Understanding End-of-Life Care within BAME Communities

Contents

Background

Sunderland Bangladesh International Centre (SBIC) is an established community anchor located in Hendon, Sunderland, which has an IMD score of 1%. Formed in 1999 by the local Bangladeshi and Black Asian Minority Ethnic (BAME) community, the SBIC board comprises 20 Black and minority ethnic leaders elected by a Black and minority ethnic membership base of 1,847. Trustees meet monthly to monitor, review, and frame strategy. Supported by a small multicultural staff team, the officers are responsible for day-to-day operations. SIBC's membership base is 1,847, of which 1,524. black and minority ethnic background members voted in this year's AGM, with an 82.5% turnout rate; there were 850 males (55.9%) and 674 females (44.2%) who voted, and 113 young people aged between 18-24 also voted.

In collaboration with Macmillan Cancer, the Sunderland Bangladesh International Centre (SBIC) wishes to improve the palliative and end-of-life care needs of Sunderland's local BAME population. This is phase three of our project to improve care facilities and services tailored to the needs of the BAME community. This collaborative effort is driven by a shared commitment to ensure that BAME individuals receive compassionate and culturally sensitive end-of-life care after a diagnosis of cancer that meets their unique needs and preferences. Through this partnership, SBIC and Macmillan Cancer Support seek to address existing gaps in service provision and work towards achieving more significant equity in end-of-life care for BAME communities.The project is led by Nahida Aktar.

A recent The NHS Race and Health Observatory. Ethnic Inequalities in Healthcare: A Rapid Evidence Review February 2022, observed that:

> *'Ethnic inequalities in health and care outcomes are evident at every stage throughout the life course, from birth to death'[1].*

According to the 2023 JSNA report

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[1] https://www.nhsrho.org/wp-content/uploads/2023/05/RHO-Rapid-Review-Final-Report_.pdf

"There are more people in Sunderland living with, and prematurely dying from, cancer, cardiovascular disease, and respiratory disease than elsewhere in the country"[2].

We have conducted in-depth interviews and explored the experiences of three culturally and linguistically diverse communities about their recent care support and hospitalisation and access to interpreters, including the Bangladesh Community, Indian Community and African Community. We also conducted focus groups with 47 local families in receipt of care and carried out a BAME care survey with 120 respondents, in addition to 4 Stakeholder structured interviews with local Islamic scholars.

Our research and consultation indicate that a culturally competent health and social care service can help improve health outcomes and quality of care and contribute to eliminating racial and ethnic health disparities.

In the UK, older ethnic minority people are among the most deprived and excluded groups in society. This is reflected in studies which show increased rates of poor health and well-being[3] and fewer socio-economic resources among migrant and ethnic minority older people. The reasons behind these inequalities are rooted in racism and socioeconomic disparities. There is a large body of evidence showing the association between experiences of racism and poor physical health[4] , as well as the effects of vicarious racism (racism experienced by family members) on ethnic minority people's health[5].

A recent review into Black and minority ethnic Inequalities in Healthcare by the NHS Race and Health Observatory, published in February 2022, highlighted ongoing Black and minority ethnic inequalities across several focus areas, including mental health care, maternal and neonatal health care, and the NHS workforce[6]. Socially, ethnic minority older people are more likely to be lonely[7], leading to social exclusion.

[2] Joint Strategic Needs Assessment Summary 2021–22. https://www.sunderland.gov.uk/media/24522/Sunderland-JSNA-2021-220-Oct-Review/pdf/oce22413_Sunderland_JSNA_2021-22_Oct_Review_Web.pdf?m=637865705944230000

[3] Bécares, L. (2015). Which ethnic groups have the poorest health? In S. Jivraj & L. Simpson (Eds.), Ethnic identity and inequalities in Britain (pp. 123–140). Bristol: Policy Press
Evandrou, M., Falkingham, J., Feng, Z., & Vlachantoni, A. (2016). Ethnic inequalities in limiting health and self-reported health in later life revisited. Journal of Epidemiology and Community Health

