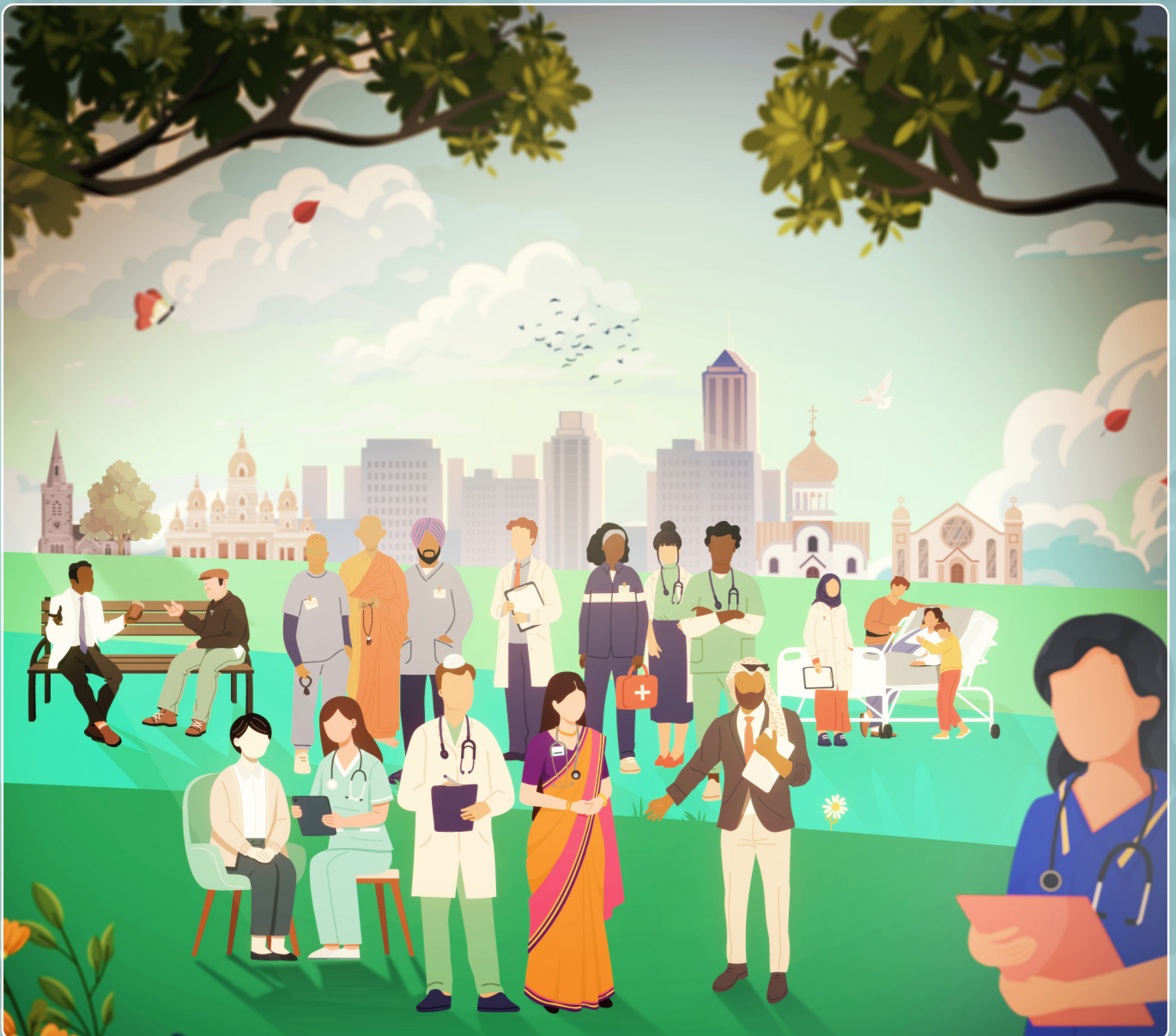


ETHNICALLY DIVERSE FAITH PERSPECTIVES ON DEATH LITERACY AND END-OF-LIFE CARE: A COMMUNITY-BASED PARTICIPATORY RESEARCH PROJECT IN BIRMINGHAM

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Executive Summary

This pilot study examines the challenges faced by ethnically diverse faith communities/groups within end-of-life care in healthcare settings and explores how best to enhance death literacy within ethnically diverse faith communities. Based on community-based participatory research through a Community Advisory Group and focus groups held between February and July 2025, this pilot study directly responds to Lord Darzi's findings about healthcare disparities in ethnic minority communities and the House of Commons Health and Social Care Committee's recommendations for enhanced death literacy.

By speaking with several participants from Muslim, Hindu, Buddhist, Jewish and Sikh backgrounds, this research has identified important religious and cultural practices needed during end-of life care: the importance of sacred books/sacred verses and prayers/meditations, the giving of holy water, the importance of the placement of the body, and post-death rituals. This pilot study also highlighted challenges faced by ethnically diverse faith groups/communities in hospital/healthcare settings including challenges around caring for the body, reciting prayers and rituals on noisy hospital wards, and insufficient space for families to gather at the bedside of a loved one. Finally, the research advocates for enhancing death literacy in ethnically diverse faith groups/communities by improving understandings about life and death from different religious traditions and showcases some positive examples of death literacy in communities as well as some challenges including death being considered a taboo subject.

This study puts forward recommendations for healthcare and faith community settings to work together to enhance culturally sensitive end-of-life care within ethnically diverse faith groups/communities:

- **Dialogue and connection** between health workers and faith communities: healthcare workers should visit places of worship to understand death rituals, and community members should inform healthcare workers of religious practices around end-of-life care.
- **Education:** information about death practices in all religions should be available, with information presented bilingually and visually/creatively.
- **Death literacy:** enhancing death literacy by encouraging workshops and conversations about death from and within ethnically diverse faith communities/groups.



Introduction

Birmingham, the UK's second-largest city with one of Europe's largest migrant populations, faces a key challenge in end-of-life care. Despite having the largest Muslim population of any English local authority (over 340,000 people), plus significant Buddhist, Hindu, Jewish and Sikh communities, these ethnically diverse faith communities/groups remain under served by existing hospice services.

