> I think culturally that's our nature. As Muslim children you're thinking about your loved ones... family orientated. Yes we can be emotionally attached. Especially if they're suffering, then definitely you suffer.

Muslim Voices

The palliative care needs of British Muslims during the Covid-19 pandemic and beyond

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Foreword from Matthew Reed

Everyone deserves the best possible end of life experience. For too many people in need of palliative and end of life care and their families, the reality falls far short of this.

Too often, it is those who have been most likely to experience health inequalities throughout their lives who are most at risk of a poor end of life experience. The Covid-19 pandemic exacerbated these pre-existing health inequalities and disproportionately impacted the health of people from minority ethnic groups.

Understanding the complex intersectionality of religion, ethnicity, national identity, family living situation and locality is vital to understanding these health inequalities.

This report, a collaboration between Marie Curie, the Muslim Council of Britain, University College London, and the University of Leeds, brings together the experiences of a group of British Muslims with palliative care needs in London during the Covid-19 pandemic. It highlights examples of families, communities and organisations coming together to support Muslim people with palliative care needs during different waves of the pandemic. It also underlines the importance of ensuring that service providers and policymakers who are making decisions affecting the lives of Muslim people at the end of life create meaningful opportunities for families and communities. These opportunities should engage families and communities in sustained dialogue and shape the design and delivery of health policies and services.

We call for a person and family-centred approach to health and social care for people in need of palliative care and their families. This approach should consider the dynamics, norms and preferences within families and personal wishes and preferences – not for only medical care but for the full range of social, cultural and religious needs and circumstances. We also call for greater recognition of the resources, assets and strengths that Muslim families and communities can bring to end of life care, and to the creation of compassionate communities around people at the end of life.

As the UK's leader in end of life experience, Marie Curie is committed to investing in high-quality research evidence and engaging with decisionmakers to better understand and address inequalities and inequities in palliative and end of life care.

This year, Integrated Care Systems in England will embark on delivering their first ever legal duty to commission palliative care services contained in the Health and Care Act. We hope this report can help ensure Muslim voices are clearly heard in conversations about commissioning of palliative care services for local populations under the new act.

Everyone deserves the best possible end of life experience, but improving access to and experience of palliative and end of life care for all communities will require concerted action by national and local government, commissioners, and service providers like Marie Curie.

We look forward to working with all of you to make this a reality.

Matthew.

Matthew Reed, Chief Executive, Marie Curie

Foreword from Zara Mohammed

With the long-awaited inquiry beginning in October of this year, we find ourselves reflecting on the impact the pandemic has had on all our communities since its outset. As such, this report is a timely intervention. For British Muslims, both serving on the frontline as key workers and for those in some of the most socio-economically disadvantaged areas in the UK, the impact of the pandemic has been felt to devastating effect.

This report highlights the deep-seated nature of health inequalities and their particular prevalence within British Muslim communities. Evidence from Public Health England and Office for National Statistics confirms that minority ethnic groups had the highest rate of Covid-19 deaths; 1 in 3 of minority ethnic groups are British Muslims and further evidence shows British Muslims experiencing unmet needs towards the end of life. With a diverse and growing population, the release of this report presents an important opportunity to better understand the intersectional nature of these issues and the policy and political intervention required to make sure we have a system that works to address these inequalities.

From the outset of the Covid-19 pandemic, the Muslim Council of Britain and its partner organisations have worked tirelessly to provide for British Muslim communities across the UK. Throughout the course of this grassroots engagement, we have spoken to everyone from families who have suffered loss across generations within a household, to the funeral care providers specialising in Muslim burials who were struggling to meet the exponential increase in demand for bereavement care and support. We listened and paid heed to healthcare workers on the front line who warned of the disproportional impact Covid-19 was having on ethnic minority communities, long before it was acknowledged in mainstream discourse. This period of intensive learning has reaffirmed the systemic nature of inequality, health-centric or otherwise, and the pressing need for an evidence-based, multi-channel approach to addressing it.

I am grateful for this partnership with Marie Curie, the work undertaken by their teams and the MCB's own Research and Documentation Committee, and I welcome the release of this vital piece of work. Together, may we continue to strive to affect change for the betterment of society, the common good.

Zara Mohammed , Secretary-General, Muslim Council of Britain

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Executive summary

The Covid-19 pandemic has exacerbated pre-existing health inequalities and disproportionately impacted the health of people from minority ethnic groups. Evidence from Public Health England and Office for National Statistics notably shows highest Covid-19 deaths among people from minority ethnic groups, and almost 1 in 3 of minority ethnic groups are British Muslims.

Muslims comprise 4.8% of the total population and are the second largest religious group in England and Wales, with 77,000 living in Scotland and 3,800 in Northern Ireland. The majority are living in Greater London and nearly half of Muslims in England were found to be living in the 10% most deprived Local Authority Districts. Although diverse, Muslims were predominately from Asian Pakistani and Asian Bangladeshi ethnic background.

Evidence suggests British Muslims experience unmet needs towards the end of life. Challenges can include limited training of healthcare professionals regarding faith and cultural values and their implications on care plans. In addition, there is a lack of awareness of palliative care services among British Muslims.

This report draws on collaborative peer research conducted by Marie Curie, Muslim Council of Britain, University College London (UCL) and the University of Leeds in which the experiences of British Muslims (patients and carers) with palliative care needs during the Covid-19 pandemic are explored, and recommendations proposed.

This report describes how the British Muslims with palliative care needs and their families involved in our research experienced delays and challenges in accessing health and social care support and treatment. Families described feelings of increased responsibility, isolation and anxiety while patients felt unsure about how to access information or support for their care needs. The shift to online and virtual delivery of care compounded challenges to access as a result of digital exclusion. The physical and mental health of the people that we spoke to were adversely affected and people felt forgotten in the system.

The families that we spoke to felt that the cultural needs of British Muslims had not been considered in the development of Covid-19 guidance or its implementation, meaning that they were adversely affected by them. Variation was clear in the level and availability of support from British Muslims with palliative care needs from both local councils, community and faith groups. Where support worked well, it was delivered in partnership with community and faith groups, but many worried about other vulnerable and older people with limited family support.

Although there is emphasis and recognition of the active role families played in supporting loved ones with palliative care needs, it must not be assumed that British Muslim families should take on those roles alone and unsupported by health and social care infrastructure.