[4] Williams, D. R. Lawrence, J. A., & Davis, B. A. (2019). Racism and Health: Evidence and Needed Research. Annual Review of Public Health

[5] Heard-Garris, N. J., Cale, M., Camaj, L., Hamati, M. C., & Dominguez, T. P. (2018). Transmitting Trauma: A systematic review of vicarious racism and child health. Social Science & Medicine

[6] NHS Race and Health Observatory, Ethnic Inequalities in Healthcare: A Rapid Evidence Review, February 2022

[7] Salway, S. Such, Preston, L. Booth, A Zubair, M Victor, C & Raghavan, R. (2020). Reducing loneliness among migrant and ethnic minority people: a participatory evidence synthesis. Public Health Research and
Victor, C. Dobbs, C Gilhooly, K. & Burholt, V. (2021). Loneliness in mid-life and older adults from ethnic minority communities in England and Wales: measure validation and prevalence estimates. European Journal of Ageing,

Across the UK, more people from Black and minority ethnic backgrounds are likely to be in poverty (i.e., have an income less than 60% of the average household income) than white British people[8]. According to the ONS[9] i, nin2019, 29% of Bangladeshi, 24% of Pakistani and 22% of black children were living on low incomes and suffered material deprivation (i.e., a family income less than 70% of the average income before housing costs).

The key message from the research work is that connecting with socially isolated people aged 50+ in BAME communities needs genuine, interested people who understand the community in which they work. Connecting people to projects or programmes needs trust, and activating the community's strengths can help this happen. Be aware that filling out forms may be a considerable barrier that generates distrust, particularly for people who have experienced challenges with immigration or benefits. Be wary of stereotypes and take time to co-research and understand communities when seeking to connect with socially isolated people within them.

In 2010, the Marmot Review highlighted that people from disadvantaged backgrounds were more likely to have underlying health conditions and shorter life expectancies. Marmot asserted that outcomes.

> "Were *even worse for minority ethnic population groups and people with disabilities*".

In addition, these communities were more likely to be impacted by the broader determinants of health, such as housing, education, employment and access to healthcare that intersects with their age, sex, religious beliefs, ethnicity, and gender.

Ten years after the first Marmot Review, the outbreak of COVID-19 in 2020 highlighted the inequalities that still exist and just how disproportionately the virus impacted the BAME population with a greater risk of mortality and morbidity. Marmot Review 2020[10] also again outlined "clear systematic inequalities".

In addition to health inequalities, the structural, institutional, and interpersonal drivers of racism have a direct impact on the physical, mental, psychological, and physiological well-being of BAME communities. These are outlined in the Turning the Tide Strategy[11] , which states.

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[8] https://irr.org.uk/research/statistics/poverty/
[9] https://www.ons.gov.uk/economy/nationalaccounts/uksectoraccounts/compendium/economicreview/february2020/childpovertyandeducationoutcomesbyethnicity#:~:text=In%20contrast%2C%20Indian%20and%20White,lower%20than%20the%20national%20average.
[10] Marmot, 2020
[11] Turning the Tide, 2020. https://www.england.nhs.uk/south-east/wp-content/uploads/sites/45/2020/10/SE-Turning-the-Tide-Strategy.pdf

"Once we understand the way BAME health inequalities are driven, we need to consider how our daily decisions and considerations either reaffirm and strengthen the elements that will lead to more inequality in health and society, or we can actively and consciously look to dismantle these through how we deliver our core functions".

Evidence shows that health outcomes are much poorer when there is a lack of 'Culturally Appropriate Care'[12]. Improving cultural responsiveness can not only remove barriers to accessing healthcare but may also reduce inequitable health outcomes for marginalised and vulnerable groups.

Culturally appropriate care, sometimes called 'culturally competent care', is sensitive to people's cultural identity or heritage. It means being alert and responsive to beliefs or conventions that might be determined by cultural heritage. Cultural identity or heritage can cover a range of things. For example, it might be based on ethnicity, nationality, or religion. Or it might have to do with the person's sexuality or gender identity. Lesbian, gay, bisexual, and transgender people have a particular culture. So do Deaf people who use British Sign Language[13]. A person's cultural background can affect their communication, decision-making, and health management. As a health professional, you must understand how culture impacts people's understanding of health, well-being, disease, and illness.

