction as an account of place**

### **7.4.1 Home as haven for religious dignity**

In this study home was revealed as a place that participants believed gave religious dignity during the end of life. Previous studies have highlighted the importance of religious aspects in the delivery of end of life care, particularly among ethnic minorities (Colleen *et al.* 2003, Koffman *et al.* 2008, Payne *et al.* 2005, Rashid *et al.* 2003, Worth *et al.* 2009). In a comparative study of Black Caribbean and white people, more Black

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Caribbean participants than the white participants reported that religious beliefs helped them at times of loss (Koffman & Higginson 2002). Among older South Asian Muslim and Sikh patients with life-limiting diseases in Scotland, any illness and suffering was viewed as God's will and a test of faith (Worth *et al.* 2009). A study of Bangladeshi caregivers in East London also found that South Asian people express a need to conduct religious practices during death and dying (Spruyt 1999). Consistent with the literature (Deshpande *et al.* 2005, Firth 2005, Ismail *et al.* 2005, Kemp 2005, Sheikh *et al.* 2003), participants in this study expressed that religious practices were often seen as essential to achieving peaceful death and gave a sense of completion of religious and filial duties.

This study found that people prefer home at end of life as it provides space for their own family to exercise their religious practices and was considered to be a place in which they felt familiar and confident. A study among Indian migrant women in New Zealand reported that the home was considered to be a personal space where they could continue to practise their own cultural practices (Nayar 2009). Furthermore, similar to other studies (Diver *et al.* 2003, Jones 2005, Perreault *et al.* 2004, Small *et al.* 2005), the participants perceived various barriers to the observation of their religious beliefs in places other than home.

To evidence the theory of continuity, study participants expected that dying at home provides proximity to the family and opportunities for executing religious practices. In fact they believed that dying in settings other than their home would create a barrier between them and their family. This is consistent with another study that found that people from Bangladesh living in Tower Hamlets prefer to be around their family during

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their death and dying (Spruyt 1999). Studies among other ethnic groups have shown that similar expectations are expressed regardless of ethnicity (Koffman & Higginson 2004, Seymour *et al.* 2007, Teno *et al.* 2004).

In fact, other research has indicated that essential qualities of home include a sense of security, privacy, self-expression, warm social relationships and the physical structure itself (Smith 1994). Consistent with those findings, the study reported here implies that dying around the family gives a sense of security, safety and comfort, and compensates for difficulties in interfacing with the outside world, such as access issues, language and knowledge. Participants also reported that dying at home is believed to be a way of avoiding dying alone, and helps them to manage their perceived anxiety about dying in other settings, in keeping with other research findings (Bowes 2006, Chan & Pang 2007, Gomes & Higginson 2006, Rainwater 1966).

Participants who reported their experiences of caring for dying relatives attached less importance to religious practices than other pragmatic concerns like physical care, facilities at home, space and professionals' support during the end of life. In other words, this is possibly because when people have an unknown fear about death (Bowling *et al.* 2010) and have not planned for it, the provision of physical comfort and dignity become more pressing concerns than religious practices. This finding is consistent with a previous study in the USA (Steinhauser *et al.* 2000) which found not only religious practices, but also other factors including: being mentally aware, having funeral arrangements planned, not being a burden, and helping others, as important aspects in end of life care for patients, family and physicians. Similarly, in another study

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in Canada, trust in the treating physician, avoidance of unwanted life support, effective communication, continuity of care and life completion were considered most important for Canadian patients when seriously ill (Aspinal *et al.* 2006).

Indeed, preferences for being with family and performing religious practices were not concrete, and there were different views among subgroups of South Asians. For example, one ethnic difference between Bangladeshi and Gujarati people and other South Asian ethnic groups was that former appeared to express stronger views about dying around the family at home. One of the reasons postulated for this in the existing literature is that Bangladeshi and Gujarati communities who came to the UK from the 1930s onwards have stronger extended families (Bowling *et al.* 1995, Phillipson *et al.* 1998) than others, for example Malayalee, who mainly migrated since the 1970s. For example, this study suggests that other South Asian subgroups, including Tamil and Malayalee Hindus, and Pakistani Muslims, who accept that it is likely that they may live alone during their old age and some who often live alone or with older spouses, expressed their preference to die at other places of care, particularly in hospitals. On the other hand, people who have recently immigrated, for example as asylum seekers, and were living with their extended families, appeared to have stronger expectations about dying at home and family presence. Thus findings of this study are consistent with the argument that preferences are heterogeneous even within the same ethnicity (Koffman *et al.* 2008).

Another reason for their reconstruction may be that many older people in this study reported about their conscious of the complexities and practical difficulties of expecting



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their children to care for them at home. These findings are supported by studies of social network theories (Bowling *et al.* 1995, Butt & Moriarty 2004, Phillipson *et al.* 1998), which reported that the changes surrounding family and kinship mean that presence of family at the time of death is no longer ensured. In other words, although people preferred family to be around them to perform religious duties, they accepted the need to be flexible and to accept help from non-family agents to fulfil their religious responsibilities, or at least to achieve a comfortable death.

### **7.4.2 Diaspora**

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 (Falzon 2003, Graham & Khosravi 1997, Vertovec 1997). However, recent socio-anthropological literature often uses the term diaspora as source of resistance and cultural identity. For example, Vertovec (1997) described diaspora as a term calling for a 'recognition of combined workings of structural and non-structural, conscious and non-conscious factors in the reconstruction and reproduction of identities and socio cultural groups outside of some place of origin'. A similar deconstruction of the meaning of diaspora was presented in this thesis, whereby participants often highlight a number of observations in relation to 'homeland' and their end of life.