The “Ambitions for Palliative and End of Life Care: A national framework for local action 2021-2026” (NHS England, 2021) recognises this gap, stating that “community partnerships between different faith groups and cultural communities” are essential building blocks for high-quality palliative care. The document emphasises: “Dying, death and bereavement affects everyone, so everyone must be able to get care that works for them personally, for their family and carers and for their communities. Local plans should include the development of community partnerships between different faith groups and cultural communities” (NHS England, 2021).

The Health and Social Care Committee's 2024 recommendation for a national death literacy strategy highlighted persistent inequalities – geographical, diagnostic, and patient characteristic-based – that particularly impact ethnically diverse faith communities/groups (House of Commons, 2024). Death literacy can be understood as “the knowledge and skills that people need to make it possible to gain access to, understand, and make informed choices about end of life and death care options” (Graham-Wisener et al., 2022; Leonard et al., 2020). The report highlighted inequalities in access including geographical, diagnostic and inequalities in patient characteristics (House of Commons, 2024). Such recommendations of enhanced death literacy from the Health and Social Care Committee extend to ethnically diverse faith communities/groups.

This pilot study contributes to these aims by examining the challenges faced by ethnically diverse faith communities/groups within end-of-life care in healthcare settings and exploring how best to enhance death literacy within ethnically diverse faith communities/groups.

Aims of the pilot study

- i. To co-produce knowledge about culturally appropriate approaches to discussing death and dying within ethnically diverse faith communities/groups.
- ii. To identify cultural and faith-specific barriers and facilitators to end-of-life conversations and preference recording.
- iii. To develop preliminary recommendations for culturally sensitive approaches to enhancing death literacy in ethnically diverse faith communities/groups.

Key research questions

- What are some culturally or religiously appropriate practices during end-of-life care within ethnically diverse faith communities/groups, and what challenges prevent such practices in healthcare settings?
- How can we facilitate better discussions about end-of-life wishes and care preferences within ethnically diverse faith communities/groups?
- How can healthcare and faith community settings work together to enhance culturally sensitive end-of-life care within ethnically diverse faith communities/groups?

Method

This research was conducted between February and July 2025 and was focused on Birmingham as a case study. There were two groups of collaboration partners: a newly formed Community Advisory Group, and an expert collaborator group. Data for the research was gathered by 2 focus groups.

Case Study

Birmingham was selected as case study city for this pilot study. Birmingham is the second-largest city in the United Kingdom and has one of the largest migrant populations in Europe, with a great diversity of faith traditions. Birmingham has the largest Muslim population of any local authority area in England and Wales (over 340,000 people), the second largest Buddhist community (over 4000 people), and the eighth largest Hindu community (approximately 22000 people). It also has sizeable Jewish and Sikh populations (over 1500 and 13000 people, respectively) (Office for National Statistics, 2021). The project team's discussions with Marie Curie Hospice in Solihull and Birmingham Hospice have identified the need for greater outreach into minority communities in the area, who are currently underserved by the hospices. Birmingham has been accredited as the UK's first Compassionate City, and there have been some initiatives on improving palliative care services, such as the 'Culturally sensitive end of life care toolkit' for health and social care professionals (NHS Birmingham and Solihull, n.d.), and 'End of Life and Palliative Care for Muslims: Guidance for Service Providers and Users' (Asad & Shahid, 2022). There is a need to build momentum on this work and produce resources which represent a diversity of faith groups in minority communities and also drive change at policy level. This project therefore centres on Birmingham, to draw upon the existing connections and initiatives, with the intention of designing and disseminating outputs to deliver impact both within and beyond the city.

Collaboration Partners

Community Advisory Group

The project established a Community Advisory Group (CAG) of 4 community members: Simon Romer, Shobha Sharma, Shahin Akhtar, and Suni Patel. The members represented different faith traditions including Hinduism, Buddhism, and Islam. All CAG members had a particular interest in the topic based upon professional experience, previous work and current work in their communities. The CAG guided the research process, supported the literature review (offering readings and sources of information), helped recruit focus group participants, inputted into the findings and recommendations, and helped to explore ideas for future studies.

There were many benefits to having a CAG. Firstly, members of the CAG were able to share their knowledge of faith traditions and rituals to improve how end-of-life healthcare works for people in their community. Secondly, they were able to advocate for stronger connections between their faith community and healthcare services, making it easier for people to talk about and ask for help with end-of-life care and creating helpful information that will benefit future generations. Thirdly, the CAG helped different faith communities work together by regularly meeting and talking with other faith leaders/community members about shared experiences, finding out what different faiths have in common while respecting our different beliefs about death and dying, showing how different faiths can work together to make healthcare better, and creating an example that other cities might follow.

Expert collaborators

'Experts' from healthcare, faith and academia were also drawn upon to collaborate on this pilot study. Some of these 'expert collaborators' were internal members of staff at St Mary's University (Professor Sara Spear, Professor Karen Sanders, Professor Jacob Phillips), but also individuals from Lancaster University Medical School (Dr Amy Gadoud), the Royal Marsden (Dr Joanne Droney – Consultant in Palliative Medicine), the Archdiocese of Birmingham (Patricia Whitney – Chair Interreligious Diocese Commission), and included Professor Julia Verne (Consultant in Public Health Medicine), and Professor Jim McManus (National Director,

Health and Wellbeing, Wales). They all brought great expertise to the project, including helping with the formulation of questions for the focus groups, gaining participants for the Community Advisory Group, supporting the literature review and supporting potential future research projects.

Focus Groups

Between May and June 2025, we conducted 2 focus (discussion) groups online with participants all from or based in Birmingham. Each focus group lasted between 1 – 1.5 hours. Focus group 1 was attended by 4 participants representing a range of ethnically diverse faith communities/groups. Participants were working in places of worship and were members of the community or came from families that were culturally part of the faith community. Focus group 2 was attended by 5 participants representing Islam, Judaism and Buddhism. Participants included faith leaders, community workers, and community members. The data from each focus group was transcribed using zoom and coded by the researcher.

