

## Health Education Kent Surrey and Sussex Vision

*'Through creative partnerships we shape and develop a workforce that impacts positively on health and wellbeing for all.'*

### End of Life Practices and Palliative Care among Black and Minority Ethnic Groups (BME)



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November 2015

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## Executive Summary

The End of Life Practices and Palliative Care among Black and Minority Ethnic Groups (BME) project was a one-year feasibility study on health needs BME groups particularly regarding palliative care and end of life needs. The project took place from June 2014 to June 2015 in the South East of England. In terms of research outputs the project sought to: i) document some of the declared palliative health needs of four of the major BME groups in Kent (Medway, Gravesend, and Swale); ii) document the end-of-life practices in these BME groups; iii) build the capacity of Kent community services by making them part of a Learning Alliance; iv) Monitor the process of networking and increase the opportunities of working with different stakeholders including the multi-professional team; and v) disseminate, locally and nationally, electronically and by other means, the experience of creating a Learning Alliance (LA) to serve BME populations, especially concerning end-of-life practices.

It was expected that with the accomplishment of the above five outputs, the project will lead to both community health services and services users i) incorporating new working practices regarding palliative care and end of life according to the needs of the four BME communities; ii) generate a network of interest in Swale, Medway and Gravesend in continuing working on palliative care and end of life practices for all BME communities; and iii) inform the development of a multi-professional education pack that can be implemented and evaluated within the Health & Social Care sector within KSS, which is being developed from data and information collected during the project.

Methodologically the project used a qualitative perspective made up of focus groups and a Learning Alliance of stakeholders interested in the theme. The groups were: Africans, South Asians (one mix and one Punjabi) and one with Gypsies and Travellers. Most of the participants spoke English. The indicative interview schedule covered the participants' experiences, beliefs and practices surrounding the end of life and end of life care; participants' understandings of the concepts of end of life and palliative care; experiences of accessing and using palliative care in formal healthcare settings and identifying unmet needs and obstacles to effective palliative care and end of life. The interviews also considered how palliative care could be organised and provided to better suit the needs of the participants. Despite the help of BME organisations it was not easy to find a sample and many people who said they would attend failed to show up. In the particular case of the LA called Learning Alliance on Palliative Care and End of Life (LAPECEL) three meetings were held during the one-year project. The focus groups sought to capture participant's understandings of end of life and palliative care; experiences of accessing and using palliative services and highlighting unmet needs and barriers to effective provision for these groups. Certain themes emerged strongly depending on the group while other themes were crosscutting and were raised by all groups.

For the African migrants their own experiences of working in the care sector strongly shaped their beliefs and attitudes towards palliative and end of life care along with experiences of racism at work. Their own perceptions of poor standards of care towards elderly and frail patients made many afraid should they have to enter such care themselves in later years. Family based care is very much the norm and formal palliative care is regarded largely as cold and impersonal. There was a strong preference for being cared for by family members and at

home. Cultural beliefs and taboos surrounding death and dying emerged as strong themes surrounding palliative and end of life care. There was a belief that talking about death is to evoke death making people reluctant to discuss the topic. The wish to return “home” to die in one’s country of birth has a significant bearing on first generation immigrant’s practices concerning the end of life and instead of encouraging uptake of formal palliative care it was noted by participants that they would prefer support to enable home and family based care.

Among South Asians communication in general was an important theme and in particular, the roles of insiders/outsideers. In certain contexts participants noted they would prefer to communicate with health staff via someone from their own community and in other situations someone from outside their community would be easier to communicate with indicating a need for sensitivity and a case by case approach. Stigma surrounding illness and death was a major theme in these groups which means people can be reluctant to disclose illness to family and friends. This stigma, combined with a low level of knowledge about palliative care means that use of such services tends to be low. First generation immigrants also expressed a wish to either die or be buried in their country of birth, which is important when considering advance care planning. Also the idea of making a will is seen to be ‘calling’ death making many hesitant to make advance plans and arrangements concerning their own deaths.

The main themes in the Gypsy/Traveller group were i) their experiences of discrimination in society generally and in using health care services more specifically, ii) a reluctance to disclose their ethnicity iii) conflicts around customs and end of life care in formal healthcare settings and communication problems with staff. Previous experiences of prejudice and discrimination in healthcare settings meant many approached these situations with a ‘defensively hostile’; attitude which, when combined with a lack of understanding and inflexibility by some healthcare staff meant that this could become a self-fulfilling prophecy. Further, the customs surrounding death and dying such as visits from large numbers of relatives when someone is entering the end of life and covering mirrors and lighting fires following a death is not easy to accommodate in palliative care settings. A need for more sensitivity regarding communication was apparent and the use of cultural brokers or mediators was suggested.