Background to the report

British Muslim communities in the UK

Muslims are the second largest religious group in England and Wales with 2.71 million people belonging to this group (4.8% of the population). A further 77,000 Muslim people live in Scotland and 3,800 in Northern Ireland (1). More than a third of the Muslim community lives in Greater London, with other large populations in the West Midlands, Northwest and Yorkshire and Humberside (2).

British Muslims come from diverse ethnic backgrounds and cultures. The largest ethnic groups among British Muslims are Asian Pakistani (38%) and Asian Bangladeshi (15%) followed by 11% from other ethnic groups which includes those who identified as Arab, 10% from Black ethnic groups and 8% from White ethnic groups including British and Irish (2). According to a Muslim Council of Britain analysis of the 2011 Census, nearly half of Muslims in England are living in the 10% most deprived Local Authority Areas (2).

Health and palliative care need among British Muslims

There is a need for palliative care services that are accessible to all, particularly for groups that may have historically had poor access to them, such as those from minority ethnic backgrounds. Older Muslims (aged 65 and over) have a higher prevalence of chronic illnesses such as diabetes, heart conditions and high blood pressure than the rest of the UK population (3). Older Muslim women are twice as likely to report having “bad” or “very bad” health than the general female population (3).

The unmet need for end of life care amongst British Muslim was identified before the pandemic. This need is reflected in poor uptake of advanced care planning and hospice services, including community-based services and on-site care.

During the Covid-19 pandemic, existing inequalities faced by people from minority ethnic backgrounds were exacerbated. The highest rates of Covid-19 deaths were within minority ethnic groups. People of Bangladeshi ethnicity, for example, had twice the risk of death of White British people (4). Covid-19 patients from Black, Asian and other minority ethnic groups also waited longer to be referred to palliative care services (5), while hospice and palliative care teams found Covid-19 policies such as visiting restrictions and the need to wear personal protective equipment had disproportional adverse impacts on people from minority ethnic groups, including communication challenges and unmet religious and faith needs (6).

Studies have indicated that during the Covid-19 pandemic, people from minority ethnic groups living with dementia and their family carers expressed distrust and confusion around Covid-19 messaging from the UK Government, as well as concerns about prejudice and a lack of person-centred and culturally sensitive care from healthcare professionals (7). A recent UK study exploring access to bereavement services found that nearly half the groups identified with unmet support needs were from minority ethnic groups (8).

It is clear that we need to learn more about the experiences of groups such as British Muslims who experience health inequality and barriers to the health and social care support that is vital to a good end of life experience. This report outlines the findings and recommendations from a collaborative project undertaken by Marie Curie, the Muslim Council of Britain, University College London and the University of Leeds and examples of good practice. We hope that the voices in this report, and the recommendations provided will be useful in tackling the inequity that we have observed and improving end of life experiences for people with palliative care needs and those close to them.

We have used the APA guidance for the language/terminology on ethnicity and ethnic group names in this report. American Psychological Association. (2019). Racial and ethnic identity. https://apastyle.apa.org/style-grammar-guidelines/bias-free-language/racial-ethnic-minorities

Key findings of this study

1. Covid-19 impacted the physical health of this group of British Muslims. This potentially accelerated the physical decline of people living with chronic conditions and neurodegenerative diseases as a result of delayed access to healthcare, difficulty in getting medication and reduced social interaction and movement.
2. Covid-19 had significant implications for the mental health of the people with palliative and end of life care needs and their families involved in this study. Certain groups experienced particular challenges including people living with dementia and their carers, elderly people who were shielding and those who had experienced multiple deaths or were unable to carry out traditional funeral services and rituals.
3. Participants described a ‘postcode lottery’ in local support. Some people received good support from their local council, local communities, and mosques, and others were not offered any support at all. Many worried about more vulnerable people than themselves, particularly those who had limited family support.
4. British Muslims with palliative and end of life care needs experienced challenges in accessing healthcare services during the Covid-19 pandemic. Older and more vulnerable groups such as those living with dementia faced language barriers, digital exclusion and challenges adjusting to telephone and video consultations.
5. Family members were central in supporting people with palliative and end of life care needs.
6. British Muslims with palliative and end of life needs had trouble accessing clear, concise information relating to Covid-19 that met their needs.

Recommendations

1. Providing culturally appropriate services

Organisations delivering or commissioning health and social care services should:

- Ensure that local services are designed to meet the cultural needs of the local population. Providers and commissioners should work with local communities to understand these needs and ensure they are reflected in service design and delivery. Examples of this could include ensuring diversity in workforces, and including representatives from British Muslims and other faith groups in patient panels.

Improve access to advice and support for people with palliative care needs:

- A designated telephone line for people with palliative and end of life care needs and their carers should be available 24/7, in every part of the UK. This service should be accessible to all who need it. For example, providing support in multiple languages or access to interpretation services.

2. Supporting family and carers of British Muslims with palliative care needs

Organisations delivering or commissioning health and social care services should:

- Promote person and family-centred care which considers the dynamics, norms and preferences within each individual family and for each individual.
- Ensure that every family or carer is offered a fast-track carer needs conversation and that recommendations are acted upon promptly.
- Ensure that carers have access to the information, support, and services they need to meet their own needs – including social and religious needs - as well as those of the person for whom they are caring. Support to access existing services should be provided and information should be available in a variety of formats, languages and places.

Statutory services should proactively work with community networks and organisations to:

- Identify individuals and families that may have additional health and social care needs, such as those related to social isolation or advanced ill health and support these individuals and families to access health and care services.

3. Tackling health exclusion through early involvement

The Department for Health and Social Care, NHS England and the Office for Health Improvement and Disparities should:

- Ensure that organisations representing British Muslims are involved in the design of public health policy and messaging.
- Increase resourcing for community outreach activities aimed at ensuring health and social care services reach underserved communities, and address inequities in access.

The Department for Health and Social Care, NHS England and Improvement, Local Authorities and organisations delivering health and social care services should:

- Ensure that British Muslims and organisations that represent them are involved in the design and delivery of digital inclusion activities, to ensure that British Muslims have equal opportunities to develop the skills and confidence to engage with health and social care services digitally.

Palliative and end of life care researchers and organisations should:

- seek to involve a diverse range of people in the projects that they undertake across all stages of project development and implementation.