I found that when most respondents considered their own death, their thoughts turned to their homeland - the countries from which they had emigrated. This continuity of cultural influence over the immigrants was also observed in by Falzon (2003), who

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studied a group of Sindhi people who immigrated from Mumbai, and considered 'Mumbai' as their cultural heart. He presented the relationship between diasporic communities and homeland as follows:

*'To reiterate, then, 'homeland' and 'diaspora' are related in two ways. First, a diaspora population is understood to be one which is dislocated relative to a place of origin (Graham & Khosravi 1997). Second, it is assumed that the homeland will continue to exert its influence on the social relations of a people in diaspora, either because they 'transport' aspects of the homeland to their diasporic destination/s or because they continue to cultivate ties with it, or both. It is ambiguous that a people are defined as being in diaspora by virtue simultaneously of their separation from a homeland and their enduring association with it. A homeland is, as it were, something a people in diaspora are stuck with even as they are unstuck from (Falzon, 2003, p. 624).*

Cassarino (2004) argued that returning to their homeland was viewed as an ultimate goal for those who migrated for economic reasons, such as better job opportunities, and for refugees. Bonacich (1973), when describing South Asians in the USA in his 'middle man theory', observed how they practised 'thrift' - short-term deprivation to hasten a long-term objective of returning to the homeland. This is not consistent with the findings presented here, which suggest that in spite of social change and family circumstances, many participants felt settled in the UK. Returning home remained an aspiration for many, but was also regarded with ambivalence and seen as a challenge.

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This study finding suggests that there are possibilities of some differences within South Asian ethnic groups in relation to their attitudes about their homeland. In this study, the participants who migrated in the early 1970s and 1980s, for example the older Malayalee South Asians, and older people from the Tamil community, remain ambiguous in their views about their homeland. In contrast, people like the Gujarati's, who mainly migrated from the early 1930s to 1950s, reported stronger views that home was not their 'homeland'; home was where their family live, i.e. the UK. This is because these early settlers have their own sisters, brothers, adult children, and parents residing in the UK, while in contrast, the extended families of recent settlers still live in their homeland. However, as presented earlier, Bangladeshi participants who emigrated prior to the 1970s reported that most of the older people from their community would prefer, and were commonly seen to return to their homeland to live their last days. This is consistent with the concept of homeland as diaspora identified by Falzon (2003) in his ethnographic study about Indian Sindhi people who migrated to Pakistan and still had a desire to return to their homeland in Bombay which they viewed as a place of pilgrimage.

Existing research suggests that migrants from South Asian countries increasingly view their home as where the family lives and understand homeland in terms of cultural values (Spruyt 1999). Consistent with this, one of the reasons voiced among my study participants for their return at the end of life was to see, say goodbye to, and die surrounded by their family and friends in their homeland. However, this study found that participants perceived that the social networks that existed prior to their emigration no longer existed; this had begun to change their attitudes to returning.

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The study findings suggested some differences between religious groups towards their attitudes related to homeland. Most of the Bangladeshi participants interviewed were Muslims, and preferred to return to their homeland to live the final days of their lives as they believed that that would help them to practice their end of life practices, including being around the family and dying at home. This tends to confirm the findings of earlier studies that emphasised the ways different ethnic groups respond towards religion and preferences (Koffman & Higginson 2004, Seymour *et al.* 2007). However, one study of Bangladeshi carers living in East London showed that though people preferred to die in Bangladesh, only a few achieved this, although many who died in London were buried in Bangladesh (Spruyt 1999). This suggests that returning to homeland after death may be important for Bangladeshi Muslims.

In contrast to Spruyt's (1999) study, this study found that most Indian Gujarati's, Tamil and Malayalee participants who were Hindus and Christians reported that they would be able to practice their own traditional end of life rituals even in the UK itself. For example, in the Gujarati focus group, people reported that having religious places such as *mandhirs*, temples and priests in the UK gave an opportunity to participants to practice the same death and dying rituals that they practiced in their home country in the UK. However a few Hindu participants also expressed a wish to visit the Ganges and wish to die in India to have funeral rights in UK.

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## **7.5 The theory of continuity and reconstruction as an account of family**

Recent literature has paid much attention to the valuing of family care giving during end of life (Aoun *et al.* 2005, Docherty *et al.* 2008, Funk *et al.* 2010, Grande *et al.* 2009, Hudson & Payne 2009, Hudson *et al.* 2009, Stajduhar *et al.* 2010). In addition, existing research already explored the processes or mechanisms of family care giving (Keith 1995, Lai 2010), particularly among ethnic minorities (Katbamna *et al.* 2000, Katbamna *et al.* 2004, Merrell *et al.* 2005, Neufeld *et al.* 2002). To add this wider body of research, this study contributes by exploring some insights about family care giving at the end of life from the perspectives of older South Asian ethnic minorities.

Values attached to family care giving among ethnic minorities, similar to any population have been demonstrated in several studies (Aoun *et al.* 2005, Fonseca *et al.* 2010, Hudson 2004, Keith 1995, Lai , Mok *et al.* 2002, Perreault *et al.* 2004). This study adds insights into this body of research by drawing attention to two distinctive family values that are associated with end of life care giving among South Asian communities: caring within marriage or spousal care giving, and filial responsibility. Furthermore, despite having smaller social networks (Blakemore 2000, Kahana *et al.* 2004), participants in this study also suggested that social support from community members and peer groups has a positive role in family care giving at the end of life.

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### 7.5.1 Spousal care giving

Elements of continuity and reconstruction were evident in the reports of those who talked about spousal care giving in this study. In this study, participants reported that most often older spouses were needed to act as primary caregivers for their dying relatives. For most of the South Asian families in this study, where adult children live far away, the spouse at home reported that they provided personal care giving and support, at times leading and organising care at the end of life. This is consistent with previous studies which reported spouses as the main carers for people with disabilities (Katbamna *et al.* 2000), people with chronic illness (Heyland *et al.* 2006, Merrell *et al.* 2005) and people with mental illness, including dementia (Bowes & Wilkinson 2003).

Clearly this study finding suggests that the intention to retain the continuity of their social values of caring for the dying relatives motivate these older South Asians, particularly for their older spouses, to act as primary care givers. Participants, who spoke about their caring experiences for their dying spouses, reported a gratitude for the dying person who brought them to the UK and gave them a better life. Honour, respect and their need to fulfil their promise or duty to keep their marriage vows were the core values related to family care giving at the end of life. In the same way, an ethnographic study in the USA (DeSanto-Madeya *et al.* 2009) identified that spousal care giving at the end of life was viewed as a promise, a desire to provide a normal life and a way of avoiding institutional care. A similar study in Canada demonstrated that love and duty to care were predominant values (Steele 1994). In another study (Stajduhar & Davies

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2005), Canadian family carers valued caring for the dying relatives as a duty to care, and felt obliged to fulfil their dying relatives' wishes. They reported that the main reason for their desire to make home the place of death was to keep a promise to the dying person.