In the light of the findings the main recommendations are:

- Further training in cultural proficiency for health care professionals.
- The need for greater sensitivity around communication.
- Explore in more depth the role of stigma and how this shapes decisions during terminal illness and the end of life.
- Targeted public health campaigns aimed at the general public and specific BME groups.

## Introduction

This one-year feasibility research on health needs in Black Minority and Ethnic groups (BME) particularly regarding palliative care and end of life needs of these groups took place from June 2014 to June 2015 in the South East of England. In terms of research outputs the project sought to:

- Document some of the declared palliative health needs of four of the major BME groups in Kent (Medway, Gravesend, and Swale).
- Document in particular the end-of-life practices as experienced in these BME groups.
- Build the capacity of Kent community services by making them part of a Learning Alliance
- Monitor the process of networking and increase the opportunities of working with different stakeholders including the multi-professional team.
- Disseminate, locally and nationally, electronically and by other means, the experience of creating a Learning Alliance (LA) to serve BME populations, especially concerning end-of-life practices.

It was expected that with the accomplishment of the above five outputs, the project will lead to both community health services and services users i) incorporating new working practices regarding palliative care and end of life according to the needs of the four BME communities; ii) generate a network of interest in Swale, Medway and Gravesend in continuing working on palliative care and end of life practices for all BME communities; and iii) inform the development of a multi-professional education pack that can be implemented and evaluated within the Health & Social Care sector within KSS, which is being developed from data and information collected during the project.

Methodologically the project used elements of an LA as its main approach and took into account the ageing and demographic trends related to the BME communities in the UK and more specifically in mid and north Kent. The use of a Learning Alliance (LA) approach has become a significant and well recognised practice (C. Moreno-Leguizamon et al 2015) in as much as it addresses institutional constraints and enhances institutional learning at the same time as improving delivery of services. In a very general way, a LA is a series of connected multi-stakeholder platforms at different institutional levels (national, local), involved in knowledge innovation and its scaling-up (S. Smits et al., 2007).

In the particular case of this project a LA called Learning Alliance on Palliative Care and End of Life (LAPECEL) was formed and three meetings were held during the one-year project. These were implemented with the aim of bringing a group of stakeholders together as well as to disseminate as early as possible the preliminary findings. Key stakeholders who participated and collaborated in the LA meetings were Diversity House from Sittingbourne, The Medway Ethnic Minority Forum, Ellenor Lions Hospices and Medway Council. Other collaborations developed by the project were Public Health England and the Gypsy support group One Voice 4 Travellers. Some of the LAPCEL members are currently working together in identifying further possibilities in terms of research and collaboration.

Regarding the demographics as the immediate context of the project it was clear that the composition is not only changing rapidly but is also ageing. It is predicted that BME groups by 2026 will account for 27% of the population, with 1.3 million aged 65 or over. Similarly, it is foreseen that, by 2026, there will be significant differences between the different BME groups. For example, 21% of white British will be aged 65 or over compared to 36% of Irish, 12% of Pakistanis, 6.5% of Black Africans and 6% of Gypsies. This will take place within a general context in which the UK's population of 10 million over-65s is projected to rise by 5.5 million in 20 years, reaching 19 million by 2050 (N. Lievesley, 2010). Between 2007 and 2017 the population of older people (50+) in Kent is projected to increase by over 16% compared to an overall rise in the population of just over 13% in the same period (KCC, 2008)<sup>1</sup>. The ethnic minority population of Kent increased by 103% between 2001 and 2011 and there are now over 100,000 people from minority ethnic groups living in Kent with the highest populations in North East Kent: Dartford, Gravesham and Medway. The largest group are Asian/ Asian British; followed by Mixed/ Multiple Ethnicity and then Black African/Caribbean groups (KCC, 2011)<sup>2</sup>. Kent is also home to the largest Gypsy/Traveller population in the country with a minimum of 12,000 residing in the county (ITMB, 2013)<sup>3</sup>. The project findings to be discussed below in many instances follow the trends mentioned here in terms of demographics and age.

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<sup>1</sup> KCC (2008) *The Older People of Kent*

<sup>2</sup> KCC (2011) *Ethnicity in Kent and Medway*

<sup>3</sup> The Irish Traveller Movement in Britain (2013) *Gypsy and Traveller population in England and the 2011 census*

In fact the rationale for implementing the project was based on the fact that the End-of-Life Care Strategy (2008) suggests that the health and social care needs of the BME groups need to be taken care of against the background of changes in epidemiological and demographic trends. Similarly, it was assumed that forming an LA around these themes could help to successfully demonstrate innovative models linking research, capacity-building and networking among community health and social care providers and community and voluntary sector organisations. Thus in order to provide further details about the project the remainder of this report is organised according to how the project was conducted, the findings of the review of the literature, the main data collection activities conducted and the main overall findings of the project and finally what are the main conclusions and recommendations.