4. Information sources and needs

Organisations delivering or commissioning health and social care services should:

- Proactively work with local community groups and organisations that work with British Muslims to raise awareness of existing palliative and end of life care services and sources of support for people living with terminal illness in the local community, supporting people to access these services when needed.
- Work with local communities and organisations that work with British Muslims to ensure that literature, guidance and materials about palliative and end of life care services are representative and reflective of the cultural needs of all groups, including British Muslims.

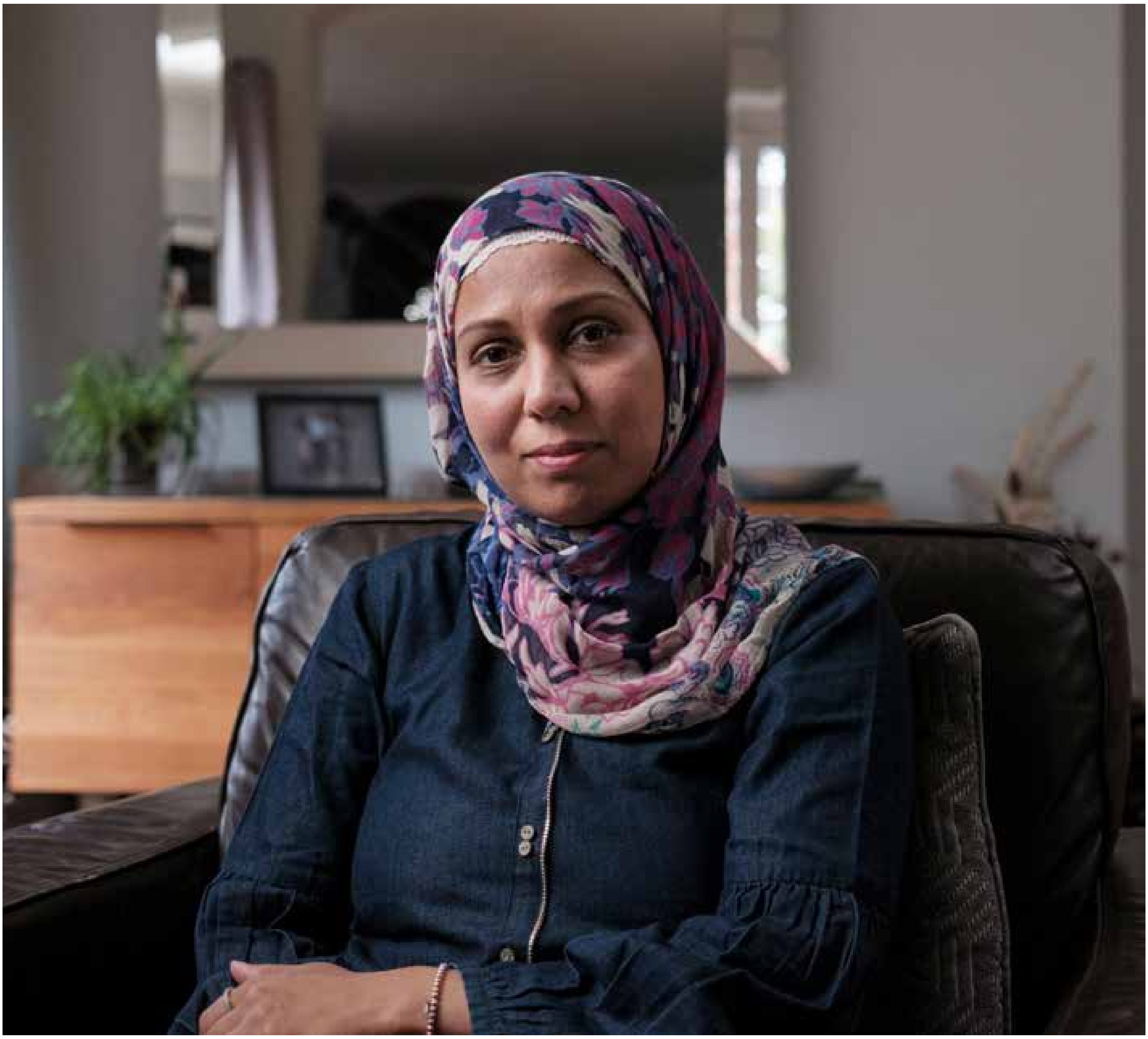


Photo credit: James Rippingale/Marie Curie

Working with the British Muslim community to explore issues for people with palliative or end of life care needs

This report contributes to our understanding of the experiences of British Muslims in need of palliative care and their family carers during the Covid-19 pandemic but has wider implications for health and social care. Based upon peer research conducted in collaboration with Marie Curie, the Muslim Council of Britain, University College London and the University of Leeds this report provides practical recommendations with the potential to improve support for British Muslim with palliative care needs and their families in the UK.

What is peer research?

Peer research involves people with lived experience of an issue playing an active and integral part in the research process, from developing the questions to be answered, collecting and analysing data and sharing the findings (9). Benefits of peer research include facilitating access to participants and shaping the topic guide, interpreting findings and shaping recommendations.

What did we do?

Together, the Muslim Council of Britain and researchers from Marie Curie, UCL and the University of Leeds identified, recruited and trained people from the British Muslim community to act as peer researchers in this project. Marie Curie provided training in qualitative research methods to the peer researchers and supported them to carry out telephone interviews with British Muslims with palliative care needs and their families using a codesigned topic guide.

As part of the research team, the peer researchers were also involved in the qualitative analysis of the data collected and the shaping of the recommendations stemming from the report.

Who took part in the interviews?

11 interviews were undertaken by three peer researchers between August and September 2021, with 12 participants sharing their experiences. Pseudonyms have been assigned to participants throughout this report. This is to protect the identity of participants in this study.

Limitations

Given the snapshot nature of this research, the sample recruited was small and the ethnic representation of British Muslims was limited. The experiences of people with heritage from other parts of the world are not represented in this report and warrant further exploration. In addition, all participants in this research were supported by family members. We acknowledge that relationships within families differ and not everyone has the support of family members.