Some participants suggested a desire to avoid the 'social stigmatisation' that was a consequence of being perceived as letting their relative die without family care. This was a strong motivating factor for them to pursue family care giving at the end of life. In the study by Katbamna *et al.* (2000) of family carers for South Asian people with disabilities, social stigmatization and family values were identified as reasons for caring for older people with chronic illness. This is also consistent with Somerville's study (2001), which found that among Bangladeshi communities, as well as a sense of responsibility and duty, there was a wish to avoid criticism by members of their own society to provide family care at the end of life. Participants in this study similarly argued that a factor of social prestige in maintaining the continuity of social values around death and dying often places the older spouse under obligation to be a primary care giver at the end of life.

Previous research has identified the role and division of labour among men and woman in South Asian communities (Barnes *et al.* 2006, Fikree & Pasha 2004, Grewal *et al.* 2005, Katbamna *et al.* 2000, Neufeld *et al.* 2002). Gender differences in labour among South Asian family members, which is commonly reflected in other studies (Katbamna *et al.* 2004), is also manifested during the end of life. Whereas women in this study viewed such duties of care as a form of gratitude and respect, men perceived it as a form of organising and arranging for the best possible care for their wives. Findings of this

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study suggest that they may rebuild those values more strongly as they become aware of their own and other social constraints of family care giving while living in the emigrant society.

On the other hand, participants in this study also reported some evidence of the adverse effects of spousal care giving at end of life, including physical symptoms such as tiredness, lack of sleep, ignoring own physical health, caring alongside dealing with their own multiple health problems, and postponing own treatment. However, participants in this study generally reported that they continued to care for their dying spouses as they did not want to intrude upon their children's lives. This is consistent with previous studies that looked at the impact of spousal care giving among older carers, highlighting emotional disruptions, feelings of tiredness, exacerbation of previous health problem, sleep disturbances, resentment, and difficulty in coping and feeling of distress (Aoun *et al.* 2005, Hearson & McClement 2007, Lavela & Ather 2010, Perreault *et al.* 2004). Findings in this study are also similar to those of Somerville's study (2001) among informal care givers in Bangladeshi communities in Tower Hamlets, who reported weakness, lack of sleep, and difficulties in the practical aspects of caring.

Some studies have reported that family care giving depends on the nature and strength of family relationships. For example, Adamson and Donovan's (2005) study of British South Asian families showed that family care giving was dependent on the nature of kinship ties. In this study, participants reported that when their adult children are scattered, busy leading their own lives, older spouses are left with no option but to be



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the main carer for their dying partners. Penrod et al. (1995) suggested that older spouses are often seen as a carer by the 'virtue of being co-resident' with people who need care. Similarly, Lewis and Meredith (1988) reported that it seems to be the case that older spouses at times 'drifted into caring', particularly when they were co-resident.

Reports of the participants suggested that some accepted and were positively inclined towards forms of extra-familial support, including support from health and social services for spousal care giving at end of life. One possible reason that consistently emerged in this study was that these older people were increasingly aware of the compromises they would have to make in providing family care at the end of life in a 'new' country., which prompted them to accept and adopt such 'extra familial ways of meeting needs' (Blakemore 2000) for support at end of life. Such signs of change can be rationalised as a point of acculturation, whereby people assimilate themselves to avail support similar to the majority population (Blakemore 2000). However, for the participants in this study, such extra familiar ways were limited to the extent of their own knowledge and experience with other formal support such as hospitals and hospices.

Some scholars have used the term of 'biculturalism'; to explain how people seek to accept the best from their host country while at the same time attempting to maintain the continuity of traditional practices (Robinson *et al.* 1996a). This study also presented some evidence for an impact of biculturalism among older participants in spousal care giving at the end of life. Biculturalism was often expressed in the trade-off between holding one's own cultural values and choosing the best from the host culture (Nayar

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2009). Similarly, whilst spousal care giving was rooted in traditional ideals of honour, marital commitment, and moral reward, in this study participants expressed willingness to seek and accept any services they knew were available.

### **7.5.2 Filial responsibility at end of life**

An equal number of study participants lived alone or lived with their children, however many of the former reported that their adult children often lived within a twenty-mile radius and would readily support care giving. Similarly, other studies about older people and their living arrangements also reported that over 90 % of South Asian parents had at least one adult child living locally in their study (Bowling *et al.* 1995, Scharf *et al.* 2005). Respondents in this study usually reported that their children visited often, typically once or twice a week.

In the context of end of life situations, participants reported that living in such close proximity helped their children to take over their filial responsibilities of care giving for their dying relatives. Similarly, they reported that although their adult children lived elsewhere, for example in other British cities or in other countries, they attempted to be around when a relative was dying to take part in family care giving. This is similar to the findings reported from a study of Chinese immigrants (Seymour *et al.* 2007), wherein older Chinese participants looked for support from the children at their crisis.

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In this study, many older participants reported that they had a few fixed expectations of their children for their future care at the end of their lives. This is possibly because the older people who expressed these views expected their adult children to ‘pay them back’ for the opportunities which flowed from emigration by caring for them during old age and at the end of life. To this extent, findings of this study suggested that older people have high expectations that their children will preserve the continuity of cultural values attached to family care giving, but the reasons for this were complex and related to a sense of sacrifice rather than simply allegiance to ‘homeland’ or a set of traditional values.

### **7.5.3 Social support for family care giving**

Participants also highlighted the significance of social network and its support to maintain the continuity of holding the values around family care giving at the end of life. This is consistent with existing research by Katbamna *et al.* (2000): [the] presence of the support person and continuity of other family members and friends is pivotal support for family care givers. Similarly, Merrell *et al.* (2006) argued that when ethnic minorities have less knowledge and experience of using existing health and social services, social networks are critically important to support family care giving for any illness.