## The project

During the twelve months of the project the following were the main research activities conducted:

<p>March, April, May 2014</p>	<p>Ethical approval for the project via the university's ethics committee (UREC) was obtained.</p> <p>The first Learning Alliance meeting was convened by Dr Smith and Dr Moreno and attended by representatives of Medway Ethnic Minority Forum, Diversity House and health care professionals.</p> <p>A literature review outlining the main trends and themes in research into end of life practices and palliative care was undertaken. Summary of the main findings is described below.</p>
<p>June, July, August 2014</p>	<p>Advertising and recruiting of the main researcher for the project was completed and the research fellow hired.</p> <p>The questionnaire was developed in collaboration with members of the Learning Alliance and other colleagues.</p> <p>Relevant partners for the Learning Alliance in Kent were identified and contacted and a research network is being established. The name of the LA is Learning Alliance on Palliative Care and End of Life (LAPCEL) and a website created.</p> <p>Pilot focus groups was undertaken at Diversity House, Sittingbourne in August 2014</p>

<p>September, October November, December 2014</p>	<p>Extended the exploratory literature review and systematically organised literature according to themes, locality, focus of study.</p> <p>Implemented the proposed learning alliance in the form of LAPCEL (Learning Alliance Palliative Care and End of Life), created an online environment to facilitate LAPCEL activities, disseminate material and encourage dialogue.</p> <p>Additional relevant stakeholders (hospices palliative care health professionals, community groups) have been recruited for LAPCEL.</p> <p>The second in-person meeting Learning Alliance meeting was held with representation from health professionals, hospices, community groups and researchers in which the study, preliminary results and future research prospects were presented and discussed.</p> <p>Identified local stakeholder networks and approached key gatekeepers in order to gain access to potential participants</p> <p>Extended stakeholder network to include local palliative care providers in Medway, such as Dr.Siva Subramaniam, Consultant in Palliative Medicine and Margaret Mary Cowan Advanced Nurse Practitioner at EllenorLions Hospices, Jenny Churcher at Medway Older People’s Partnership and Tania Blackmore Senior Lecturer in Adult Nursing at the University of Greenwich.</p> <p>Held an exploratory meeting with stakeholders to assess EllenorLions Hospice’s research needs and potential for collaboration and the building of an expert network</p> <p>Held three focus group meetings with different stakeholder groups recruited from BME communities in the study area (ca. 25 participants in total)</p> <p>Began systematic analysis of focus group/interview data</p> <p>Explored options for publication of results in a range of publications aimed at both expert audiences from the health care sector and academic audiences in the area of BME groups and health care.</p>
<p>January, February and March 2015</p>	<p>Data collection via participant observation in collaboration with EllenorLions hospice (approval has been obtained)</p>



	<p>Capacity building through the LAPCEL alliance in collaboration with local stakeholders from palliative care provision (hospices)</p> <p>Developing further related projects with EllenorLions hospice and applying for funds to extend the current work. A proposal was submitted to Marie Curie Charity.</p> <p>Data analysis of all the focus groups.</p> <p>Planning and organisation for the end-of-project LA last meeting.</p>
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## Literature Review

The first study of BME group's use of palliative care was done by Rees in 1986 and found that hospice use among these populations is 4 times lower than for Whites though the issue received little attention for another decade. A study by Fountain (1999) came to the similar conclusions to Rees and found that in Derby only 1.5% of referrals to palliative care services were made to members of BME groups rising to 3.5% after controlling for age. Studies have found that most BME members express a preference for home care though they are still more likely to die in hospital than White British patients and significantly more so in Pakistani, Bangladeshi, Indian, Black African, Black Caribbean and Chinese patients even after adjusting for age of death, deprivation and time between diagnosis and death (Coupland et al, 2011). The literature surrounding disparities in access and use of palliative care services emphasise a combination of socioeconomic, cultural and individual level factors. In their review of the latest evidence Calanzani et al. (2013, p. 37) note that key themes were

“inadequate monitoring, coding of ethnicity, lack of adequate translation services, structural inequities in society and the consequences (such as cultural mistrust) and assumptions/stereotypes based on culture and ethnicity.”

They also point out the need to differentiate between disparities, inequities and unmet needs as these are often undifferentiated in the literature.

Evans et al (2011) appraisal of the literature on end-of-life care for ethnic minorities notes that socioeconomic and geographic inequalities are a recurring theme and notes an inverse relation between areas of poverty and provision of palliative services. Ethnic minorities therefore face

a 'dual disadvantage' being over-represented in areas of deprivation and even within those areas have lower levels of service use than deprived white British residents (Evans, et al 2011). Other accounts have examined the structure and organisation of palliative care service and the experiences of health care practitioners in caring for different cultural groups at the end of life. These accounts identify a lack of knowledge surrounding different groups' customs and practices surrounding the end of life; a belief that BME groups prefer family based care and communication difficulties which can all contribute to a lower level of referrals (Ahmed et al, 2004; Badger et al, 2009).