From our lived experience and evidence, we recognise that BAME users face significant challenges when talking to doctors, finding and understanding information, making treatment and care decisions, and accessing support. People need their culture to be recognised, and their cultural needs met to feel happy and comfortable.

Method of Work

To facilitate discussions around palliative and end-of-life care, it was essential to create an environment where participants felt comfortable to engage in such conversation, as they are generally considered a cultural taboo. SBIC is a cultural hub for the local BAME population, where

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[12] Department of Health (Victoria). Review of Current Cultural and Linguistic Diversity and Cultural Competence Reporting Requirements, Minimum Standards and Benchmarks for Victoria Health Services Project. [Literature Review]. Melbourne: Statewide Quality Branch, DoH; 2009 [updated 2009 Aug; cited 2018 Jan 16].
[13] https://www.cqc.org.uk/guidance-providers/adult-social-care/culturally-appropriate-care

individuals of all ages socialise, learn, and celebrate achievements. We chose this familiar environment for our participants where they feel comfortable learning and discussing attitudes towards end-of-life care and expressing their fears and concerns. We decided a focus group of 47 males and females of Pakistani and Bangladeshi origin, varying in age from 30-70, to gain a more comprehensive understanding of care needs. Our participants were Muslim so, our study and findings focus specifically on the needs of Muslim BAME individuals.

1) Focus groups

We felt that the best approach to address the lack of awareness of palliative and end-of-life care would be through an educational focus group and one-on-one conversations. The discussions were led by End of Life Care Facilitators from South Tyneside and Sunderland NHS Foundation Trust: Angela Laybourne, Karen Crammond, and Deb Spraggon, who is also the Macmillan Personalised Care Manager at South Tyneside & Sunderland NHS Foundation Trust.

Following these discussions, we conducted surveys from November 2023 to February 2024 with 47 respondents to gather quantitative data on their understanding, experiences, needs, and preferences. The survey included carefully selected questions designed to elicit information on the following:

- Awareness and understanding of end-of-life care services.
- Access to and utilisation of palliative care and support services
- Cultural and Religious Considerations in end-of-life Care Decision-making
- Perceived barriers and challenges in accessing end-of-life care services.
- Understanding of end-of-life medications such as morphine and other pain relief.
- Suggestions for improving the quality and accessibility of end-of-life care services for BAME communities.

The survey also included open-ended questions to allow participants to express their thoughts, concerns, and suggestions in their own words.

Core Stakeholders - Interviews with Religious Leaders:

It was important to us to conduct in-depth interviews with expert religious leaders: Lead Chaplain at County Durham and Darlington NHS Foundation Trust, Imam of Sunderland Central Mosque, Abu Shueb and Religious scholar and teacher at Blackburn Jamiatul Ilm Wal Huda Islamic School, Mufti Azad. We also conducted two stakeholder interviews, one from a broader UK context. A broader perspective on the cultural and religious considerations surrounding end-of-life care within the BAME community. These discussions included:

- Religious beliefs and practices related to end-of-life care and death.

- Perspectives on end-of-life care within the BAME community will be discussed, as well as how to address best misconceptions surrounding end-of-life care within the community.
- Challenges faced by community members in accessing appropriate end-of-life care.
- Recommendations for improving end-of-life care services for BAME communities.

By employing focus groups and interviews, this study aims to provide a comprehensive understanding of Sunderland's local BAME population's end-of-life care needs and preferences. Additionally, by engaging religious leaders, the study will ensure that cultural and religious perspectives, which play a vital role, are considered in developing recommendations for improving end-of-life care services.