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Along with immediate family members, participants reported that often their peer community members visited dying individuals and provided emotional support through sharing feelings that gave a sense of belonging. Indeed, extending such support for a dying individuals and their family was expressed as being obligatory for community members. Furthermore, consistent with other studies (Butt & Moriarty 2004, Helgeson 2003, Muthukumar *et al.* 2004), participants also reported that they received most information related to health and social services when they attend their faith-based or language-based local community organisations. However, this is not consistent with other studies (Albinsson & Strang 2003, Bowes & Wilkinson 2003), which reported that immediate family members constitute primary carers who provide all emotional, informational and instrumental support. For example, Katbamna *et al.*'s study (2000) reported that female carers of disabled people felt that their community offered very little support, but merely 'watched' and were ready to comment on their ability to carry out their duty to care for their disabled relatives.

The findings of this study suggest that although personal care for the dying person was often undertaken by immediate family members, support from care agencies including Macmillan palliative services, local hospices and social services was also highly appreciated. However, this is not similar to the findings of previous studies; that people from South Asian communities prefer their own family members to provide personal care than from health and social services (Jones 2005, Katbamna *et al.* 2004, Merrell *et al.* 2006, Somerville 2001). One possible reason for this is the intensity of carer burden, especially at the end of life, which when compounded with family members' emotional stress would lead them to draw on external care support. Alternatively, such attitudes

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may reflect the fact that many people in ethnic minorities are unaware of any support available for dying individuals and their families, thus limiting them to fall back on hospital support at crisis points at the end of life.

Many participants who reported their experiences of caring for dying relatives suggested that there was limited support for family carers during end of life. This study's findings are broadly similar to other studies that reported limited use of existing palliative and end of life services (Gaffin *et al.* 1995, Koffman & Higginson 2001). A study by Merrell *et al.* (2006) showed that compared to other ethnic groups in the UK, Bangladeshi carers receive very little support from health and social care services supplementary to family caring. In fact, this limited use was similar to that of family carers of people with mental health, disability and other chronic illnesses (Katbamna *et al.* 2004).

## **7.6 The theory of continuity and reconstruction as an account of trust**

### **7.6.1 Cultural avoidance of end of life discussion**

In this study, participants reported that they would prefer to avoid any discussions around end of life topics due to various cultural barriers. This findings are consistent with another study that reported about a limited open discussion of death and dying among South Asian Sikh and Muslim patients with life-limiting illness (Worth *et al.*

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2009). Similarly, a NatCen (National Centre for Social Research) survey (2009) reported the decreasing trend of public involvement in end of life discussions in the UK. This survey indicated that 29% (compared to 34% in 2006) of UK public engaged in some form of end of life discussions either with their family or friends.

One of the reasons reported by the participants for such avoidance of discussion was their preconceptions around death and dying. For example, they reported a belief that thinking about death and dying would bring death closer to them and was an inauspicious topic for discussion. Similar beliefs have also been reported among Muslim participants in another study (Rashid & Sheikh 2002). Another reason might be explained by a survey (Bowling *et al.* 2010) in which more ethnically diverse people aged over 65 years expressed extreme fears about death (77% to 41%) for ethnic minority and white respondents respectively. This might inhibit them from thinking about death and dying. Similar expressions of unknown fear about death were also reported among older South Asian Sikhs and Muslims in another study (Worth *et al.* 2009).

In addition, participants also reported that they believed younger family members wanted to protect them in engaging in conversation about subjects perceived to be distressing. They reported that their family would encourage them to focus on what were considered more positive aspects of life. Worth *et al.*'s study (2009) reported that such resistance was a manifestation of common coping mechanisms to avoid feeling negative, by using positive thinking, fighting spirit, and denial and humour techniques.

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Participants in this study were ambiguous about the role of family in contributing to the avoidance of such a discussion. While some participants expressed their preference to discuss with their family who were perceived 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 preferred to discuss any issues related to their end of life with family members rather than with health professionals (Kahana *et al.* 2004, McDonald *et al.* 2003, Salmond & David 2005). Another multi-ethnic study in the UK identified that although there were difficulties for open debate and discussion, people alternatively believed that their family members would act on their behalf (Seymour *et al.* 2007).

Despite these preconceptions that often impeded such discussion, participants in this study reported that necessity often forced them to discuss their needs with health professionals. Participants expressed that the necessity of discussing with health professionals was generated both by the cultural barriers that inhibited discussion with their family members, and their preference of not being a burden for their children by involving them into such discussions. Such preferences were similarly found in other studies of similar populations (Back & Huak 2005, Phipps *et al.* 2003). However, this is not consistent with some existing literature that shows that people from ethnic minorities prefer not to be involved in such discussions with health professionals (Johnstone & Kanitsaki 2009, Kagawa-Singer & Blackhall 2001, Ko & Lee 2009, Tilden *et al.* 2001). Therefore, it seems to be that participants in this study tended to take a pragmatic position by sometimes disregarding their cultural mores, especially when facing end of

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life, and accepting the necessity to involve themselves in their own end of life discussions.

On the other hand, participants also highlighted that preferences to hold individual discussions and their involvement are dynamic, and might depend on the family circumstances. This is possibly because while they were confident that their family would care for them, some believed that making any decision making was unnecessary for them. Similarly, a review by Seymour *et al.* (2009) highlighted that public attitudes towards death, dying and bereavement are ‘highly contextual, contradictory and shift according to the circumstances and past experiences’. In other words, participants seem to reconstruct their beliefs and practices about death and dying and act according to their current living conditions.

### **7.6.2 Family involvement in end of life decisions**

This study suggests various practical reasons for older people to continue to trust their immediate family for their end of life decision making. One is that they expect their children to be the primary decision makers, as they were born and raised in the UK and were more aware of health services (as well as being generally more educated than their parents’ generation), enabling them to take the right decisions for their dying elders. Alternatively, older people often understand the barriers they face in identifying access



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to end of life care resources. Most therefore, continue to expect and trust their family to make decisions for their end of life.