The barriers to equal access for BME groups are most commonly identified as:

- A shortage of referrals for patients from BME groups or late referral from the patient's doctor.
- Lack of knowledge and awareness of palliative care in BME communities as many immigrants may have had little or no prior exposure to palliative care services and be unaware of available palliative services in their new countries (Koffman, 2014).
- Communication problems between palliative service providers and users. Problems continue after services have been accessed with poor communication between patients and staff a common theme in the literature (Evans et al, 2011).
- A lack of trust between BME communities and ELC service providers. Previous racial inequities and medical mistreatment were often cited by Black Americans as barriers to hospice care (Duffy, 2006).
- A lack of accessible information regarding the nature of illnesses and likely prognoses (Worth et al 2009).

Moreover a diversity of cultural beliefs and practices surrounding death and dying means that the potential for conflict when considering end of life care for patients from minority ethnic groups in a Western medical system 'dominated by the principles of patient autonomy, beneficence, non-maleficence and avoiding futile care' (Brown, 2014, p.3). Culturally oriented explanations tend to emphasise

- religion that may affect compliance or access to services and the influence of patients' religious beliefs on decision making (Laguna, 2012).

- sex, including cultural taboos about consulting with healthcare professionals of a different gender; differential presentation including “somatisation” of symptoms. An important factor, especially among women, is literacy and English language skills (Somerville 1998, Randhawa, 2003).
- “fatalism” or shyness, which may also lead to a reluctance to seek help resulting in late presentation; family dynamics (Szczepura 2005)

Policy recommendations strongly emphasise a need for education and ‘cultural competence’ among practitioners, in order to address the specific cultural needs of BME populations but there are few concrete recommendations about how to achieve this and there is a danger that such an approach becomes a ‘tick box’ exercise. Gunaratnam (1997) suggests that ‘cultural competence’ among carers should not just be understood as a cognitive process but one that involves empathy and embodied relating, and therefore in a way appeals to a ‘shared humanity’ between carer and patient rather than the emphasis on difference. Indeed research suggests that similarities in regards to understandings and experiences of palliative care between different minority groups and the majority outweigh the differences (Bosna et al, 2010). Likewise Diver, Molassiotis and Weeks (2003) found that BME palliative care patients tended to express basic human needs rather than culturally specific ones. Lau and O’Connor (2012) recommend flexible and collaborative models of care that would accommodate people’s preferences to die at home or in a hospice and at which point. Partnerships between different service providers such as home and hospital care can give patient’s access to a wider pool of expertise and specialist services while a strong link between hospital and palliative care can help to reduce some of the barriers discussed previously.

### Data Collection

The first task was gaining ethical approval, which was granted from the University of Greenwich Research Ethics Committee (UREC). Once this was obtained participation information sheets were distributed to the collaborating organisations who were contributing in organising the focus groups. At the time of the focus groups individual consent forms were distributed to focus group members. Some members were reluctant to sign the consent forms and pointed out the contradiction between anonymising the data and requiring their names/signatures for the consent forms.

Second was conducting the focus groups. A pilot focus group was run with African participants to validate the questions and receive feedback from the participants. After the pilot focus group four further focus groups were conducted with between five and 20 participants in each and lasted between one and two hours. The groups were: Africans, South Asians (one mix and one Punjabi) and one with Gypsies and Travellers. Most of the participants spoke English. The indicative interview schedule covered the participants' experiences, beliefs and practices surrounding the end of life and end of life care; participants' understandings of the concepts of end of life and palliative care; experiences of accessing and using palliative care in formal healthcare settings and identifying unmet needs and obstacles to effective palliative care and end of life. The interviews also considered how palliative care could be organised and provided to better suit the needs of the participants. Despite the help of BME organisations it was not easy to find a sample and many people who said they would attend failed to show up.

The third task was to organise and conduct a training session on cultural competence and compassionate care in the context of palliative care, and consultation with health professionals from a hospice in Gravesend. The latter task was conducted to gather the views and experiences of the health team providing palliative services to members of BME groups. The fourth task was the three meetings of the LA with the purpose of disseminating the results from the focus group and receiving validation and feedback from the LA members. Complementing this was the creation of the LAPCEL website hosted by Diversity House and a Google group to disseminate and discuss information.

The next task was transcribing the focus group data verbatim and then coded into themes and categories using NVivo software. The Punjabi focus group was not transcribed verbatim due to poor sound quality.

## Data Analysis

The first stage of analysis emerged from the analysis using NVivo software. Following this the research team individually read through and coded the transcripts thematically and into sub-themes, before comparing the outcome of this process in order to validate emerging categories. Analysis of findings took place throughout the project during the second LA

meeting where findings from the individual focus groups were discussed and examined and during the final LA when cross-cutting themes and topics were analysed and validated.