Who took part in the interviews

Medical condition

1	Arthritis
1	Multiple Sclerosis (MS)
1	Heart failure + Rheumatoid Arthritis
1	Dementia
1	Cancer

Ethnicity

2	Bangladeshi
1	British Bangladeshi
2	Pakistani British
3	Pakistani
2	Punjabi
1	Indian
1	Asian

Who was interviewed

5	Patient
7	Carer

Gender

7	Male
5	Female

Age

58.8

Average age (35-85)

Interview language

11	English
1	Urdu

What did we learn about experiences of British Muslims with palliative care needs and their carers during the Covid-19 pandemic?

Section 1. Covid-19 impact on the physical and mental health of British Muslims

The Covid-19 pandemic and the series of lockdowns that restricted social interaction negatively impacted the physical and mental health of British Muslims with palliative care needs in a number of ways.

Accelerated physical decline

Delayed access to regular health check-ups as well as procedures

Reema is a 42-year-old female from Pakistani British ethnic background living with multiple sclerosis. She is unable to work. She had to self-manage the pain she was experiencing during the pandemic because of difficulties accessing healthcare services. By the time her issue was finally addressed it had reached an alarming state.

"When I had the problem in my legs, when it was seen, at that point, it was an alarming state. So if I had been seen earlier, then I wouldn't have been through so much pain. I kept getting in touch with my GP but it wasn't addressed in the right time." Reema

Difficulty accessing medication and treatment

Saad, a 56-year-old man from Pakistani ethnic background who is a family carer, felt that access to medication and treatment could have slowed down the onset of his father's dementia. Because of the pandemic, he felt his dad was forgotten in the system and did not receive the medication that could have helped his condition.

"I think we could have slowed it down had we got the right medication or the right treatment, but I think his onset was quite aggressive. And they did say that it could have slowed down, there were medications that would have slowed it down a bit." Saad

Reduced social interaction and movement

Shehzeen is a 35-year-old bereaved family carer. She describes how her father's physical health declined during the two and half years he was strictly shielding. The first time he had visitors was when restrictions were lifted and that is when he contracted Covid-19. He was later admitted to hospital and died.

"During the pandemic I noticed he became less independent. And more tired. And he was really independent. He pushed himself to stay independent. He used to go to the Mosque five times a day. So, that was his place where he gathered in congregation and socialised because it is just opposite our house. And he used to go for short walks outside. But during the pandemic obviously, he couldn't go to the Mosque. He couldn't go to his walks. So, I noticed that he deteriorated." Shehzeen

> She was traumatised by what was going on. And, you know, almost isolated from the world...

Heightened mental health issues

Isolation and anxiety

Participants highlighted how the Covid-19 pandemic negatively impacted the mental health of patients and carers alike. Isolation, loneliness and anxiety were common themes in people's experiences. Rayyan's mother is 80 years old and is living with several progressive debilitating conditions: inoperable spinal injury, diabetes, arthritis, and hearing difficulties. She was also the primary carer of her husband who had dementia. Rayyan described how his mother's own poor health in combination with her caring responsibilities increased her risk of experiencing mental health issues.

"So, I think the care element for people suffering with dementia was highly neglected during the pandemic. I think it creates a whole new issue psychologically for patients suffering with dementia. But, more importantly I think it impacts the carers of those people, so, yes, definitely impacted my mother a hell of a lot more. She was traumatised by what was going on. And, you know, almost isolated from the world you could say pretty much." Rayyan

Challenges faced by families experiencing multiple deaths and not being able to have traditional funeral services and visits

Saad's father, who was living with dementia, had lost his wife and wasn't able to mourn or see other people for support in the way he wanted. As he was shielding, he wasn't able to meet friends after Friday prayers as he used to do. Feelings of loneliness and isolation impacted his mental health.

"Mentally he was depressed because of mum's passing so that meant he needed to be really socially very active. At the same time the covid just was devastating because it also meant that he had to lockdown. Plus, I think a few of his friends died at the same time and they had covid funerals, they didn't die of covid but they had covid funerals. So I think all of that didn't help." Saad

Strength through faith

Faith played a strong role in the personal resilience of some people living with life-limiting illnesses through the ever-changing landscape of the Covid-19 pandemic. Shehzeen describes the important role that faith played for her father.

"He was very mentally strong. His faith played a great part in stabilising him during the pandemic. So, his spiritual connection was very strong. Very disciplined. And I think that aided him a lot in getting through the pandemic with patience and perseverance." Shehzeen

Section 2. Challenges in accessing healthcare for British Muslims with palliative care needs

The section describes the barriers British Muslims with palliative care needs and their families experienced when trying to access healthcare services during the pandemic. These included language barriers, delays in getting appointments, avoidance of hospitals and the perception systems were focused on Covid-19 at the expense of other conditions.

Adjusting to the shift in online or virtual care delivery

Participants described difficulties adjusting to the virtual care delivery that was necessary during the pandemic, such as telephone and video consultations. Saad describes the challenges his father, who is living with dementia, experienced in trying to get virtual support from his GP.

"He didn't trust the phone and the Zoom calls that were being given to him, so I think that was a problem for him. He would go to see the GP, you know, have the GP physically examine him and then give him medication and I think when that wasn't possible, he probably didn't cope with it right." Saad

The challenges experienced in accessing support created additional burden for family carers, who were already struggling to support their loved ones at home

"It was very difficult. We had to do mostly online consultations. So, you couldn't just call for a GP call back. And I had to wait as well. But it wasn't always practical for me to sit and do an online consultation. Like I said, he needed 24-hour supervision during the covid. When he had covid when he was delirious. So, I had to rely on other family members to call the GP. And talk to them. And, so, I couldn't really speak to the GP myself." Shehzeen

Delays and differences in accessing care

Many participants described how the healthcare system appeared to slow down during the pandemic, due to the high level of demand.

Hasan, an 85-year-old Indian man with cancer and various comorbidities who had experienced multiple recent falls, spoke about challenges and disappointments he encountered in trying to get an appointment with his GP for his vestibular neuritis.

"With all these comorbidities I expect some attention given to it. I called them on Monday, I couldn't get access to my GP. So on Tuesday I got access to a receptionist... and that somebody would ring me. Two days passed and no one has rung." Hasan

Another issue concerned language barriers. Rayyan, who cares for elderly parents, describes his mum's frustration at not being understood by staff when trying to book a GP appointment over the telephone.

> "We needed those services, but they just completely neglected everything else..."