Introduction

Palliative and end-of-life care refers to treating patients with incurable illnesses holistically. The aim is to provide relief and comfort to achieve the best quality of life for patients and their families/carers until they die. This can be in the form of either physical, psychological, social, and spiritual support. A report conducted by Marie Curie Cancer Care[14] has shown that there are significant disparities in the end-of-life care needs of the BAME community. This has also been concluded by studies which show how the socioeconomic disparities are rooted in racism and inequality. There is a great deal of evidence to suggest the clear link between experiencing racism and declining health[15]. Healthcare professionals are unable to meet the needs of individuals due to cultural, religious, and economic barriers, and thus, it is essential to improve cultural responsiveness to reduce inequitable health outcomes for marginalised groups. This report will explore these factors and how they contribute to misconceptions within the community that result in a reluctance to seek care.

Many of our users told us that they prefer to listen to and watch information rather than be given written content. This was often because they did not need to rely on someone to interpret or read it, which meant they felt more in control.

Feeling comfortable speaking about end-of-life care

The total of male respondents	17
Total of female respondents	30

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[14] Marie Curie Cancer Care. 2012. "Next Steps: Diversity and Inclusion Research." Accessed March 7, 2024. https://www.mariecurie.org.uk/globalassets/media/documents/who-we-are/diversity-and-inclusion-research/next_steps_report.pdf.

[15] Williams, D.R. Lawrence, J.A.,& Davis, B.A. (2019). Racism and Health: Evidence and Needed Research Annual Review of Public Health

- Our study showed that men, in general, were more comfortable speaking about end-of-life care compared to women. 53% of women under 50 felt uncomfortable compared to just 6% of men.

- 63% of female respondents did not feel comfortable talking to family and friends about the service and support available for palliative and EoL care. Our responses showed that women felt their sole responsibility was culturally and religiously to love and care for their family members without outside help.

- The majority of women in their 50s were not comfortable speaking about end-of-life care

Understanding and talking about the medication given in the last stage of life

- There was a lack of understanding amongst women in their 50s and over 50 regarding medication given in the last stage of life. In total, 53% did not understand what it was

- Some participants expressed concern regarding the medication as a 'killing' drug which 'speeds up' the dying process.

- Women 50+ were reluctant to speak with family and friends regarding the medication available because of the taboo surrounding it. Many respondents shared the misconception that the EoL pain relief medication quickens death. In South Asian culture and the Islamic religion, this would be seen as a form of euthanasia which is strictly forbidden.

- 11% of men who, in other topics, showed a unanimous understanding did not feel comfortable with this medication given in the last stage of life.

Having an idea about what support services are available for palliative and end-of-life care

- There was an overall lack of awareness of the services available at the hospice and reasons for referral within the female group.

- Women were generally reluctant to access services as it is culturally and religiously seen as a great sense of responsibility to care for their loved ones at home. 38% did not have any idea of what services are available.

- Reluctant to speak about support services to family and friends due to it being seen as not an option.

Culture and Religion

1. Misconceptions and understanding cultural and religious needs

Both culture and religion play integral roles in end-of-life needs within the BAME community. Sunderland Imam Abu Shueb states that in his experience.

"People are extra sensitive regarding religious needs in this situation', and many beliefs around end-of-life and death are shaped almost entirely by these factors; therefore, healthcare providers need to understand and be aware of this to provide the appropriate end-of-life care".

While all 47 of our respondents (from Muslim Bangladeshi and Pakistani backgrounds) found our educational sessions on end-of-life care to be helpful, 61% of female participants in our survey were still 'fearful' or sceptical of conversations around end-of-life care due to cultural taboos. These include religious influences such as the Islamic belief that life is in the hands of God and letting 'fate' play its part. Further, cultural factors such as not wanting 'outside help' in their most vulnerable state play a role. Therefore, our interviews with religious figures were imperative in working to clear these misconceptions.

63% also said they would not feel comfortable discussing the topic with family or friends. Many participants also placed the *'power of prayer'* above all else (i.e. end-of-life medication) and believed that *'only God can help'* at this time. Some also had a 'fear' of this medication and equated it to a 'death injection' - which was common in the 60-70 year old category. Saquibe Ahmed, Lead Chaplain at County Durham and Darlington NHS Foundation Trust, states that according to Islamic law, there is no ruling against using modern medicine to benefit a person's health or provide ease. He recommends that educational sessions from a religious figure within the community are vital to facilitate discussions around these misconceptions. However, he also stresses the importance of healthcare providers respecting patients' wishes to stay 'more conscious' without end-of-life medication to recite prayers, which is considered pivotal at this time.