## Findings

The main findings identified in this feasibility study are organised according to how the data was collected for each group due to particular themes that emerged from each focus group, as well as overlapping issues and themes. Just as there is not one single BME group so there are differences in perceptions, understandings and experiences within different minority groups. However in order to make sense of the findings we have categorised them according to official BME categories. Tables One, Two and Three illustrate the predominant themes for each focus group.

Table 1: African Group

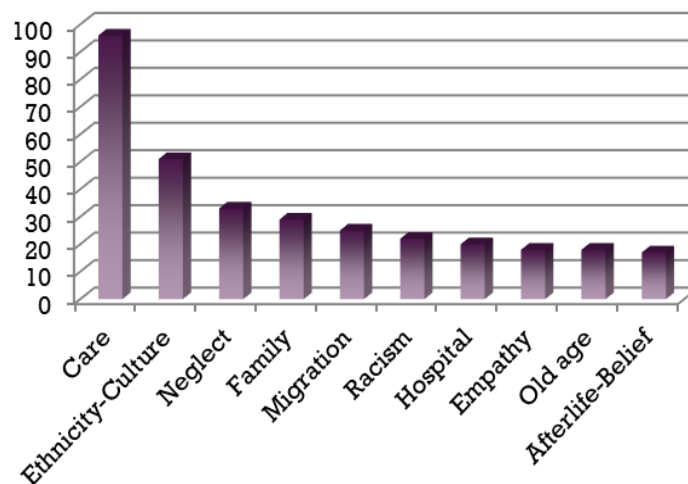


Table 2: South Asian

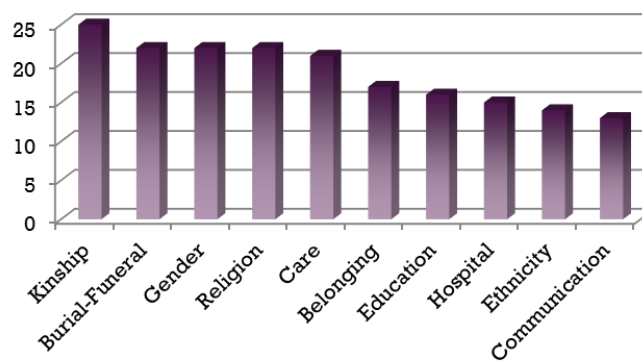
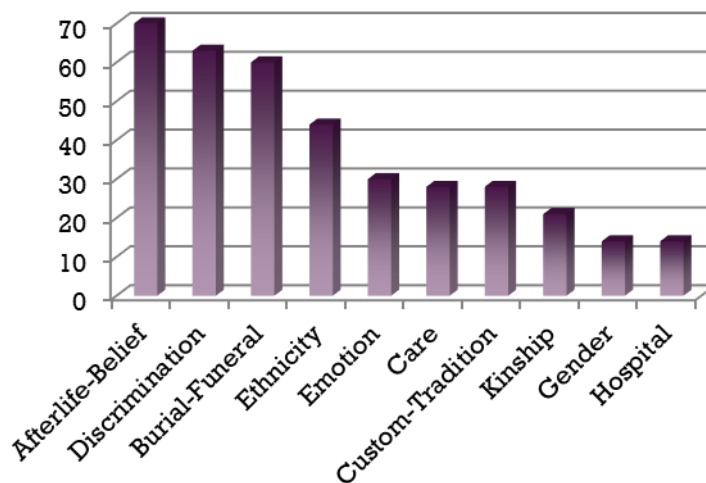


Table 3: Gypsies and Travellers



### *African Group*

The focus group with African migrants was composed mainly of women many of whom were employed as carers and healthcare staff. Their own experiences of working in this sector strongly shaped their beliefs and attitudes towards palliative and end of life care and underpinning those beliefs was mistrust related to experiences of racism.

‘Coming back to palliative care, many of the African or black people that talked in this interview have shared their experience of working in residential homes...’  
Then it begins to boil into their hearts that if we get to that stage (near death) and find ourselves in that palliative system, and so it becomes an impediment to preparing or accepting the fact that you want to go to a palliative care system. You see what I mean?’

There was a perception that in the UK the provision of services is very institutionalised with less emphasis on the role of the family as carers. This means such care is regarded as impersonal and ‘one size fits all. The fact that many participants were employed in the healthcare sector made them aware of the lack of resources and a perceived decline in service quality. The perception regarding the role of the family however needs to be taken with caution as the literature highlights a stigma among many service providers that ethnic minority family members are ‘there’ to provide care.

‘Here I think they would never have that 10 minutes care job to scoop a spoon in your mouth to swallow. They will just leave you. All they know is a question mark, you’ve got dementia, he’s mad, very aggressive...To me it’s annoying.’

Despite working in health services the participants had a clearer understanding of end-of-life care as a term than they did with the term palliative care. There was confusion about which

sites (nursing homes, residential homes, private homes, hospitals and hospices) palliative care services are offered, reflecting a wider uncertainty in the general public and an overall finding of this study.