We acknowledge that there is a wide variety of beliefs and practices within each of these religious communities, and as such not all views can be represented in a limited pilot study. Future research could engage in more specific demographic reporting to enable a deeper understanding of beliefs and practices within religious communities.



Literature Review

Religion and Public Health

Religion is recognised as a key social factor in public health. Understanding the complex ways in which religion influences health is essential for developing public health interventions that respect cultural and religious values while promoting health equity.

Religion shapes many people's 'healthworlds' – their complex ways of understanding health or illness that extend beyond biomedical science and clinical procedure (Germond and Cochrane, 2010). The public health effect of religious institutions has grown in the past decade, and it has influenced public health research, practice and policy (Idler et al., 2023). In order to build understanding of how to respect religious communities' knowledge and priorities, and create approaches that meet their needs, it is crucial to foster engagement between faith-based and public health actors (Idler et al., 2023). Durable partnerships between health actors and religious bodies, according to Idler et al. (2023), can contribute to better health outcomes.

Lord Darzi's independent investigation into the National Health Service in England (2024) specifically highlights that "people in the most deprived communities are far more likely to have multiple emergency admissions to hospital in the last year of their lives" and notes that "cultural factors" may contribute to these disparities. The report noted that minority ethnic groups experienced disproportionately longer waits for elective care, and in terms of mental health interventions, experienced worse outcomes, longer waits for assessments and were less likely to receive a course of treatment following assessment (Darzi, 2024). Lord Darzi's findings concerning healthcare inequalities in these minority ethnic communities, which are closely tied to religious communities, highlights the need to foster better communication between ethnic minority faith communities and public healthcare actors.

Faith Groups and End-of-life Care

Existential and spiritual aspects of care should play a crucial part of palliative care (Richardson, 2014, Pentaris, 2022). A study from the US recommended that palliative care providers are 'called to be advocates for the spiritual and religious rituals of patients and families, especially at the time of death' (Richardson, 2014). A study from Australia argued that all medical care of palliative patients should require training of a religious and spiritual nature too (Bradford, 2023). Echoing this, a different study argued that culture and religion at least partially affects one's perception of palliative care and decision-making at the end of life (Steinberg, 2011). This study suggested that in order to provide the best possible end-of-life care, cultural and religious backgrounds as well as personal experience and preferences were necessary to be understood by each caregiver (Steinberg, 2011).

Nearly a quarter (24%) of the UK say they have not heard of palliative care or do not know much about it, with no awareness being more profound in ethnic minority groups (22%) (NIHR, 2024). It is argued by a systematic review, that 'patients from minority ethnic groups experience lower rates of referrals to end-of-life care services, higher levels of dissatisfaction with services, and perceive some services as culturally inappropriate' (Evans et al., 2012). Existing research points to the importance of cultural knowledge and sensitivity in palliative care (Monette, 2021), and that ethnic minority groups have particular needs at the end of life including cultural and family expectations, and religious practices around dying. Religious beliefs may also impact treatment preferences at end of life (Ohr, Joeong and Saul, 2017).

Various studies have conducted systematic literature reviews on end-of-life care for ethnic minority groups in the UK (Evans, et al., 2011; Evans, et al., 2012). Research has highlighted that religious and cultural palliative and end of life care needs of minority groups in the UK are often not met, and that there is little guidance or resources offered for clinicians on the specific needs of different faith and cultural groups (Suleman, 2022). For example, Chidiac et al.'s study (2020) highlighted that Black, Asian and minority ethnic patients, especially women, tended to be referred later to palliative care compared to White ethnic patients, before and during COVID-19. For them, this reflected inequity in palliative care provision for Black, Asian

and minority ethnic groups and the non-uniformed impact of COVID-19 across ethnic groups (Chidiac et al., 2020). Furthermore, Suleman (2022) emphasised the particular challenges for Muslim communities in reconciling their religious beliefs and practices with the secular UK health system. In the study by Moss et al. (2023), the South Asian community in Bradford was not ready to engage with palliative and end of life care services, despite local awareness raising initiatives. The researchers found that service providers lacked understanding of what a 'good death' looks like for people from different cultural and religious backgrounds, and services that aimed to support people from ethnic minority communities were not effectively addressing ethnic inequities.

Barriers

There are largely three identified barriers preventing better palliative and end-of-life care for ethnically diverse faith communities/groups that have been highlighted in research: (1) lack of access to or low usage of services and information; (2) lack of cultural and religious sensitivity; and (3) communication barriers. There are a number of other barriers or challenges, that fall outside of these three major categories, that are worthy of acknowledgement too. These include: financial, structural and cognitive barriers (see George, Daniels and Fioratou, 2018); institutional cultures – limited resources, restrictive internal policies, and lack of training and education (see National Institute for Health and Care Excellence, 2019).

Lack of access/Low usage

Minority ethnic groups face suboptimal palliative and end of life care due to, in part, low access to services and information (Chidiac et al., 2020; Mayeda and Ward, 2019). Researchers have found low use of end of life care services among minority communities (Calanzani, Koffman and Higginson, 2013; Mayeda and Ward, 2019; Moss et al., 2023), and that access to end of life services, at home and in hospice, is more difficult for minority communities (Fang et al., 2016). Such access could be as a result of a lack of culturally-tailored end-of-life information to enable decision-making, or lack of cultural sensitivity and poor communication (as we will discuss below). Where models have been developed there could also be an "under-utilization of culturally-sensitive models" designed to improve end-of life care (Fang et al., 2016).

In 2017, Hospice UK estimated that 1 in 4, approximately 118,000 people, who required end-of-life care and their families were not able to access the expert care they needed including access to hospices (National Institute for Health and Care Excellence, 2019). They found that, in particular, people from "economically and socially deprived areas, BAME communities and LGBT people can experience barriers to accessing end of life care services" (National Institute for Health and Care Excellence, 2019). At a local level, a study revealed that knowledge about palliative care amongst BAME communities in Leicester were "scant" though very much valued when understood. The study suggested that whilst cultural or religious restrictions on using palliative care services were not demonstrated, better awareness especially at the local level and how to access services was deemed as important (Islam, Markham and Faull, 2014). It has also been reported, whilst factually incorrect, that 18% of people for ethnic minority groups and 5% of white people believe that palliative care involves 'giving people medicines in order to shorten their lives' (Commission on Palliative and End-of-Life Care, 2025).