Concern was expressed regarding the lack of prayer facilities, so services should ensure that suitable prayer facilities are provided for the patient. A care needs assessment for St Benedicts Hospice Sunderland by Chaplain Caroline Worsold and Sunderland Imam Yusuf Meah, who deals with Muslim and BAME patients in palliative care, notes that it is common for families of patients to wish for the direction of the bed to be facing the 'Qibla' i.e. Mecca. Facilities for ablution for patients and visitors should also be considered. Respondents also emphasised a need for help to perform 'ablution' (washing parts of the body before prayer).

Some participants also stated their distrust of healthcare providers, for example, holding that they'd be falsely told the medication is 'something else'; this shows the dire need to bridge the gap between the two groups. Religious scholar Mufti Azad states that healthcare providers liaising with religious leaders (i.e. local imam) is essential in building trust and credibility. This can be through frequent liaison and in the form of paperwork (a 'Fatwa' (religious ruling) approved by a religious

scholar) to provide to families who are against end-of-life medication to ease their concerns and clear misconceptions. Imam Abu Shueb also recommends that the local imam, preferably someone who knows the patient, 'be kept in the loop' as many BAME individuals are connected to the mosque their entire lives and 'would appreciate' an Imam visiting them in their time of need.

2. Role of family and community

There is a strong emphasis on family-centered values, and family members often play a significant role in the patient's care and decision-making, especially regarding treatment options. An overwhelming majority of participants stated that they wished to be around family rather than in a hospice during end-of-life treatment. Specifically, the elderly participants noted that the most important thing to them now would be the presence of family to provide comfort and religious support. Common themes in responses from participants saw caring for their loved ones when sick or dying as a great responsibility according to the Quran. This is so much so that a loved one dying in a care home setting would be regarded as a failure of the family. Carers UK also identified the idea of 'taking outside help' as being unacceptable to many BAME carers[16].

Concern was expressed that healthcare professionals would not know how to respect the specific requirements of Muslim women regarding their modesty. This was cited as a reason for bringing their elderly home rather than opting for a hospice. It was important to participants that their modesty and dignity be upheld during this time. Modesty is highly emphasised for both men and women, and religious scholar Mufti Azad adds that for older women, it is perhaps more so as….

> *"They live their whole lives without showing even their hair to their family members."*

Thus, ensuring that gender-specific care, as well as healthcare providers understanding these needs, is provided for the intimate needs of patients is vital to help preserve their modesty and dignity and thereby provide compassionate end-of-life care. Family presence during these examinations or private care needs would make the patient more comfortable.

The role of the community is also vital in providing adequate end-of-life care. NHS Durham Lead Chaplain Saquibe Ahmed emphasises this and states that for Muslims, visiting the sick is seen as a religious duty, so improving visiting facilities should be considered, especially for those without family. Concerns were also expressed at the focus group regarding the limited number of visitors. Community values are held very highly in Islam, and so this would be a significant spiritual need for patients to be around those of the same religious background. However, if an excessive number of visitors is unsuitable for the patient's needs and leads to distress, Imam Yusuf Meah recommends that the family explain these reasons. Imam Abu Shueb adds that healthcare providers liaising with community leaders would also benefit those patients without family to provide comfort and support.

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[16] Carers UK, Half a Million Voices: Improving Support fo BAME Carers (London: Carers UK, 2021), https://www.carersuk.org/media/mb1f2xoa/bame-report-half-a-million-voices.pdf

Postmortem

There are specific religious rituals which Muslims follow when a person becomes deceased. These include removing external items on the body, reciting specific chapters of the Qur'an, and straightening the body. This is followed by religious ablution (ghusl), which, in Islamic belief, cleanses the body physically and spiritually. Healthcare providers need to be aware of any contacts within the Sunderland Muslim community who have been designated to deal with postmortem needs, such as funeral directors. Imam Abu Shueb also recommends that a local imam help the family best navigate any rituals following death during this emotional time.