Cultural beliefs and taboos surrounding death and dying emerged during focus group discussions surrounding palliative and end of life care. There was a belief that talking about death is 'calling' death making people reluctant to discuss the topic. However, this is a universal feature as suggested by Kakar quoting 'Richard Wollheim's distinction, human beings are fated to explore death only from a peripheral and never from a central vision' (p.xiv).

'Regarding the minority groups, like my colleague said, a barrier to prepare a minority people is based on the cultural, like she said, because they don't want to talk about death, and death is part of living, because you have to prepare for where you are going to end last. Well, because of the cultural thing, they don't want to be talking about it. They don't want to invite death.'

A further practice that emerged from the focus group was the sense of belonging and returning of the body to the site of birth at the end of life. For first generation immigrants this wish to die or be buried in their home countries was particularly strong.

'If anything we prefer to either die at home or when we die they will send us back...send them back home, so we have different rights and even tribes wouldn't like people to be buried in another tribe.'

The wish to return "home" to die has a significant bearing on first generation immigrant's practices concerning the end of life. However, as it was not a focus of this project this topic was not at the forefront of this research but is an important topic warranting further investigation.

### *South Asian*

Two focus groups were conducted one with South Asian women and a further mixed (male/female) focus group of Punjabi Sikhs. Communication in general was an important theme and in particular, the roles of insiders/outside. On the one hand there is an assumption that an outsider (healthcare practitioner) would be unfamiliar with the cultural norms and practices surrounding death and dying but would also be easier to talk to due to their social and cultural distance. On the other hand, in some cases there is also a preference for discussing

such issues among kin and close friends without the need for outside intervention by health professionals. This is significant because there is a degree of ambiguity that needs to be judged on an individual basis not on the basis of formal guidelines and procedures (for example ethnic matching). One participant commented that.

“I think there are two sides of that story as well, in terms of I think there are people who would value an outsider coming in, maybe a faraway friend that they certainly have a relationship with, you know, someone like yourself coming in and speaking with them on other aspects that they maybe can’t speak with their family members. But generally what you find is they do confide in family members much more, because the family is linked to them obviously by blood relatives or otherwise, in terms of memories, and they relive the memories in that short period that’s left, and certainly it’s my experience that although I wasn’t like an immediate family member, a distant family member, a member of the community, she valued people coming in and from our community.”

Stigma surrounding illness and death was a major theme in these groups. One participant noted that stigma can accompany almost any disease/illness or condition let alone one that is terminal and stated that there is no clear distinction between contagious and non-contagious diseases, which some participants attributed to a lack of health related knowledge. Fear of stigma meant that some people remain silent concerning disclosing illness to their community. Refusal to acknowledge terminal illness means that demand for palliative care and end of life services is low which is exacerbated by lack of information about available services. Like the African participants, people in this group were unclear or lacked knowledge about the terms ‘palliative care’ or ‘end of life care’. However, some participants were able to recall family members and friends who have died in a hospice or at home. One participant had a sister who had died in a hospice and noted it was ‘like being in heaven’. He pointed out that he would prefer to die in a hospice as he does not want to be a burden on his family by dying at home and this was complemented by a general wish to be surrounded by kin and friends at the time of death.

Similar to the African group, some participants stated that first generation immigrants would return to their place of birth to die or to be buried where possible. This is important when considering advance care planning and end of life services for immigrants and will become an increasingly significant issue in future decades, but in itself is a topic that is under-researched



and warrants further attention. One focus group member encapsulated this theme with the following statement.

“So sometimes people have a very close family member who was sick and they have to try and send him back home or they were in the process of sending him back home so that he can go and die back home, but unfortunately he died before they could, you know, because they wanted him back home, but after he died still they have to try and still send him home. Also the family have to contribute so that we can use it for the fare, for the body to be sent back home”

“It’s not religion, it’s like people feel they are not supposed to be buried outside...homeland

Again the idea of ‘calling’ death was present in this group which was expressed, not in terms of talking about death as in the African group, but in making a will. It was suggested that making a will can be seen as a bad omen and noted that in two Asian media channels, advertisements are bombarding people to make wills. Although people are aware of these adverts, they do not action that.

The Hindu women in the focus group described practical aspects of care: cooking, feeding and washing dying relatives, which largely falls to female family members, as does receiving family members and friends and organizing social life following a death.

‘The men just exclude themselves just take themselves in the periphery, and let the women take charge really. I think the women just take over the emotional side, you know when people come round to visit. So the women will be very much visible.’

However, other elements mentioned by these women like after-death rituals such as bathing the body are performed by men as well as women.

‘To some extent there’s quite clear role definitions, but within our Hindu community, we all actually bathe the body but it is predominantly family members that will do it.’