Furthermore, access to bereavement support by minority ethnic groups was also noted. According to a study, 67.3% of bereavement services reported that there were groups with unmet needs not accessing their services before the Covid pandemic, of which minority ethnic communities were the highest at 49% (Selman et al., 2022). The study found that the Covid pandemic disproportionately impacted this group in particular, with 6.1% of services reporting seeing fewer people from ethnic minority groups (Selman et al., 2022).

Lack of cultural sensitivity

As well as a lack of access to and usage of services and information, delayed and unmet palliative and end of life care needs amongst minority communities is due to a lack of cultural sensitivity among healthcare providers, previous negative experiences, and conflicting values between family/religion and notions of palliative care (Chidiac et al., 2020; Fang, et al., 2016).

A lack of healthcare professionals getting to 'know' their patients, and therefore their values, faith and cultural perspectives, was also highlighted (Islam et al., 2023). In a study exploring the engagement of healthcare professionals in end-of-life care amongst terminally ill patients from ethnically diverse backgrounds, patients felt that despite religious and cultural mores being of great importance, there were "anxieties about how the system valued and enabled these" (Islam et al., 2023).

From a study outlining barriers to accessing hospice care from the perspective of people from BAME backgrounds in Cardiff, participants felt that palliative care services were not set up for people from ethnic minority groups and had concerns over whether hospices were culturally and religiously appropriate (Marie Curie Hospice Cardiff, 2014). Some specific examples were noted including the importance of prayer, washing facilities, a prayer room with a peaceful ambience and clear of furniture and clutter, the need for artefacts for prayer including prayer mats, a sign for the direction of Mecca, Tassibee prayer beads, a Quran, pictures of Hindu Gods and a copy of the Geeta holy book (Marie Curie Hospice Cardiff, 2014). Such prayer rituals and importance of such artefacts, the participants of the study felt, were not well understood by hospice staff. Similarly, a study set in Nottinghamshire and Leicestershire, described that some patients from ethnically diverse backgrounds felt aspects of planning ahead when someone is terminally ill (e.g. in practical ways such as writing wills and planning funerals) was counter to their faith (Islam et al., 2023). Based on a study beyond the UK, the study focused on the Amish community and palliative care needs. It reported that palliative care was perhaps a new concept to the Amish culture (Lalani and Cai, 2022). Such nuances amongst religious and ethnic groups are vital for healthcare professionals to be aware of and attuned to.

Whilst studies highlight the importance of spiritual aspects to palliative care (Richardson, 2014), such aspects according to one study were given less priority compared to other domains of palliative care, in part due to time constraints and workload (Lalani and Cai, 2022). The researchers suggested that at times nurses and doctors leave the responsibility of spiritual and existential concerns to the responsibility of chaplains or faith healers (Lalani and Cai, 2022). If spiritual aspects of palliative care are relegated to the domain of chaplaincy, it could lead to healthcare professionals not being fully aware of the cultural and religious sensitivities of patients from ethnic minority backgrounds.

Communication

An ever-present theme contributing to barriers preventing people from ethnically diverse faith communities/groups accessing end-of-life care is poor communication and coordination of services. One of the biggest barriers is for "professionals to recognise when someone has entered the last year of life and having the skills to discuss this with openness and sensitivity" (National Institute for Health and Care Excellence, 2019). There can also be communication barriers related to language, delegated decision-making within families, and reluctance to talk about death and dying (Puchalski and O'Donnell, 2005).

Death literacy levels amongst ethnic minority groups were raised by several studies. In a study specifically looking at healthcare amongst European Roma community, communication barriers were stated as a lack of education and health literacy amongst that community (George, Daniels, and Fioratou, 2018). In a study about Marie Curie Hospice in Cardiff, BAME community members felt that it was important that the hospice was culturally competent and respected and supported religious needs – in a language that was understood by patients and their families (Marie Curie Hospice Cardiff, 2014). Mayeda and Ward (2019) articulated that standard tools, such as written handouts, may not be sufficient when attempting to target ethnic minority communities about palliative care services.

Beyond literacy, there are also communication barriers because of cultural differences whereby in some ethnic minority communities decision-making is delegated within families who are 'gate keepers' and/or there is a reluctance to discuss death in certain cultures (Wilkinson et al., 2014). In this study, researchers explored end-of-life care for South Asians with kidney diseases. Communication was seen as an important element of the care needed to be given to patients. The study stated that where patients were not fully aware of their condition or what end-of-life care was, they were likely to be less involved in decision-making about their care (Wilkinson et al., 2014). In this way, perhaps low usage is compounded by communication barriers, including language, but also family decision-making processes and cultural norms to not discuss death.

Key Enablers

Barriers to end-of-life care from the perspective of ethnically diverse faith communities/groups – access to and low usage of services and information, lack of cultural and religious sensitivity, and communication barriers – results in potentially a lack of trust between ethnically diverse faith communities/groups and healthcare practitioners, and an experience of end-of-life care as a disjointed system that is devoid of regard for their needs (Islam et al., 2023). Furthermore, a study on the European Roma community suggested, these barriers to end of life care results in, as they describe, “psychological barriers” of mistrust, hopelessness, fear and anxiety (George, Daniels, and Fioratou, 2018).