Existing literature has already highlighted the perceived locus of authority of decision making, particularly between people from ethnic minority groups and the majority population (Back & Huak 2005, Carey & Cosgrove 2006, Doorenbos & Nies 2003, Kwak & Haley 2005, Oh & Lee 2002, Smaje & Field 1997, Somerville 2001, Werth *et al.* 2002). Kwak and Haley (2005) identified that members of ethnic minority groups in the USA prefer to operate their own decision making methods based on their values, knowledge about treatment options, and level of acculturation placed within their ethnic culture. On the other hand, in this study, living in the UK appears to have diluted such values, with participants reporting that they often reconstruct family-based decision processes at the end of life. This is not surprising, perhaps the wider literature has already demonstrated some possible explanations that include the increasing disadvantages of growing older in a 'new' country (Nazroo 1998, 2003). This may be particularly the case when their 'aspiring' middle class younger generations often live away from the older parents and they are exposed to loneliness and a fragmented extended family (Helgeson 2003, Phillipson 2000, Scharf *et al.* 2005).

### **7.6.3 Hierarchy of decision making**

There was evidence from respondents' reports that they undertook reconstructive work to reshape their approaches to care in response to family circumstances and the UK environment. Although they preferred a collectivist approach of family, rather than

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individual decision making (Werth *et al.* 2002), elders and men in the family were considered to be the chief decision makers for their dying relatives. Furthermore, participants reported that often women took supportive and carer roles in the family. However, as reported in another study, women in this study often expressed dissatisfaction and felt that their contribution was unrecognised (Katbamna *et al.* 2004).

This study has shown that the hierarchy of decision making at the end of life was often influenced by family circumstances and living in a place other than their homeland. Many respondents reported that they had no children living with them and in addition had no men in their family and no extended family. This meant that they needed to reconstruct their cultural values and engage in a diverse decision making process.

Previous studies on gender and end of life found a division of labour and responsibility between men and women in South Asian families (Katbamna *et al.* 2000, Spruyt 1999). In contrast, an interesting pattern was reported by this study whereby some older women reported that they made end of life care decisions for their husbands. Several possible explanations were given by the participants for such reconstructions. Some reported that their children felt that their mother would know more about their preferences of their dying fathers, as they spend more time with them, particularly if the children lived far away. Alternatively, a few reported a perception that wife, as elder, is more aware of traditional cultural and religious practices relating to end of life than UK-born offspring. A further reason may be that women tend to outlive men. It is thus possible to argue that spousal reciprocity may overrule the traditional hierarchy of decision making which is believed to determine preferences for their dying spouses.

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#### **7.6.4 Health care professionals in end of life discussions**

In this study, discussions with health professionals were sometimes perceived as being unproductive, raising unrealistic expectations of managing end of life care, and potentially leading to family conflict. Existing research shows that people from ethnic minorities often mistrust the health care system and its related policies which may underpin health disparities among ethnic minorities (Ackroyd 2003, Blakemore 2000, Brown *et al.* 2007, Campbell & McLean 2002, Elkan *et al.* 2007, Jones 2005, Merrell *et al.* 2006, Randhawa & Owens 2004, Vydellingum 2000, Worth *et al.* 2009). However, in this study, participants reported that acceptance of healthcare professionals, was conditional on having a trust in their medical knowledge and in these circumstances the involvement of health professionals in related discussions was valued. This is probably because when there is no extended family, elders are compelled to revise their perception of family as decision makers, which prompt them to entrust health professionals with such decisions. Fukuda-Parr (2004) supported this reconstruction, and pointed out that culture is a fluid process rather than a solid set of values, beliefs and practices, which is ‘constantly recreated as people question, adapt and redefine their values and practices to changing realities and exchanges of ideas’(p. 4).

Previous studies have highlighted the importance of trust and respect in patient-physician relations to achieve their goals in better end of life care (Cort 2004, Heyland *et al.* 2006, Lapine *et al.* 2001). Similarly, in this study, although many participants

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expressed trust in doctors, they expected that doctors and hospitals have a role in saving their lives rather than in discussing death and dying. Similar findings were observed among other immigrants to the UK. Chinese older people living in the UK expected doctors to discuss only prognostic and diagnostic information (Seymour *et al.* 2007), and not any end of life decisions. Similarly, a study in Arab Muslim countries found that the relationship between patient and doctor is one of traditional paternalism, based on principles of goodness and kindness, whereby older people do not expect doctors to discuss and decide about death and dying (da Costa et al., 2002, p. 117).

Participants views on end of life perhaps were influenced by ‘some pragmatic and realistic impact of social change’ (Seymour *et al.* 2007) and also the impact of acculturation in end of life care decision making (DeSanto-Madeya *et al.* 2009, Kwak & Haley 2005). For example, many participants reported that their family circumstances often dominate any end of life discussions. In fact, a few other participants reported that they would prefer to take their own decisions for their end of life situations based on the healthcare professional’s suggestions in order to avoid the family and themselves suffering by taking any other decisions.

## **7.7 Summary**

This discussion chapter has considered the theory of continuity and reconstruction within the context of the wider literature. Consideration has also been given to how issues around English as a second language (both for the interviewer and interviewees),

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along with gender, age and ethnic identity influenced the conduct of the research. These were considered as both methodological limitations and strengths.

This chapter explored this study's participants' attitudes with regard to dying at home in the context of the wider literature. While shedding light on the maintenance of traditional values relating to family care giving during last days of life among participants, it has been shown that people often reconstructed and reproduced those values in a new way based on their current social situation of living in the East London. Finally, respondents' attitudes towards end of life discussions and related decision making were discussed. It has been suggested that although participants often seek to maintain the continuity of some cultural beliefs and practices, such as avoidance of any discussions related to death and dying and relying on a traditional hierarchical model of decision making, these are adapted according to their family and social circumstances.

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## CHAPTER 8

# Conclusion

This final chapter reflects on the overall study. First it reviews the progress of the study, and then it evaluates the study based on criteria established for judging constructive grounded theory research (Charmaz 2006 ). It then examines the original contributions of this study to existing knowledge, as well as highlighting specific implications for clinical practitioners and policy makers. Finally, recommendations for future research are made before drawing some final conclusions.