"I remember my mum getting really stressed out because we couldn't get an answer from the doctors on how we can get this addressed. So, the receptionist wouldn't understand her maybe because of her accent. And my mum couldn't hear her properly. There's a language issue. My mum's English is good, but her native language is Pakistani obviously she needs someone who could speak that language, but you know we can't mention that all the time to the doctor's surgery." Rayyan

Hesitancy around hospital admissions as a result of compounded challenges of digital literacy, access and language barriers

Participants described concerns about their loved ones being admitted to hospital during the pandemic. This hesitation was related to Covid-19, concern about their loved one's ability to communicate with hospital staff due to language barriers, and concerns around losing contact with family members due to limited digital skills, limited access to digital devices and limited visitations. As highlighted by Shehzeen, for many families the decision to admit to hospital was a last resort when family could no longer provide the care required.

"He refused to go to the hospital, he was really scared he was going to be isolated. He can't speak English. He won't have any contact with family. He doesn't know how to use the smartphone. So, you know, I tried to treat him at home when he had diarrhoea, and my brother had to intervene. And he wore masks and PPE when he was cleaning him. Eventually, he wasn't passing urine. So, that's when we had to call an ambulance again and he went into hospital." Shehzeen

Negative experiences whilst in hospital, impact on patients and families

For some, fears around hospital admissions were not unfounded. Shehzeen describes the experiences of her father whilst he was in hospital.

"It was really difficult supporting him at home. It was even more difficult when he went to hospital and I had no access. It was really heart breaking. I insisted, I need to leave food for him because I left a phone for him. He did manage to answer the phone, because the nurses wouldn't even answer the phone for him. He told me he was really hungry." Shehzeen

Focus on Covid-19 and impact on those with palliative care needs

Participants with palliative care needs were frustrated that the provision of care for health conditions, including life limiting conditions other than Covid-19 were side-lined during the pandemic. Feelings of isolation and abandonment were common as highlighted by Reema, a 42-year-old British Muslim living with multiple sclerosis.

"I know Covid-19 is a serious health condition. I know it has taken lives. I know it has affected people and families but there were people who were unwell, like myself, for a long period of time, and we needed support. We needed those services, but they just completely neglected everything else, and the focus widely went to Covid-19. So that has been very disappointing, very, very disappointing." Reema

Recommendations: Providing culturally appropriate support

Organisations delivering or commissioning health and social care services to people with palliative and end of life care needs should:

- Ensure that local services are designed to meet the cultural needs of the local population. Providers and commissioners should work with local communities to understand these needs and ensure they are reflected in service design and delivery. Examples of this could include ensuring diversity in workforces, and including representatives from British Muslims and other faith groups in patient panels.

Improve access to advice and support for people with palliative care needs:

- A designated telephone line for people with palliative and end of life care needs and their carers should be available 24/7 in every part of the UK. This service should be accessible to all who need it, providing support in multiple languages or access to interpretation services.

Cultural competency or cultural safety?

Cultural safety rather than cultural competency has been suggested as an approach to tackle structural racism within existing systems. Components of cultural safety include professional development tools such as:

- Videos of patients describing their experiences of inequity or discrimination within services.
- Tools for professionals to support self-reflection on unconscious personal biases, privileges, and power imbalances in their interactions with their patients.
- Mechanisms for vulnerable patients to request carers from similar ethnic backgrounds if feeling culturally unsafe are also suggested (10).

Examples of good practice

Across the UK, there are examples of initiatives that aim to consider the needs of different communities, two are outlined below:

The Tameside and Glossop Mind dementia advisor commissioned by the Clinical Commissioning Group (CCG) in Oldham engages and raises awareness of dementia within minority ethnic communities where there may be limited awareness or stigma around the condition. The advisor is proficient in seven different South Asian languages and knowledgeable about the religious and cultural beliefs of the population. The advisor works with GP surgeries and memory services to ensure that the local diagnostic pathway is culturally appropriate. They also identify and engage with different organisations and hubs such as at places of worship and money transfer agencies where they could potentially engage with people from different communities (11).

A dementia worker in **Touchstone dementia services in Leeds** was commissioned by local CCG to engage with ethnically diverse communities about dementia. The dementia worker collaborates with local faith leaders to raise awareness around dementia to ethnically diverse communities. They also help people to access health services and are involved in dementia boards and steering groups to further develop local services. They support and deliver talks in English, Punjabi, Hindi or Urdu at day centres, local community groups and religious centres about dementia and dementia services. They also support weekly dementia café and music sessions for people living with dementia and their carers who are from a South Asian background. (11).

Section 3. Recognising the role of family carers in supporting British Muslims with palliative care needs

All participants with palliative care needs in this research were supported by family members. Many family members described difficulties accessing support from health and social services during the pandemic for their loved ones. Family members described taking on additional responsibilities around the physical and emotional wellbeing of their loved ones with palliative care needs.

Family as a source of connection and emotional support

Family members in this research described the important role they played in supporting the emotional needs of loved ones with palliative care needs, particularly when lockdown restrictions were in place. This included acting as a source of connection with the community and extended family members and providing emotional support and reassurance. Ali, a 42-year-old man with scoliosis describes the role family played in supporting his elderly mother. He also shared concerns about struggles faced by those without family nearby.

"I've got two sisters... so they would pop by and bring certain things and socialise within the means, whatever the situation was. Yes, I think it's just the family that kept her going. I can't imagine what it's like when you're on your own. I know last year there was a lot of help that was needed for people who are on their own." Ali

For many families the tension between wanting to look after their loved ones and also protect them from Covid-19 was difficult. Rashid describes the impact that limited visits from family had for his father.

"And I could tell that he was very lonely not to have any sort of family around him. And eventually he went very quiet. And tired. And just slept a lot." Rashid

Family members advocating for support for loved ones

The elevated role of family members also included facilitating access to primary care, securing medications and even advocating for necessary investigations from secondary care services. Rayyan describes the challenges his family faced in accessing support to manage their mother's pain.