By contrast the participating Muslim woman in the group observed that due to their length of residence in the UK, funeral parlours and hospitals are familiar with their customs and practices surrounding death. Washing the body is performed by close family members, preferably women.

‘Because it’s a Muslim woman, and even though it’s her son or sons, whatever, they actually are not part of the actual bathing ritual. Just the women of the community, the close members of the family bathe the lady.’

As shown above, a diversity of practices and rituals surround death in South Asian groups according to various factors such as nationality, religion and gender and these need to be taken into account when providing palliative services.

### *Gypsies and Travellers Group*

Unlike the other groups interviewed the Gypsies/Travellers, not being recent immigrants referred to issues that although similar to the other groups, came from a different perspective. The predominant themes were i) their experiences of discrimination in society generally and in using health care services more specifically, ii) related to the first point is a reluctance to disclose their ethnicity and to 'pass' as a non-Gypsy (white British) iii) conflicts around custom and end of life care iv) related to the above is the subsequent communication problems.

Regarding the first point, much of the literature points to ongoing prejudice and discrimination towards Gypsies and Travellers and in their experiences of accessing and using health care services (Parry et al, 2004; Cemlyn et al, 2010). On one hand, previous negative experiences in health care settings influence subsequent interactions with many of the participants anticipating conflict. On the other hand, a lack of cultural understanding in the health services, means this often becomes a self-fulfilling prophecy in how the two sides relate to each other. One participant stated how this shaped her attitude towards engaging with palliative services.

“And all our life, these other people, these gorgers (non Gypsies) and other people haven't wanted us. They've moved us on from the roadside, they haven't wanted us in their pubs, they haven't wanted us in their village halls, they haven't wanted us in their shops, they haven't wanted us, and now, at this most important moment, they are there and they have no right to be...They have no right to be, no matter how passionate that one person is, because their people have moved away from us all the time, and then at that crucial moment they're saying “oh yeah, we do”.

Secondly, a consequence of the anticipation of conflict or discrimination noted by some participants is that some community members would hide their ethnic identity in healthcare and palliative care settings. One woman recalled the following experience in hospital, which made her reluctant to disclose her ethnicity, and further confirmed the belief of widespread prejudice among health staff.

I said to her “was that a traveller man out there?” “Yes” she said, “he only stayed in overnight and he's gone home thank god”. So I thought she meant thank god the man's better. So I said “yes I agree with you, thank god”. She said “my god because when

they're in here, they don't half play up". She said "I'm telling you, I'd refuse to nurse somebody like that", and I'm thinking do I say "actually" [laughs], or do I leave it?"

Thirdly in Gypsy/Traveller cultures the process of death and dying is surrounded by particular and significant practices and customs. In healthcare settings, this is a further source of conflict for providers and users. For example the tradition that when somebody is in hospital that large numbers of extended family and other community members, including children, will demonstrate their concern by either calling or visiting the hospital in large numbers. One participant recalled the tensions this can cause. Similarly traditions such as lighting a fire once a person has passed away and covering mirrors when somebody is dying is not always easily accommodated by health services. The lengthy quotations below illustrate very vividly the conflict that can exist between these service users of palliative and end of life care services.

But this was the hospital. It was like at night, they was saying there's a lot of people, and one of me uncles said to her, "well look", trying to compromise, he said "what we'll do is we'll stay in the hallway then" and she said "you can't do that". By then she's getting confrontational. She said "you can't do that". She was tired. She'd done a long shift. She said "I'm going to have to get security up here". He said "well then give us a café to sit in". She said "you can't, they're all shut". He said "well then we'll sit in the cars in the car park", and she said "you can't do it".

"Well then we'll fucking sit up the side of the road, but I'm telling you now, we're not going home". And he said to her "do what you like. Bring who you like". He said "if you want the police here, bring the police. If you want security, bring them, but I'm not going anywhere, and to be honest, I'll down anybody that tries to make me". Because by then, no one's listening are they?"

"Because when we went to the hospital and hospice, everything's like, "you know, the trouble is it blocks our telephone system up because when we have somebody in from your community, everybody's ringing up to see how they are". And I said to them "that's a show of love".

"And with me mum we sat up, and my aunt's girl is married to a non-traveller man, and he said "why are we doing this", and she said "it's our custom, it's what we do", and she said that her biggest regret was she couldn't do it for her mother because her mother was in a hospice, and they wouldn't let them bring her home because they knew that she was most probably going to die that night. She said "but they wouldn't let us", like you say, cover the mirrors. She said "they wouldn't let us light a fire outside and I felt cheated". She said "I was really angry with them".

The last theme, which is related to the previous points, was to do explicitly with communication between providers and these service users. Again as the example below illustrates, in a

situation so highly charged, that any slight situation can be magnified into a distressing and tense event. What is interesting is that the participant offers a potential solution to these type of situations.