### 8.1 Review of the study

This thesis reports a study that was conducted to explore end of life issues among older South Asians living in East London. The researcher is from the same ethnic milieu as the participants, with multilingual skills that helped to access these ‘hard to reach people’, and was thus able to explore sensitive topics. Five focus groups and 29 individual interviews were conducted in four South Asian languages and in English. Participants were recruited with the support of 11 local community organisations in East London. Multilingual data were collected and transcribed into English before being qualitatively analysed with use of N-Vivo software. Using a grounded theory approach,

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the theoretical framework of ‘continuity and reconstruction’ was developed. This framework captures the three categories of ‘home’; ‘family’ and ‘trust’ at end of life which emerged from the data analysis. The validity of the findings is clearly conditional on the various methodological strengths and limitations of this study, which include matters associated with gender, recruitment issues and the languages of the interviews.

Findings provide some new insights into the perspectives on death and dying among older South Asians living in East London. The category ‘home’ explores accounts of home and homeland at last days of life. End of life care giving experiences informed the category ‘family’ and explains how family care giving at end of life falls primarily to older spouses when adult children (who traditionally have the responsibility) live away; the latter are often reported to be generally supportive, however only to provide care during the last days or hours of life. The final category of ‘trust’ explores both attitudes and experiences of participants regarding end of life discussions and decision making.

## **8.2 Evaluation of the study**

Charmaz (2006 ) recommends four criteria for evaluating the values of grounded theory research and products: credibility, originality, resonances and usefulness (see Box 3)

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**Box 3 : Criteria for evaluating grounded theory studies (Charmaz 2006)**

Criteria	Questions
Credibility	<ul style="list-style-type: none"><li>-Have you reached intimate familiarity with the setting and topic?</li><li>-Do your data sufficiently support your claims?</li><li>-Have you made systematic comparisons between categories?</li><li>-Is there a strong logical argument linking data, argument and analysis?</li></ul>
Originality	<ul style="list-style-type: none"><li>-Are your categories fresh?</li><li>-Do you offer new insights?</li><li>-What is the social and theoretical significance of your work?</li><li>-How does it challenge current ideas and concepts?</li></ul>
Resonance	<ul style="list-style-type: none"><li>-Do the categories portray the fullness of the studied experience?</li><li>-Do the findings make sense to those people central to the phenomenon?</li><li>-Do the findings offer those people deeper insights about their lives and worlds?</li></ul>
Usefulness	<ul style="list-style-type: none"><li>-How can your analysis be applied in everyday settings?</li><li>-Does it suggest any generic processes?</li><li>-Can the analysis spark further research?</li><li>-How does it contribute to knowledge?</li></ul>

### 8.2.1 Credibility

For credibility, the truth value of any study, Charmaz (2006 ) recommends that the researcher needs to be ‘immersed’ within the study setting and topic. To achieve such intimate familiarity in this study, as well seeking to draw on the relevance of my own background and experience to understand the phenomena of interest (see above), I actively involved the local community groups in the planning and recruiting for the study. Data were collected over eight months in East London. Such prolonged contact with my research setting led me to engage with the participants over time, which helped



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to develop rapport and understand the context in where they lived (Ingleton 2000). This also helped to interpret and shape data analysis.

To strengthen the accuracy of ‘inner accounts’ of grounded theory (Chiovitti & Piran 2003), the language of the participants, such as transcriptions from the interviews and focus groups, was used alongside the voice of the researcher to construct the initial codes. Carpenter (1999) argues that the credibility of constructed theory is dependent on focusing the exact meanings of the phenomena from the participants’ perspective. Indeed, Charmaz (2006, p. 47) recommends using both researchers’ and participants’ words as codes that allow the researcher ‘to stick closely to the data’.

Furthermore, this research has followed a rigorous, detailed and thorough process. Specific themes were constructed and labelled with supportive quotes from participants. Logical argument and visual presentation of tables have been used to connect the subcategories and categories that illustrate the relationships and how the important concepts such as categories are defined. Figure 3, Tables 4,6,7,8 and box 2 describe information related to visual presentation of how coding procedures, and the formation of subcategories and categories show logical links between the gathered data and analysis, adding further transparency to the research process.

Well-defined proposed categories in this research are supported by using a wide range of empirical observations. These include field notes, codes, participants’ quotes, personal experience of the researcher, reference notes about living contexts and demographic data (Ingleton *et al.* 2009). Charmaz (2006, p. 182) suggests that using such a wide range of

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empirical observations may provide enough evidence for the claims of the researcher and to enable the reader to form an independent assessment. However findings of this study are limited to the extent it originated only from the reported views of the participants rather than from the direct observation of those experiences. Nevertheless, in relation to data sufficiency, my sample included a diverse array of South Asian communities, in terms of language, religion, culture and other demographic factors including age, gender and various living contexts including asylum seekers (see table 2 in chapter 3).

### **8.2.2 Resonance**

A diversity of categories and related subcategories that are presented and explored in the findings demonstrates that a range and breadth of understanding of the phenomenon under investigation. Findings are supported by both practical and theoretical explanations for any behaviours and experiences that were reported by the participants. Such presentation as outlined in the findings helped to provide some insights about their lives and worlds of those people. On the other hand, this also helped me to get underneath some issues that I myself might have taken for granted, meanings which I outlined in the findings with explanations. For example, it was possible to differentiate between gender roles, and provide theoretical explanations for them in family care giving, showing that while men in the study often described their caring experience as

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that of coordinator, women explained their experience as attending the personal needs of their dying relatives.

The findings have their own limitations in terms of their resonance; for example, some participants had difficulties in providing full descriptions of their experience, since they might have perceived that such disclosure to me may affect their family prestige, or the prestige of their particular South Asian culture. In particular, they did not want to blame their children for any difficulties they encountered. Furthermore, being a novice qualitative researcher, my style of questioning also sometimes obscured the fullness of the experience that I intended to explore with the participants. In particular, I often felt it was inappropriate to talk with elders of my own ethnicity about sensitive topics and, on reflection, can see that I might have avoided some exploratory questions that may have explored their experiences more fully.