"[My sister] spent days on the phone trying to get through to the correct department to get even a phone appointment to speed up Mum's care. So, finally... my sister organised for checks to be done on my mum... but it was after months and months. And it would have been impossible for my mum to have done that... she just can't hear on the phone properly. And when they speak, they speak too fast. They'll ask the same questions and they get frustrated because they're asking a question and they think they're asking it but they won't understand that she can't pick it up. One because of her hearing; and two because of the language." Rayyan

Family members taking on more caring responsibilities

Many families supported their loved ones with palliative care needs at home for as long as possible, due to fears about hospital admissions. For some families, anxieties were partially alleviated by family or social connections with medics, but for the majority access to timely medical advice was limited. Shehzeen supported her father at home, often without medical advice or support.

"I feel like there were a few things I could have avoided if I had more access to medical advice. And speak to the doctor. Have somebody come and visit him at least at home. But that didn't happen. So, some things I just had to go by reading the labels." Shehzeen

Providing this level of care was challenging and exhausting for Shehzeen and her family.

"So, we had some trouble. Like, there were a few times where I did hear something and I used to go in just to make sure that he hasn't had any falls. So, there was that worry, especially during the time when he was ill. He became delirious. So, I had to supervise him like all night for two weeks." Shehzeen

Other families also found the responsibility and lack of knowledge about how to support their loved ones difficult, as Saad describes in relation to supporting a family member with dementia.

"It's been very traumatic in the sense that we didn't know what to do. He's very agitated and he's anxious, he is depressed, so our experience has been that we haven't been well prepared, we didn't know what to do and I think also things meant that we weren't very good at it." Saad

Cumulative impact of existing responsibilities and caring for a loved one

These additional caring responsibilities means that some family members had to place their own lives on hold while they supported their loved ones. Shehzeen describes how she had to pause her studies to care for her father.

"I know I was risking my own self... but I did eventually go in anyway. I would have liked to at least have access to him, to be able to feed him and communicate his needs... with the medical staff that are dealing with him. But we didn't have that facility for the first four or five days. So, by the time they did let me stay with him – I stayed for 12 hours. Really exhausting. But I did have to put my studies on hold and everything else. But I felt that it was really necessary." Shehzeen

Recommendations: Supporting family and carers of British Muslims with palliative care needs

Organisations delivering or commissioning health and social care services should:

- Promote person and family-centred care which considers the dynamics, norms and preferences within each individual family and for each individual.
- Ensure that every family or other carer is offered a fast-track carer needs conversation and that recommendations are acted upon promptly.
- Ensure that carers have access to the information, support, and services they need to meet their own needs – including social and religious needs – as well as those of the person for whom they are caring. Support to access existing services should be provided and information should be available in a variety of formats, languages and places.

Statutory services should proactively work with community networks and organisations to:

- Identify individuals and families that may have additional health and social care needs related to social isolation or advanced ill health and support these individuals and families to access health and social care services.

Section 4. Experiences of social support and social exclusion

A range of examples of social support and social exclusion were described by participants during the pandemic. Some participants received good support from their local council, communities and mosques, while others were not offered any support at all.

Digital exclusion

Participants in this project identified that at times older loved ones were either not engaged with technology or didn't know how to use smartphones, remote meeting technology (such as Zoom, MS Teams, Skype) or the internet. This may have restricted access to different health and social care services or information during the pandemic.

"*I got my information directly from NHS, either in my email or my text message...The text message the difficult thing is I can't open...they want my password and my date of birth but my fingers are not keeping pace with my requirement, so I have to request my daughter to open the digital thing...this is an outpatient appointment.*" Hasan

Digital exclusion figures

The pandemic has accelerated the use of technology in health, social care and community settings. Although 1.5 million more people are online in 2021, there is still a digital divide with 10 million people lacking basic digital skills and 14.9 million with very low digital engagement in the UK. Older people (over 65) and those living in low income households are more likely to be digitally excluded (12). Now more than ever, there is a need to promote digital literacy, build community support and ensure the internet is accessible and affordable for everyone.

Exclusion from policy planning and making

Saad and Rayyan are both family carers for older relatives. They worried that vulnerable members of the Muslim community had not been considered when policy plans were put in place during the pandemic at a national, local or community level.

"But, yes, it would be nice to see the government doing more for Muslim vulnerable elderly people who have worked all their life and paid taxes in this country. And I think there's not enough in return for them people. They're just expecting the carers, their sons and their daughters, their children to do it, the care. And that's what we have to do. And there's not enough support I think for them." Rayyan

Rayyan also describes how he felt Muslims in Britain were impacted in three ways: by the pandemic itself, by the lack of consideration of their faith, cultural and social practices, and because they were older with healthcare needs. Rayyan describes the impact of these policies during Ramadan and Eid.

"And obviously if it impacts the Muslim community then, yes, it's affecting the elderly, the vulnerable a lot more than it might be the youths. So, if you're vulnerable and elderly and you've been told you can't go anywhere. You can't go out or whatever. And you can't celebrate. And you can't have more visitors and normally you would have. And, yes, it is kind of traumatising because we've been doing it all our lives, right. And then you're told you can't do it. So, definitely it's had an impact, the pandemic has had an impact on the Muslim way of life in Britain." Rayyan

Community, local and national government support

The co-operative support people received from local councils and national government during the pandemic was mixed. Ali, who cares for an older relative, described how no-one from the local council reached out to him at all.

"I think social care wise, as in government wise, I don't think we have had any care at all. I'm not sure what there was on offer, but I don't think anyone reached out to us for that." Ali

Hasan, an 85-year-old man with cancer, described how his local council could help with some of his needs, but not all of them.

"I made the adjustment [to my bathroom] out of my expense only, I asked [the council] they said I'm not entitled. The only thing the council has given is an electric bed and [waiting] electric chair". Hasan

In contrast, others like Reema who has multiple sclerosis and also cares for her mother, were offered support with shopping and received check-ins from their local council.

"... a few months into this pandemic, I did get a phone call from my local council, asking if I needed any help with the shopping. At that point I said no because I had family members, my brother, and my son. Then a few weeks later, again, I had another call which was for my mother who is 61 years old. So, the support the local council gave was excellent. They kept asking us, enquiring was everyone okay, are you isolating, would you want help? So that was very impressive." Reema

Aside from councils, neighbours and local communities were a source of support for many. Support from neighbours included help getting to appointments and grocery shopping.

Fawzia describes the support her parents received, but she also worried about people who were less established within local community networks, and the lack of support they might have.