That being said, several studies noted key enablers to improve end-of-life care amongst ethnically diverse faith communities/groups. A study based on the training of future doctors in Birmingham identified the characteristics of a culturally sensitive doctor, as well as suggesting recommendations for training (Greenfield, et al., 2001). A research study set in Nottinghamshire and Leicestershire suggested four ways of improvement: effective communication with trusted individuals – so patients feel known and their faith and culture are valued; healthcare professions getting to 'know' their patients; increasing healthcare professionals' confidence, skills and training through stories; and behavioural change techniques (Islam et al., 2023). Another study by Mayeda and Ward (2019), who conducted a systematic review of studies on methods for overcoming barriers in palliative care for ethnic minorities, discussed three avenues to overcome barriers in palliative care for ethnic or racial minorities. They suggested: methods to enhance patient education, increase access to healthcare, and improve communication to establish better rapport with the target population (Mayeda and Ward, 2019). A scoping review based mainly on interview studies of older people in the USA, equally recommended that healthcare providers should develop more culturally appropriate palliative and end of life care practice, including building trust and improving communication, sharing information, reducing language barriers, addressing stigma, and, if relevant, acknowledging the importance of culture and religion (Aker et al., 2024).

Positive interventions to increase equity amongst minority ethnic groups accessing bereavement support included “collecting client demographic data; improving outreach, language accessibility and staff representation; supporting other professionals to provide bereavement support; local collaboration and coproduction” (Selman et al., 2022).

Findings

There are three key areas of findings from the focus groups that respond directly to the first two research questions which are: 'From the perspective of ethnically diverse faith communities/groups, what are some culturally or religiously appropriate practices during end-of-life care, and what challenges prevent such practices in healthcare settings?' and 'How can we facilitate better discussions about end-of-life wishes and care preferences within ethnically diverse faith communities/groups?'

We acknowledge that there is a wide variety of beliefs and practices within religious communities, and that many ethnic and cultural factors are also important factors presenting diverse views within a particular faith community. As such, not all views could be represented in this limited pilot study.

Important cultural or religious practices during end-of-life care

Participants of the focus groups, from a range of ethnically diverse faith communities/groups in Birmingham, highlighted several important cultural and religious practices when it came to end-of-life care for people in their communities. They included:

(1) Importance of sacred books/ sacred verses and prayers/ meditations

The importance of reading or reciting from sacred books whilst someone was dying was highlighted as very important. In some cases it may be the dying person themselves, but often it was family, friends or faith leader/volunteer from the faith community who read sacred scripture or recited sacred verses to the dying person. A Hindu participant said,

"We have many sacred books so one of those is the Bhagavad Gita people tend to read – I'm not Chaplain but I am a volunteer and I go there to the community wherever I am needed to go there and to read one or two verses of that Bhagavad Gita."¹

Similarly, a Muslim participant stated,

"So the religious procedures are to be followed and they are that we recite the verses of Quran and their special verses. So what I do is when I get the news that somebody is very ill in the hospital so I have saved all that on my e-mail on my iPhone and then I send it to them and they recite these verses of holy Quran."²

A Sikh participant shared,

"So if someone is dying a slow death, on death bed for example, they will hopefully have the chance to hear certain prayers for example some prayers such as Sukhmani Sahib or Japuji Sahib which is the Sikh morning prayer and also meditation on the name of God which is probably the key practise in Sikhism."³

Meditation was also spoken about in the context of Buddhism. A Buddhist participant spoke of the practice of meditation as a training to overcome fear, anxiety, and loss. He also spoke of

"meditation trainings associated with physical pain. So we're encouraged to work with pain as soon as it comes and not reject it, not fight it. Obviously, if you can do something about it, of course you do something about it, but not to reject it and tense against it"⁴

Meditation training was seen as something Buddhists were encouraged to spend their life training for death.

1. Focus Group Participant 1; 2. Focus Group Participant 3; 3. Focus Group Participant 2; 4. Focus Group Participant 7

A Jewish participant spoke of the prayer rituals around the deathbed itself. She shared, **“when they did die...then we said some prayers before as they died, and afterwards, and then all the rest of it came afterwards.”**⁵

(2) Holy water

Some participants spoke of the importance of the giving of holy water to the dying person at the moment of their death. A Muslim participant said,

“Then we have this holy water which is from Mecca, which is Zamzam holy water and then if the doctors allow then we give a teaspoon of the holy water to the dying person and if they don’t allow then we just give us a sponge and we dip the sponge in the holy water and we just put it on the lips or whatever.”⁶

Similarly, Hindu participants spoke of their holy water from the River Ganges which is needed at the moment of the last breath. This holy water is placed over the body along with a tulsi leaf in the mouth, whilst prayers are recited.⁷

(3) Placement of the body

The correct placement of the body before and after death was also noted by a few participants. A Muslim participant shared that,

“The bed should be moved if there are no tubes or anything...to turn the bed in such a way that the feet of the dying person are facing the Kaaba in Mecca.”⁸

The correct placement of body from a Hindu participant was also shared. He said, **“the placement on the floor the person which we know that the person is going to die at some point soon.”**⁹ This was suggested because of the idea that our bodies came from the earth so it should be close to the earth at death.

A Muslim participant spoke of the Islamic traditions for the body immediately after death too. She said,

“And then as soon as the person dies then immediately the eyes and mouth. We shut their eyes and the mouth and we straighten the arms and the legs and then we cover the whole body including the face with a cloth and we inform funeral director so that he starts the procedure.”¹⁰

(4) Burial/cremation processes

Most participants spoke of religious and cultural practices requiring a rapid burial or cremation process. A Jewish participant spoke of a relative dying in the morning and being buried by 3pm the same afternoon. She said, **“so it’s very important to us to get the body in the ground...it’s dealt with as quickly as possible.”**¹¹

5. Focus Group Participant 6; 6. Focus Group Participant 3; 7. Focus Group Participant 1; 8. Focus Group Participant 3; 9. Focus Group Participant 1; 10. Focus Group Participant 3; 11. Focus Group Participant 6

A Sikh participant shared,

“And when the person has actually died then the funerary process funerary ritual is called Antam Sanskaar which means something like the ‘last rites/ last passage’ and that’s usually accompanied with singing prayers, recitation of scripture and I and well yeah also most importantly probably in night time prayer which is recited one last time for the person, for the departing person. And then we also have traditional usually the eldest son or a close relative is the one who starts the cremation process and then the ashes are usually scattered in a body of water or something like that. Burial is also allowed but I think but because of cultural reasons people tend to choose cremation.”¹²