“I think one of the ones that really stuck in my mind was the mum who had a child who was dying, and she was in hospital with this child and she was very distressed, because she felt that her special time with her child, because her child was dying, was being interrupted all the time by members of staff telling her what was happening, telling her what she felt was superfluous...maybe there should be designated another member of the family that could take on the role of listening to all this information which has to be given. She felt that she basically, my interpretation of what she said was she felt robbed of her special time with her child before the child died”

## Conclusions

This one year feasibility project has fulfilled its aims of i) documenting some of the palliative health needs of four of the major BME groups in North Kent (Black Africans, South Asians/ Punjabis, Gypsy/Travellers) and to identify their end of life practices. A Learning Alliance has been formed (LAPCEL) which has brought together various organisations and practitioners with an interest in, or experience of, working in palliative care. LAPCEL are continuing to collaborate in further projects.

Besides the Learning Alliance methodology the project mainly used a qualitative approach. This comprised of four focus groups, two in-depth interviews and one interactive workshop with twenty staff members of a hospice in Gravesend. The methodology proved difficult at times, despite the networks with BME organizations in Medway and Sittingbourne. The topic may have been a limitation as some participants commented that people do not like to talk about death and dying.

The findings suggest that differences exist between and within specific groups (by gender, social class, religion and generation) and providers of palliative care need to be sensitive to these distinctions and not to assume that palliative care needs are the same because they belong to the same ethnic group. In this context, one of the most significant recommendations from this report is more training for health professionals in cultural proficiency covering two components: the demographic trends and ageing population in the UK, as well as the importance of understanding the nuances of different groups when they interactive with health services. However something that needs addressing and that the project shows is not

to assume that there is a blueprint for interacting with BME groups. Health services need to be flexible when providing palliative and end of life care services.

Nevertheless, death and dying is a universal process and certain themes and issues did emerge prominently in all the groups. For example, there was a widespread lack of knowledge of what palliative and end of life care entails and the cases where people were aware was either because they had experienced relatives receiving this or that they had worked in healthcare themselves. Secondly among first generation immigrants the concern over returning home either before death or having their bodies returned after dying was a cross-cutting theme in the African and Asian groups and needs to be accounted for when advance directives are being discussed. Muslims were the exception to this as the concern was for a rapid burial and funeral. The role of gender in caring for people at the end of life and carrying out necessary duties after death was another crosscutting theme in all the groups. Although gender specific roles were apparent in all the groups, this ranged from a fairly equal distribution of roles to one where the females were expected to undertake the bulk of duties.

Communication was another issue raised by all groups and in some cases a preference was expressed to communicate with palliative care practitioners through a family member whereas it was also noted by some that they would prefer to discuss such topics with an outsider unknown to them. The second recommendation therefore is a greater need for sensitivity around communication at such a delicate and emotionally fraught time as when a relative is dying. This is significant because there is a degree of ambiguity in preferences for communication that needs to be judged on an individual basis not on the basis of formal guidelines and procedures according to stereotypes of each group. As one member suggested cultural brokers and mediators would be beneficial and assist communication in some palliative and end of life care settings.

Regarding differences between the groups the fact that a high proportion of the African participants worked (or had worked) in the health and social care sectors and that they were all women, played an important role in shaping their views towards palliative care, with experiences of racism and examples of poor care making many wary of accessing such services themselves. This is an alarming finding that the BME individuals most familiar with the health system in their role of carers are most adamant they do not want to enter palliative care

themselves. On the other hand, the two South Asian groups stigma surrounding illness (contagious and non contagious) was an important factor in not disclosing illness and all the consequences as a result of that and a recommendation would be to explore in more depth, the role of stigma and how it can shape decisions during terminal illness and end of life. Among the Gypsy and Traveller group, conflict in health care settings, which was perceived as a symbol of wider social prejudice, was the dominant theme. This could become a self-fulfilling prophecy as they approach health care with the expectation of discrimination, which is confirmed due to poor understanding of their culture and practices among health care staff, and a certain inflexibility towards accommodating those practices. Interestingly one participant noted the importance of cultural brokers/mediators in dealing with such tensions.

To summarise the participants' views on what their ideal palliative care services would consist of the main areas for improvement were identified as: better information on what palliative and end of life care entails and the recommendation is that there should be public health campaigns informing the general population and campaigns targeting specific BME groups to raise awareness of available palliative care services and how to access them. Next were the issues of cultural proficiency among health care providers. Participants stated that the relation between faith/religion and palliative care services should be taken into consideration and this consideration should be extended to issues such as gender, ethnicity, class, sexuality, disability: palliative and end of life care are not exceptions to these intersectional issues in health care services, which present challenges to equality frameworks and requires a more sensitive and nuanced approach, which is in line with the demographic trends discussed earlier. Finally the last theme related to the provision of 24-hour support services for people dying at home and the corresponding respite for their carers.

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