"There's been a lot of community help, but that's mainly because my parents have been in this area for a long time, and they are known in this area. So, I feel for people that don't know anyone. I think it's really hard. There's no systematic help if that's what you're thinking." Fawzia

Support from mosques and local Muslim communities

People's experiences of support from local mosques and local Muslim community groups during the pandemic was very varied. Shehzeen wondered whether mosques could have done more to help people feel connected during the pandemic.

"I don't know if they could do anything more because the mosques basically just closed their doors. And that was it. I don't really know how they could go about it. Everybody was really scared and they wanted to social distance. But I mean for the vulnerable communities, you know members of them could have people they're familiar with or trust and can speak to them. And can communicate with the Mosque. Come door to door to at least inform them. And say this is what's happening. You know, we need to deal with it as a community. Then perhaps that spirit would have been there. As a community, like going forward. Everything was just shut down. And everybody was just told like everyone's on their own. So, there was no community life." Shehzeen

In her area, Reema highlighted how technologies helped her to stay connected to the wider mosque community.

"The Muslim community, Alhamdulillah, that has been great because through Zoom, we have been connected and they would ask me every time, did I need any help or if I was okay, if I was unwell, they would ask me, have you had your covid test? So, Alhamdulillah, I had no problems with respect to the community and the level of help and care I received from the community. So I didn't have any problems at all." Reema

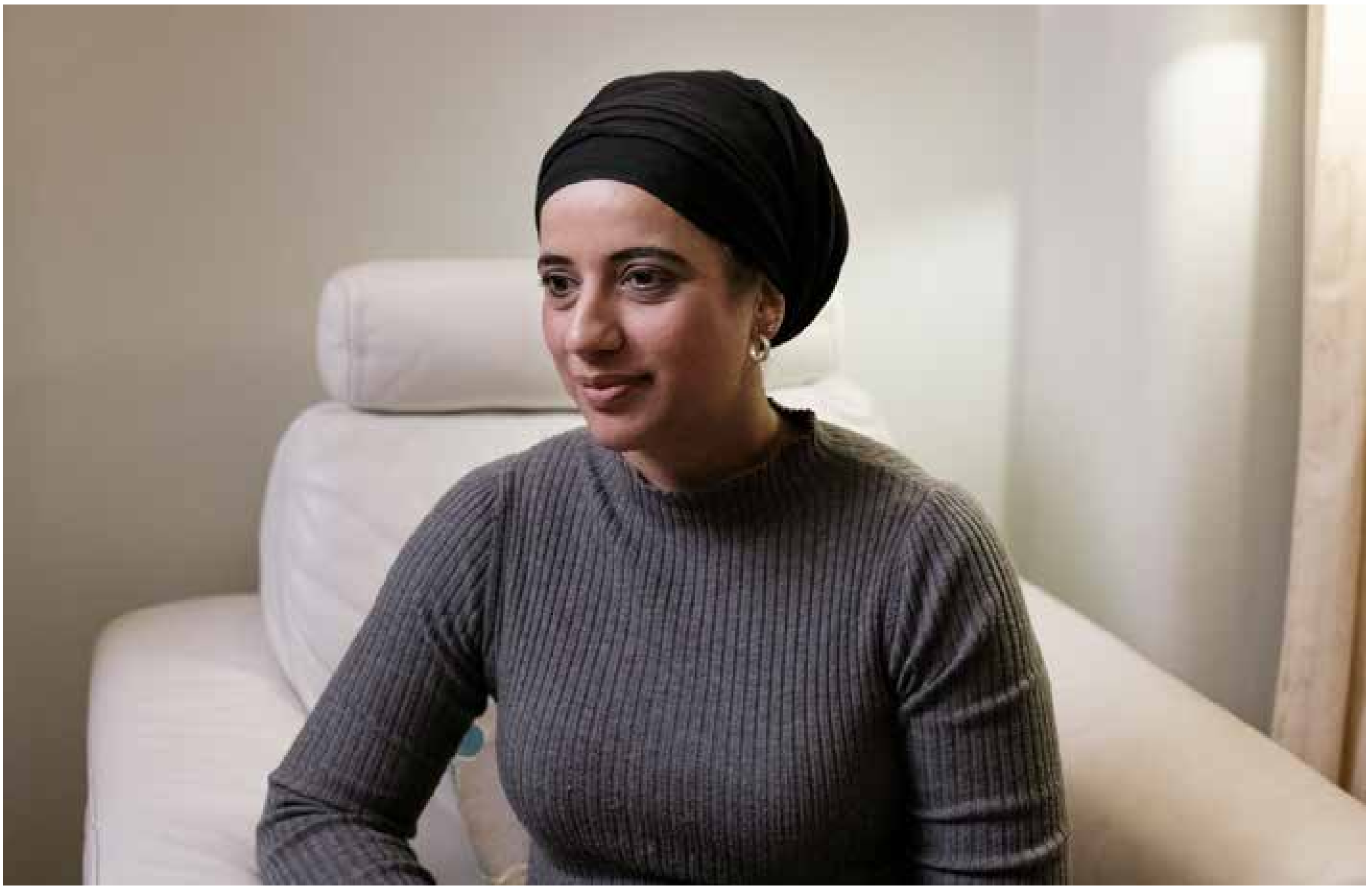


Photo credit: James Rippingale/Marie Curie

Where there was success in providing support, it came from the wider 'mosque community' as a whole, with the Mosque working together with local Muslim groups, families and individuals to provide support.

"Some of the Muslim groups, they did contact and ask whether you're vulnerable. The Mosque were reaching out to say subscribe to the vulnerable families' packs and stuff like that. Then family and friends would ask, do you need shopping done... Should you be going shopping, why don't you do it online. Those kinds of things to shield my mum and protect her. So, that was good, but Alhamdulillah, I don't think we needed that support, but it was on offer." Ali