Contrarily, a Buddhist participant shared that it is the opposite in Buddhism. He shared that in Buddhist teaching the longer the body was left, the better as it allowed for dead person to experience peace.¹³

Challenges honouring cultural and religious practices at end-of-life care in healthcare settings

Focus group participants highlighted several challenges and barriers upholding these end-of-life cultural and religious practices within healthcare settings. They included:

(1) Challenges saying prayers/religious rituals

Participants drew attention to the fact that hospital wards were not always conducive to allowing for prayer as they were often too noisy. A Hindu participant said,

“The hospital was fairly good but there isn’t any personal space to stay with parents and there are rituals as well that you want to do like prayer. We prayed daily but it was ensuring that nobody else was disturbed, so quietly but it wasn’t the best.”¹⁴

Similarly, a Sikh participant stated,

“...for Sikhs who are in this situation either dying or death bed in the hospital and the religious and cultural practises to listen to Gurbani, listen to Sikh prayers and the name of God and just try to build that that sort of connection in the final moments, it can probably be difficult in a hospital environment.”¹⁵

He went on to explain that for baptised Sikhs, it was even more important for the dying person to be able to uphold the sanctity of the 5 Ks. These are

“the uncut hair, the Kara (the bangle), the Kachera (the white underwear), the Kanga (the comb), and the Kirpan (the ceremonial dagger) - and so those articles of faith are supposed to be treated with the utmost respect.”¹⁶

He shared the challenges around upholding the respect of these 5Ks,

“And also within Sikhism it’s just that it’s a very important sign that this person has dedicated their life to the Guru and it’s considered like disrespectful if you sort-of if you’re a doctor and you kind of move the dagger out of the way very quickly or with unclean hands.”¹⁷

12. Focus Group Participant 2; 13. Focus Group Participant 7; 14. Focus Group Participant 4; 15. Focus Group Participant 2; 16. Focus Group Participant 2; 17. Focus Group Participant 2

(2) Spaces in hospitals for families

Another challenge faced by ethnically diverse faith communities/groups is having a place to go to in a hospital setting when a loved one is dying. One Hindu participant shared,

“There aren’t many places in hospital where you can actually go and pray, you know, just be with God just to get that peace... one of the things we looked at was people worship differently and some worship with nobody there and others may worship idols or others may have holy books, but one room sometimes doesn’t suit all and so there are there are issues it’s about understanding.”¹⁸

Another Hindu participant agreed highlighting that having a place for the family to grieve in the hospital was essential. He said,

“You can’t have so many people around the bed, then to respecting that so at least few people can go at a time and then the rest can stay in that multi faith room or any kind of area where you can, then that’s the best way to share the grief as well to share your good or bad memories.”¹⁹

(3) Care of the body post-death

One challenge that was mentioned by several participants was keeping the body in a certain position post-death. A Hindu participant stated that there are **“challenges maybe the hospital are not aware of... the keeping [of the body] in certain direction, it’s the head that needs to be faced a certain way.”²⁰** Furthermore, it’s encouraged that there is minimal handling of the body until the family are ready. The body may be washed and dressed by loved ones, and then the body could be brought home before cremation so the Priest can say prayers and perform Hindu rituals.

For a Jewish participant, it was important that the body was not touched by non-Jewish people. She said,

“If you die in a hospital, it’s important to us that, for example, the body isn’t touched or prepared by non-Jewish people. So that that’s quite important, and that and it’s treated with the respect. So just. you know, left until a Jewish and a firm that deals with Jewish people would come and remove the body.”²¹

From a Buddhist perspective, it is preferable to keep the body in its place when it has died. One Buddhist participant said,

“One that affects so the Buddhist thing is quite different from the Jewish or Muslim response to death, which is, the longer the body is left, the better. So it’s very, very different. And so for the individual who’s died to give them as much peace after actually stopping breathing, the better. But of course we have the problem here that if somebody dies and the ambulance comes, or they might have to. I don’t know. Try and revive them. And then they’re taken away, and maybe there has to be an autopsy and obviously legally fair enough. And then they might be put in the fridge for a few weeks so there can be all kinds of drama that the body goes through after death rather than leaving it alone.”²²

18. Focus Group Participant 4; 19. Focus Group Participant 4; 20. Focus Group Participant 6; 21. Focus Group Participant 6; 22. Focus Group Participant 7

Autopsy was also a topic that came up with some participants sharing that their religious tradition did not condone it. A Jewish participant shared, **“Autopsy is frowned on, not, I mean, obviously, if you, if it’s needed and it has to be, but these days with scans that that helps”**.²³ A Muslim participant shared that **“people aren’t aware that there’s a body scanner and they don’t use it. So they’re waiting. And there’s a delay in the body getting released...I think we need more awareness around where there are body scanners available.”**²⁴

Many participants shared this sentiment of the delays in the process caused by delays in getting the death certificate, or delays in the body being released. One Muslim participant stated,

“when a Muslim personal dies it is very, very important that that person is, that the burial takes place as soon as possible... until the burial takes place, the family are very unsettled. Once the burial takes place then the family feel that over now we can go to the graveyard and we can pray there etc.”²⁵

She went on to explain,

“We have challenges because we need because our religion says that burial has to be done immediately so the challenges we face are the hospital sometimes a person will pass away and they won’t issue a certificate saying that the doctor who was looking after her or him, the doctor is not available and it’s Friday today and he won’t be there on Saturday won’t be there on Sunday so come on Monday 9:00 AM, and then you go there at 9am and they say oh his shift starts at 1:00 PM and then 3:00 PM the registry office closes you know, so we face lots of problems.”²⁶

Similarly, a Hindu participant shared from her own experience saying,

“I think we’re all on the same to the wavelength and around the delay in funerals. The funerals in the Hindu tradition generally take place on the same day that could be weather related in India, but in the UK I can only go by my own experience so when my father died it was nearly over a month, a month and half before we could actually have a funeral.”²⁷

Religious or cultural customs, rituals or practices that help facilitate discussions about end-of-life wishes and care preferences

When discussing end-of-life wishes and care preferences, participants of the focus groups shared ways in which this is positively happening within their communities, as well as presenting some barriers too.