In addition, just as my cultural role as a younger person induced respect for them (and inhibited me to use more exploring or direct questioning), they as elders perhaps wanted to demonstrate their intention to protect cultural values, (may have felt a duty to be protectors of tradition and moral values), and thus projected this role in their expressed views. My interpretation of findings might also be obscured by the fact that, as a recent South Asian immigrant who has particular views and expectations about end of life care issues, I would inspire certain reactions from the first-generation immigrant study participants. In other words, such expectations may also have influenced, directly and indirectly, the contents of the interviews, structures of the questions, and in fact the selection of quotes used to represent general participants' views; this may have biased

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my data collection and analysis process. The claims made by this study are therefore somewhat tentative in nature, and need to be endorsed by further research in this field. Furthermore, the findings of the study are limited in terms of their relevance to the wider views and experiences of the South Asian community in the UK, as the participants came from one deprived inner city population in London (Brown *et al.* 2007)

An additional point to note is the target population; this thesis sets out to analyse the accounts of South Asians immigrants living in East London, most of whom came to Britain as first generation immigrants from the 1950s to 1970s. However, populations are dynamic phenomena, and in future the demographic profile of South Asians will change; there will still be first-generation immigrants, but one would expect to see that as time goes on, the population of the South Asian ethnic minority will increasingly be comprised of second- and third-generation immigrants – indeed, not ‘immigrants’ at all, but elderly people inheriting the same religions, customs and cultures of the first generation South Asians who form the participants in this study. This is one of the deeper limitations to this study in terms of relevance for long-term provision of end of life care; it takes as its basis a snapshot of a particular population cohort which will change significantly in the coming decades.

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### 8.2.3 Originality

Overall, the original contribution of this thesis is its construction of the theory of ‘continuity and reconstruction’ at the end of life. This discovered theory sheds new insights into understanding home, homeland and family at end of life among the older South Asians living in East London. The significance of this theory was already explored in chapter seven (discussion), which placed its worthiness in the context of existing literature. In this section, I explain the originality in terms of the extent to which the original aims and objectives were addressed. The findings of chapters four, five and six respectively addressed the specific aims of the study, which were:

- To explore older South Asians’ attitudes and preferences relating to death and dying.
- To examine older South Asians’ experiences of providing end of life care.
- To explore older South Asians’ knowledge, attitudes and preferences related to end of life discussions and decisions.

The findings in chapter four suggest that people perceived home as a haven during death and dying, as it provides a safer environment to maintain the continuity of their religious practices during end of life. Indeed, findings on returning home provided insights into diasporic sentiments that showed an increasing importance of culture at the end of life, wherein people viewed place of death as less important than their cultural practices.

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In chapter five, the findings about family shed some light on how older spouses try to fulfil, and thereby continue to hold their deeply held expectations and social values relating to the value of caring within marriage as a duty to care for one's spouse. On the other hand, this theory of continuity and reconstruction was also demonstrated by their adult children, who intended to continue to care for their older relatives according to their social and cultural values in accordance with their sense of filial responsibility. Furthermore, community members in those social networks often held onto social values of offering social support for the dying person and their family.

Chapter six showed how, as in many cultures, participants reported that they 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. On the other hand, in light of understanding the changes in family and social circumstances, values around avoidance and hierarchy of decision making were reported to be of diminishing practicability.

### **8.2.4 Usefulness**

The criterion for usefulness is examined in terms of how this study's categories offered 'interpretations that people can use in their everyday worlds' (Charmaz 2006 ). In the following paragraphs, such everyday use is discussed in terms of implications for policy, practice and future research. In practice, some community leaders requested a copy of

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study results, as they wanted to understand their community preferences and positions on this particular topic. I assured them that this will be sent to them after the formal completion of my study. Furthermore, findings could offer them some insights about living conditions, existing social networks, and how death and dying is viewed and managed in East London.

#### **8.2.4.1 Implications for practice**

Other studies have already explored the issues for the health professionals who are responsible for caring for older South Asian ethnic minorities in hospital and elsewhere (Gunaratnam 1997, Gunaratnam 2001, Vydelingum 2000, Worth *et al.* 2009). A narrative literature review conducted by Rigby *et al.* (2010) evidenced that the physical environment makes an important contribution to enhancing the quality of life of older people with life-limiting diseases. This study's implications for practice lie in their contribution for insights into issues related to caring for older South Asians at the end of their lives. Box 4 presents some generic recommendations from the findings from chapter four about the better space for death and dying.

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**Box 4 : What makes the better environment for a comfortable death and dying?**

1. Keep the room clean and neat.
2. Keep the environmental noise level low.
3. No external stimuli, like watching sports and loud music from the television.
4. Provide privacy while family and friends are around.
5. Allow spacious room for their family and friends to visit.
6. Allows time for family, so that the dying person may negotiate and perform unresolved family duties.
7. Space and facility for practicing religious practices such as *bajans* and *puja*.
8. Space for religious leaders to visit and perform rituals.
9. Being surrounded by holy books and personal possessions.
10. Facilities for their family to provide personal care.

Furthermore, while the majority of deaths still occur at the hospital (Gatrell *et al.* 2003, ONS 2009) , the chapter on family offered various recommendations for caring for older South Asians at hospitals during end of their lives. The following box 5 depicts recommendations on some best practices towards caring at hospital:



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**Box 5: Caring at hospital: some best practices**

1. Offer one-to-one nursing support at high observation level during the last hours.
2. Personal cleanliness is paramount element to maintain bodily purity.
3. Allow family to give emotional support in their own way such as holding hands.
4. Provide adequate medication support especially effective pain management.
5. Assess and meet nutritional needs as preferred by the family; for example, feeding until last hours is considered to give a comfortable death.
6. Create trusting relationship with the dying person and family.
7. Offer flexible and lengthy visiting hours in a spacious area.
8. Offer professional support, including adequate attention by the doctors.
9. Allow them to observe religious/ethnic mourning rites and customs; for example, Hindus prefer to cry out loudly and Muslims prefer to mourn silently.
10. Allow family to meet all personal needs and provide personal care for the dying person.
11. Provide adequate family time to practice their family obligations.

In addition, chapter six on trust offered some practical implications for holding end of life discussions with older South Asians (Box 6).