It should be noted that Islamic teachings emphasise the prompt burial of the deceased. The care needs assessment recommends avoiding taking the deceased to the mortuary if possible. Imam Yusuf Meah adds that the mosque is willing to pay for non-invasive MRI scans if needed for families who are against postmortem for religious reasons. Mufti Azad emphasised the importance of completing the logistics of death to ensure that the Janazah (Islamic funeral) can occur within 24 hours of passing. Healthcare providers should issue death certificates promptly to expedite the process. This underscores the importance of accommodating religious practices and beliefs within the framework of end-of-life care services for the Muslim BAME community.

Linguistic barriers

Linguistic barriers can significantly impact the quality of end-of-life and palliative care for patients and their families. Carers UK has also identified this as a leading challenge BAME careers face. Language barriers can cause misunderstandings, miscommunication, and anxiety in patients, so the appropriate interpreters must be involved in accommodating and explaining the patient's needs adequately. Translated material in the form of information leaflets should also be made available to patients and families to help them navigate the process. Many participants also wished for family members to explain their needs, with females expressing they would only feel comfortable explaining pain management needs with their female family members or female staff who understand these cultural needs. Gender-specific care and cultural competency training will also be applied here.

Economic factors

Economic factors significantly affect the ability of low-income Black, Asian, and Minority Ethnic (BAME) individuals, as well as those living in impoverished areas, to access adequate end-of-life care. These communities often face barriers due to financial constraints, limited healthcare access, and low literacy rates in their neighbourhoods.

In deprived areas, individuals may struggle to access healthcare services due to financial limitations and a lack of awareness about available support services. Moreover, low literacy rates

exacerbate this issue, as individuals may not fully comprehend the available resources and assistance.

Housing instability further complicates matters, as inadequate living conditions make providing suitable end-of-life care at home challenging. Resolving housing issues becomes paramount because many prefer to receive care in familiar family environments rather than hospices. Additionally, providing specialised medical equipment, which may otherwise be financially out of reach, in their homes can help meet the care needs of patients.

To address these challenges, education programmes must specifically target and include BAME individuals from low-income backgrounds. These programmes should provide information about available services and help with transportation to ensure access to these services.

By addressing these economic disparities and providing targeted support, we can work towards ensuring that all individuals, regardless of their financial status or ethnic background, receive the end-of-life care they deserve.

Matrix of Cultural Appropriate Care Responses.

Area of potential need or concern	Responses to help define culturally appropriate care
Food and drink	• Certain utensils may need to be provided, and some people may prefer to eat with their hands. • If someone is from a culture where it is polite to refuse food the first time they are offered, you may need to provide the food 2 or 3 times. • If someone follows a Kosher or Halal diet, food may need to be prepared differently to avoid cross-contamination.
Communication	• Use the correct language - learn some keywords and phrases. • Use interpreters and advocates to support communication needs. • Provide literature or access to TV shows with subtitles or in a language the person can understand.
Religion and spirituality	• We are providing religious or spiritual items like pictures, prayer beads, spiritual statues, or holy books. • Support is needed to attend church, gurdwaras, mosques, or temples. This may include allowing time before or after a service to talk with their religious community. • To access online services as an alternative to face-to-face services. • Support praying at certain times and having a suitable space to do so. • Support eating at different times or eating a different diet during religious festivals like