Understandings about life and death from different religious and cultural traditions

Participants brought up different understandings about life and death from their own religious traditions. A Buddhist participant shared,

“I can say in Buddhism, the first proper training is death. So as a beginner, a beginner Buddhist, your 1st training is death...so even the youngest Buddhist student will train in death. And the reason is because, if you understand we’re going to die, then your life will be in a more balanced perspective.”²⁸

23. Focus Group Participant 6; 24. Focus Group Participant 8; 25. Focus Group Participant 3; 26. Focus Group Participant 3; 27. Focus Group Participant 4, 28. Focus Group Participant 7

Within Hinduism and Sikhism, participants were keen to share their understandings around liberation. As a Hindu participant shared, 'Moksha' means

"liberation from this body onto a new body....I think within Hindu religion it says well cycle of life – if you're born, you are going to die. That's accepted. Moksha which is liberation and this is what people look or they look at karma is another thing people are very afraid to talk about karma in UK but it's something that's kind of widely talked about in Hindu religion."²⁹

Similarly, from a Sikh perspective,

"It is very important to know about how Sikhs view the afterlife and what happens after death. Again it's very similar to Hinduism it's called Moksha, in Sikhism it is called Mukti which is the exact same word but in Punjabi, it's this liberation from this cycle of birth and death."³⁰

Another Hindu participant stressed that life and death were intertwined and in reincarnation. He said,

"When we talk about death, I think we talk about life and death it's all linked so life is not different than death and death is not you can't keep them apart... we always believe that the philosophical view of death as a transition like I said in the previous question that reincarnation and karma is just we see as the planet earth we're just came as a transition, this is a transit place and then we will be moving from one body to another. We believe in reincarnation, so it's just a changing of one body to another really"³¹

Beyond religious traditions, it is also important to highlight that cultural aspects play a significant role. One Muslim participant shared,

"One thing I think that needs to be quite apparent is, yes, there are set ways of doing things. But so somebody that would be Arab might not follow the same path of somebody that is from Pakistan or from Bangladesh, because culture comes into a lot of things as well."³²

Positive end-of-life conversations/workshops in communities

When asked about end-of-life conversations and care preferences within communities, there was a mixed picture: some positive conversations between families and within communities and workshops were mentioned. A Muslim participant shared,

"...the religion recommends us [the community members] to know about death and to participate in funeral arrangements etc in our community. It's easy to talk with people about death and whenever we have arranged the workshops and whenever we have arranged any seminars about death or whenever there is a discussion we get a huge response and people come, they do participate... they do ask questions and they are always willing to know more about death and all that."³³

29. Focus Group Participant 4; 30. Focus Group Participant 2; 31. Focus Group Participant 1; 32. Focus Group Participant 9; 33. Focus Group Participant 3

A Hindu participant also shared that death as a topic was brought up in family settings. He said,

"I think people have become very much aware of people are talking about end of life wishes, like in my family we all have given our organs and most of our family so we know that it's we're not only given the organs or donated the organs we also told the family member that that's very important part of...although if I say death is comfortable, it's this never is going to be comfortable but yes we do talk about it in general get togethers as well and but that time it's easy to talk about when it is somebody else's death but when it's your own family it's always people lose their own knowledge and that time."³⁴

Beyond talking about death within families and communities, there were also some practical aspects mentioned. A Muslim participant mentioned teaching members of the community Islamic rituals of washing the body and shrouding. She said,

"When the family member passes away, if it is a man then their sons and if it is a woman their daughters or daughters-in-law or nieces they would come forward and ask us if we can take part in the washing and shrouding etc and we always encourage them of course. Two of our committee members have to be there because they have to be able to teach them because if they've never done it before, so two of our committee members have to be there but then we do allow two of the family members to come into the washing and to the shrouding and they come they're willing to help us. And many, many ladies would come and say that is there anything we could do or things like that and many discussions like this have to have taken place."³⁵

Another Muslim participant spoke of community coming together when someone has dies. She shared,

"What I find is that as communities, we are very good, because I think a lot of our communities are quite prepared with death because we've got a thing called a death committee, where we put money in, and it's a fund which certain people are part of. So if somebody passes away, you know the kind of certain things are taken care of in that aspects, it's good."³⁶

Struggles talking about death in communities

However, there were also some struggles when talking about end-of-life care within families and communities including feeling awkward, making jokes and not speaking about taboo subjects.

Many participants shared a sense of awkwardness at times when speaking about death amongst people in their families or communities. A Sikh participant said,

"For example in my family, we're probably not the most religious family we're more culturally Punjabi and Sikh and death is very much a taboo topic. Whereas in the Sikh ideal, Sikhs are supposed to have this sort of radical acceptance about death and it's just inevitable it's going to happen, it's the only one of the only guarantees in life. However, many people in our community do you feel a bit awkward talking about these kind of things and it and they don't like talking about these things."³⁷

34. Focus Group Participant 1; 35. Focus Group Participant 3; 36. Focus Group Participant 8; 37. Focus Group Participant 2

A Jewish participant spoke of making jokes when talking about care preferences. She shared,

“I think that finding, finding it easy to talk about death and dying, some people can and other people can’t. So in within our community, I guess those of us who are more comfortable about it. One of the things I think Jewish people do quite a lot is they make a make a joke out of, or they take a subject that’s serious, and they make it a bit funny.”³⁸

Significantly, speaking about deaths beyond natural deaths were considered a taboo subject and often not talked about. A Muslim participant stated,

“Unfortunately, we’ve got a lot of taboo subjects we don’t discuss. That’s cancer deaths. It’s drugs, domestic violence, you know, trafficking, anything that’s difficult. We kind of shy away from it... And we need to discuss and have these conversations and normalize these conversations.”³⁹

Similarly, a Hindu participant said,

“I think the only thing when we feel is difficult to talk about when there is a bad death, say suicide or so that kind of be very difficult to discuss at that time it’s very sensitive I think at the time. So those kind of things can be difficult to discuss.” Similarly, infant deaths were also raised as another topic that is often not spoken about.”⁴⁰