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### **Box 6:How to initiate any end of life discussions and decision making**

#### **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 ,i.e, 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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#### 8.2.4.2 Implications for policy

The *End of Life Care Strategy* (DH 2008) aims to deliver the highest possible quality of care for everyone approaching their end of life, ‘irrespective of age, gender, ethnicity and religious beliefs’. One of the aims in the strategy to achieve quality of end of life is expressed as facilitating dying at home, which many people prefer (DH 2010). This study’s findings suggest that despite the existence of diverse attitudes towards death and dying similar to many other people, many older South Asians want to die at home, as they perceive it provides various physical, psycho-social benefits for the family and dying individual. However, this study suggests that lack of knowledge about existing end of life care services remained the main barrier to supporting the preference to die at home. Several strands of national end of life care policy for example work of Dying Matters Collation (DH 2009) focus on raising awareness about death and dying at the society level. However, this research suggests a need for identifying effective means of improving knowledge about end of life care services among this population. Working collaboratively with local faith- and linguistic-based community organisations could go a long way to addressing this deficiency. For example, the study partner of this thesis, St Joseph’s Hospice, East London, provides opportunities for ethnic minority volunteer staff of Social Action for Health, a local community development organisation, to spend time at the Hospice to understand its work; these volunteers are then expected to work with religious centres, local community centres, social clubs and schools to talk about the work of the hospice (DH 2008).

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This study found that among older South Asians living in London, home is usually perceived as a haven, as it provides a safer environment to maintain the continuity of religious practices during end of life. The National Council for Palliative Care report (2010) highlights that there remain unmet spiritual needs at end of life among any population in the UK. This study shows how spiritual issues are bound up with issues of place of care and death, reinforcing the need to identify the spiritual needs of the people at end of life and their family members; one of the quality markers in achieving quality of end of life care (Department of Health 2008).

The importance of supporting family carers is widely accepted as one of the prerequisites to achieve quality of end of life care (DH 2008). However, this study found that despite participants' values concerning family care giving at end of life, difficulties around caring at home were often magnified by their communication problems, and family circumstances led many of them to report that dying in hospital was a more practical choice. A Kings' Fund report (2010) demonstrates that several health professionals encounter difficulties in predicting which patients are approaching end of life. A Race Equality Foundation report (2007) criticises current policies that have no national standards for training health professionals to improve their trans-cultural palliative knowledge. Therefore, this study suggests that identifying prospective family carers and planning ahead for support needs of their family is crucial to address this gap in practice. Health professionals who work in community settings, for example GPs, district nurses and community palliative nursing teams should be trained to be proactive in such identification and planning for the provision of supportive care for the family care givers.

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#### **8.2.4.3 Recommendations for future research**

This study found some new insights into the meanings of home, homeland and family during end of life. Consistent with wider literature on family carer in palliative care (Andreassen *et al.* 2005, Aoun *et al.* 2005, Barnes *et al.* 2006, Grande *et al.* 2009, Hudson *et al.* 2010, Spence *et al.* 2008), this study recognised that family support is essential for making home a place for death and dying. However, it has not addressed some issues within generational attitudes towards end of life among these South Asian communities. Therefore, future research should explore the perspectives of second-generation adult children in those care decisions. This would be useful to compare and contrast and validate the findings of this research.

In addition, although this study provides understanding about issues around family care giving, further research is needed to explore the family care giving needs at end of life among this population. Furthermore, as this study only gathered reports of care giving at end of life, further research is needed to observe family care giving in ‘action’ among these ethnic minorities. Additionally, further research focussed on more specific ethnic groups of South Asians may also give some more in-depth insights into some of the issues revealed by this research. This is because I found that approaching South Asians in general, particularly while researching sensitive topics, gained a partial insight of what death and dying meant for some ethnic groups in particular.

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### **8.3 And finally.....**

The research reported in this thesis explores the theory of ‘continuity and reconstruction’, particularly at end of life, among older South Asians living as emigrants in a Western European country. Box 7 highlights the concluding remarks on the contribution of this thesis to the existing knowledge.

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### **Box 7: Contribution of this thesis**

#### **What is already known**

1. Within ethnic minorities, some groups often experience difficulties to access and use existing palliative care services.
2. Often professionals have difficulty in approaching and providing appropriate care at end of life.
3. Family care giving needs at end of life care for minority groups are poorly understood.

#### **What this study adds**

1. Limited knowledge and lack of experience with existing end of life care services remains a challenge for achieving better end of life among older South Asians living in London.
2. Family care giving at home is often viewed by older South Asians as an opportunity to maintain continuity of socio-cultural values attached to death and dying, particularly where spouses often serve as the primary care givers, and children who live away join in family care giving at the last days/hours of dying relatives.
3. Although people have smaller social networks, community members often demonstrated their social responsibility to support dying people and their families.
4. Returning to homeland for death and dying is often an unachievable desire, as immediate family members are settled in the emigrant country.
5. End of life discussion within families is often regarded as culturally inappropriate; however discussions with health professionals, trusted for their medical expertise, are sometimes favoured.
6. End of life care decisions negotiated by family members are dominated by traditional hierarchies favouring males. However, older people themselves prefer their family to make decisions for them, and de-prioritise their own preferences.

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To conclude, the theory of continuity and reconstruction presented in this thesis offers some insights into end of life perspectives among older South Asians living in East London. Older South Asians living in the East London seek to maintain the continuity of their value of providing family care during end of life by constantly adhering to the principles of trust between their family members. To do this, they actively engage in promoting the values of family obligation and social and community responsibility to support people at end of their lives. However, many pragmatically reconstruct such values in order to balance, counteract or adapt to existing socio-environmental constraints encountered within the UK.



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## **Appendix 1 Participant Information Sheet**



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## **Appendix 2 Ethical Approval letters**

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## **Appendix 3 Participant demographic profile**

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## **Appendix 4 Study Invitation card**



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## **Appendix 5 Informed consent for focus groups**

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## **Appendix 6 Informed consent form for individual interviews**

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## **Appendix 7 Focus group aide memoire**

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## **Appendix 8 Initial Interview Topic guide**

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## **Appendix 9 Topic guide for further interviews and focus groups**

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**Appendix 10 Example of the process undertaken to develop the themes, sub-categories and categories from codes produced from N-Vivo for the first core category ‘Home’.**

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**Appendix 11 A marked up interview transcript for Mrs Dolly Islam**

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## **Appendix 12 Study update letter to the community organisations**