	Ramadan or Chinese New Year. • Support is needed to ensure the hair/beard is maintained in line with cultural expectations. • To arrange for a local priest or religious leader to visit the home.
Health care	• I am checking if medicines contain ingredients such as gelatine or other animal products. These may not be suitable for people following a Kosher or Halal diet and will also not be suitable for vegetarians or vegans. • They are reviewing medication timings with a GP to support the person in taking part in Ramadan or another cultural event where the effectiveness of the medication could impact their ability to engage in the artistic event. • Consult with a GP to support someone taking complementary or alternative medicines in line with their cultural beliefs—for example, Kola Nut or Miswak.
Clothes and personal presentation	• They are supporting people in dressing in line with their culture. This could be every day or for family visits or special events.
Personal and shared space	• They are supporting people in personalising their room with objects that are important to them. • To decorate and furnish shared spaces that promote the culture of people living there and do not cause offence.
Activities / Community connections	• I was watching TV shows or listening to important music. • They are playing a particular game with cultural importance. • Support to visit a community event like a carnival, Mela or art event. • Support to volunteer in a charity shop or at a charity event. • Support to fundraise for a charity closely associated with someone's culture.
Emotional support	• They are supporting someone to talk about past events and memories if they want to or facilitating access to emotional support to deal with traumatic experiences.
End of was reading	• Arranging for Imam or religious leader to vist family. • Arranging funerals and burials in line with cultural beliefs and customs. It is clearing misconceptions regarding EoL medication, which is seen as a form of euthanasia or 'quickening' death. This can be done in a religious ruling document ('Fatwa') or a one-to-one with a trusted religious scholar. • Awareness of postmortem Islamic rituals: - Facing the head towards the direction of

	Mecca (Qibla)
	- Straightening the body (hands by the side, etc)
	- Closing the mouth/ covering the mouth
	- Recitation of specific Quranic chapters by chaplain or family members
	- Islamic ablution (ghusl)
	- Burial Certificate of death and registration to be issued as soon as possible to ensure a prompt burial, which is vital for Muslims

Recommendations: From our lived experience, BAME users face the constant challenge of stereotyping diverse communities. This often sees these communities as homogenous (pretty much all the same) and isolated primarily because of 'cultural factors' rather than excluded through systemic features such as under-investment of inappropriate support, mechanistic processes for accessing support, and lack of flexibility within mainstream provision.

1. Cultural and Religious Competency Training: Healthcare providers should receive cultural competency training to understand better and address BAME patients' cultural and religious needs. Educational sessions facilitated by religious leaders and community engagement can help dispel misconceptions and build trust between healthcare providers and patients. Imam of Sunderland Central Mosque Abu Shueb, Imam of Baytul Ilm Madrasa Yusuf Meah, and a former Public Health Practitioner would be suitable figures for this as they have ample experience and connection with Sunderland's BAME Muslim community as well as dealing with end-of-life and death. Frequent liaison between religious leaders and healthcare providers would also help bridge the gap between the BAME community and healthcare providers. This would also help educate healthcare providers on how to best approach the care needs of patients in their last moments and postmortem.

2. End-of-Life Care Planning:
Encouragement and support should be provided to BAME individuals and families in developing advanced care plans that align with their cultural and religious beliefs and preferences. This can be in the form of providing resources and guidance for families navigating postmortem rituals with the help of local religious figures. Also, it is crucial to ensure timely completion of the logistics of death to facilitate prompt burial following religious practices.

3. Improving Linguistic Services: Provide professional interpreters and translated materials to facilitate effective communication between healthcare providers and patients.

4. Financial Support: Develop programmes to assist low-income BAME individuals in accessing end-of-life care services, including transportation assistance and provision of specialised medical equipment in patients' homes.

Conclusion

The disparities in end-of-life care within BAME communities are multifaceted, often stemming from cultural, religious, linguistic, and economic barriers. This report has shed light on the complexities surrounding end-of-life care within BAME communities, mainly focusing on the Muslim Bangladeshi and Pakistani communities. It has also emphasised the need for culturally appropriate care that is sensitive to the cultural identity of the BAME Muslim population in Sunderland.

Misconceptions and fears surrounding end-of-life medication, as well as the importance of religious rituals and family-centered care, underscore the need for culturally sensitive end-of-life care services. By engaging with religious leaders, conducting focus groups, and surveys, this study has provided valuable insights into the specific needs and concerns of Sunderland's local BAME population regarding end-of-life care. Recommendations such as educational sessions led by religious figures and improved communication between healthcare providers and religious/community leaders have been identified as essential steps towards providing culturally sensitive end-of-life care services for BAME communities.