Furthermore, a Muslim participant spoke of communities not being good at dealing with grief within communities. She said,

“But if you look at the actual person who’s passing away and their loved ones that are left behind - there is no counselling, or people don’t recognise that everybody suffers from grief differently, and their journey and their healing time is different. I think people feel like that they should just snap out of it after a couple of weeks. And I think that’s where we need to educate our communities, that actually everyone is different, their journey is different, their loss is different.”⁴¹



38. Focus Group Participant 6; 39. Focus Group Participant 8; 40. Focus Group Participant 1; 41. Focus Group Participant 8

Recommendations

The third research question of this pilot study is: “How can healthcare and faith community settings work together to enhance culturally sensitive end-of-life care within ethnically diverse faith communities/groups?” To answer this question, we are listing here the main recommendations presented to us by the participants of the focus group:

Healthcare settings

- Build a culture of trust and dialogue between healthcare workers and places of worship
- Connect with religious healthcare workers to be that bridge between faith and health
- Create environments in hospitals and healthcare settings for loved ones and community members to pray with and for the dying person in an open way
- Encourage healthcare members/coroners to speak with and visit places of worship and understand the faith rituals and requirements so they have a better understanding
- Ensure a quick turnover of the post-death phase to enable a quick burial/cremation and understanding why this is crucial in some religions.
- Establish a 24hr phone number so healthcare staff can phone to discuss any religious rituals with relevant faith leader/representative
- Hospitals/healthcare settings to invite community members to speak to/give talks to healthcare workers about religious rituals and practices around death
- Make known and readily available guides developed by faith communities about religious rituals at end of life (e.g. develop lanyards for healthcare workers on end-of-life care rituals from different religious perspectives)
- More sensitivity required by healthcare workers to allow family to visit their dying relative and allowing the space for them to remain in the hospital
- Raise awareness of religious rituals and practices from all the different faith groups through education

Community settings

- Communities to offer workshops to understand death rituals (e.g. washing the body, shrouding)
- Ensure that all educational material is distributed bilingually e.g. Punjabi and English.
- Faith leaders to actively inform healthcare workers, community members, wider society of religious rituals/customs/practices surrounding death
- Faith leaders to invite healthcare workers into their places of worship
- Increase the understanding different world views within society e.g. Moksha, Mukti, etc.
- More open discussions within communities of unnatural deaths that may be considered taboo subjects including drugs, suicide, and cancer
- Source creative ways to speak into the subject of death through religious agencies, organisations, religious TV channels, radio stations. Visual as well as verbal communication is important.
- Workplaces to be more understanding of the importance of the mourning period within religious traditions

Conclusion

Understanding the religious and cultural end-of-life care needs of individuals from ethnically diverse faith communities/groups is important because everyone deserves access to end-of-life care that is respectful to them. Faith communities have different ways in which they talk about death and dying and have distinct rituals and practices which ought to be understood and adhered to within healthcare settings. Death literacy needs to be increased within ethnically diverse faith communities/groups, as well as between faith communities and healthcare workers.

This pilot study has highlighted the importance of sacred books and prayers; the sacredness of holy water and the correct placement of a body both before and after death. It has also underlined the emphasis placed on rapid burial or cremation, except within the Buddhist tradition where it is believed that the longer the body is left, the more that dead person will experience peace.

Barriers to prayers and rituals included hospital wards being too noisy; the need for a private space in hospitals during a loved one's death and early grief and care of the body post death. It was felt that there were opportunities to build a greater understanding of different cultural and religious traditions.

Talking about death and dying is still a taboo within ethnically diverse faith communities/groups – as in wider society – and a number of recommendations have been put forward by the participants to enhance death literacy including faith leaders inviting healthcare workers into their communities and healthcare settings inviting community members to educate staff about religious death rituals and practices.

This pilot study aimed to help to make sure that everyone's beliefs and practices are respected by outlining religious and cultural practices during end-of life care of patients from ethnically diverse faith communities/groups and presenting challenges that are often presented. Although, we must acknowledge that there is a wide variety of beliefs and practices within each of these religious communities and that ethnic and cultural factors are also at play, and as such not all views can be represented in a limited pilot study. This study also highlighted, both positives and negatives, of ways in which end-of-life wishes, and care preferences are discussed within ethnically diverse faith communities/groups. Most significantly, it suggested ways in which healthcare and faith community settings could work together to enhance culturally sensitive end-of-life care within ethnically diverse faith communities/groups, which would overall enhance death literacy amongst these communities.

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Appendix A: Interview prompts

- What cultural or religious practices surrounding death and dying are important within your faith community?

- Do you think people find it easy to talk about death and dying within your community?

- Are there specific customs, rituals, or practices within your faith or culture that help facilitate or encourage discussions about end-of-life wishes and care preferences?

- What challenges have you observed or experienced when trying to honour cultural and religious beliefs about death in healthcare or community settings, and how might these be addressed?

- How can healthcare providers and community leaders better engage with ethnic minority faith communities to ensure that death and dying are discussed in a culturally sensitive and respectful manner?

- What do you think healthcare professionals need to know and understand to ensure that discussions about death and end of life are culturally sensitive and respectful?

- What is the best way to share information with people in your faith community about initiatives to support conversations about death and end of life care?

- What specific cultural or religious teachings about death and the afterlife from your faith community should be included in educational efforts to improve death literacy, and how can these teachings be communicated in a respectful and engaging way?

The Art of Living & Dying Well



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This research project was conducted by Dr Marianne Rozario (Research Assistant) and Associate Professor Maggie Doherty (Lead) from the Centre for the Art of Living and Dying Well at St Mary's University, Twickenham and supported by Professor Sara Spear, Professor Karen Sanders, Professor Jacob Phillips from St Mary's University. The work was supported by the joint efforts of Birmingham Diocese Interreligious Commission, Lancaster University Medical School and the Royal Marsden. The authors wish to acknowledge the support and resources provided by the Participatory Research Fund, Research England which has made this study possible.



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