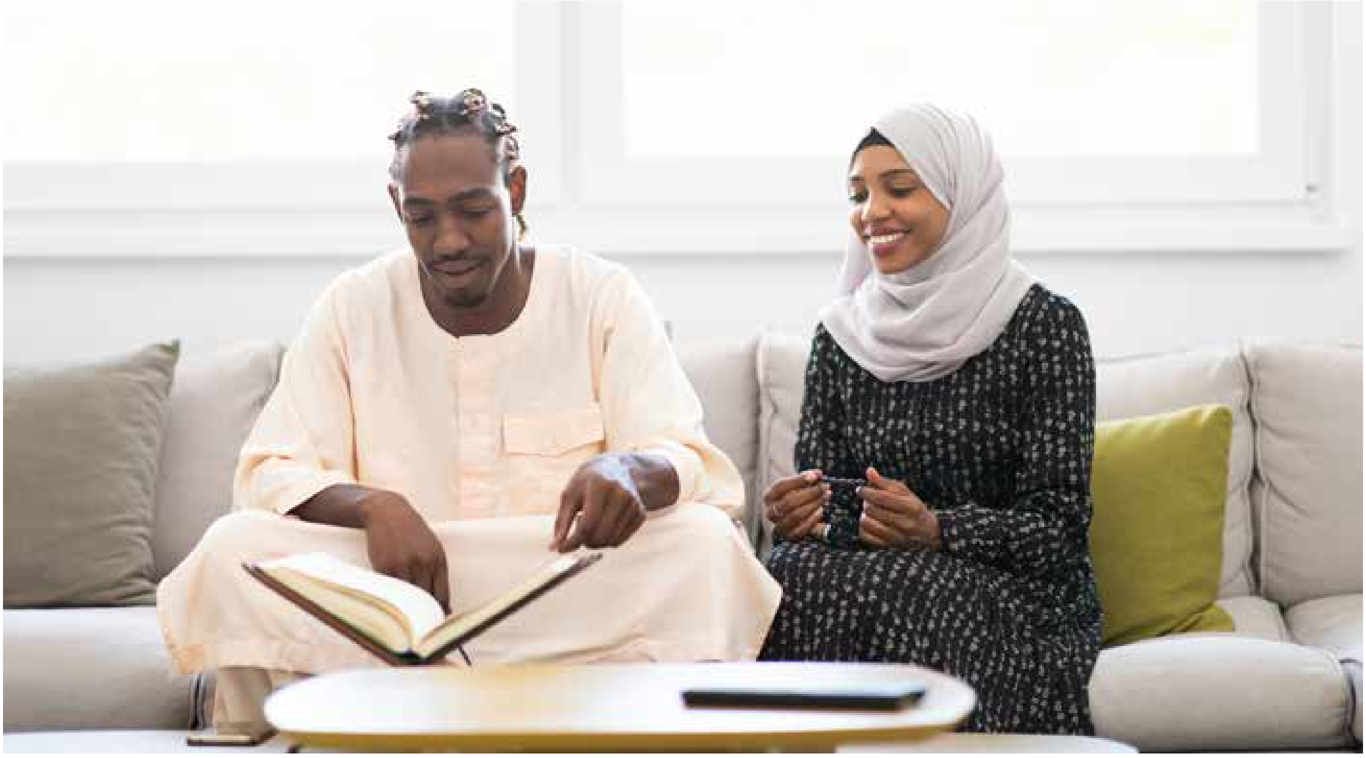
Hasan described how he received support from a local community faith group, which he valued greatly.

"Each time I had to go for my covid jab, they took me. And for other appointments... it's a voluntary service, they do wonderful work, they pick me they put me in their car and then they have an attendant with them... and once I have finished, they take me back... they also bring food whenever I want." Hasan

The impact of health conditions on connecting with mosques

Other participants such as Rashid recognised that after restrictions were lifted, it was his father's declining health and mobility that prevented him attending the Mosque and connecting with the Mosque community, not the pandemic.

"He used to go for Jamaat quite regularly. But as I said with his declining health, and that probably mirrored the last two years in terms of the pandemic, because of his heart he had been finding it more and more difficult to go, and because of arthritis as well. So previously he had always gone by himself on a bus or whatever just to get to the mosque, he was quite keen to go by himself where possible. He would take his grandsons with him. But towards the end as I said, because of his mobility, he found it more and more difficult to go." Rashid



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Recommendations: Tackling health exclusion through early involvement

The Department for Health and Social Care, NHS England and the Office for Health Improvement and Disparities should:

- Ensure that organisations representing British Muslims are involved in the design of public health policy and messaging.
- Increase resourcing for community outreach activities aimed at ensuring health and social care services reach underserved communities, and address inequities in access.

The Department for Health and Social Care, NHS England and Improvement, Local Authorities and organisations delivering health and social care services should:

- Ensure that British Muslims and organisations that represent them are involved in the design and delivery of digital inclusion activities, to ensure that British Muslims have equal opportunities to develop the skills and confidence to engage with health and social care services digitally.

Palliative and end of life care researchers and organisations should:

- Seek to involve a diverse range of people in the projects that they undertake across all stages of project development and implementation.

Good practice examples:

Muslim organisations during Covid-19 providing health information and resources that are culture and faith sensitive

The collaborative work between Muslim Council of Britain, British Islamic Muslim Association and other Muslim organisations in the formation of Covid-19 Response Groups. This included producing a variety of resources, virtual seminars and community briefings translated to different languages targeting individuals with advice on how to safely celebrate Ramadan and Eid al-Fitr at home, on Umrah/Hajj travel, vaccinations as well as to mosques on how to safely re-open.

Existing Muslim helplines such as Muslim Youth Helpline and Muslim Women's Network Helpline continued providing confidential faith and culturally sensitive mental health support services to communities during the pandemic. The Muslim Youth Helpline officers quickly adapted to working from home receiving calls from their living room and bedrooms to face a 313% increase in calls. Some of the primary concerns of Muslim youth were surrounding faith and spirituality, family issues, suicidal thoughts, depression and anxiety due to long period of staying at home and fear of losing jobs and opportunities. At the beginning of lockdown, the Muslim Youth Helpline also engaged with the BBC and BBC Asian Network to develop spaces to speak more openly about mental health struggles.

The Muslim Woman Network UK produced and circulated short safety message videos in English, Arabic, Urdu, Sylheti Bengali and Gujarati mainly through WhatsApp to help reach out to victims of domestic abuse that may not be able to access support, potentially as a result of living with extended families and not having safe spaces or time to call during lockdown. The Helpline also supported by receiving enquiries and referrals from frontline services including GPs, mental health services and police among others.

Islamic Centres in Harrow also started an initiative of providing free oxygen monitoring devices on a loan basis to those with Covid-19 symptoms to help prevent patients going into hospital too late (13).

Additional support to families during the Covid-19 pandemic

In 2020, 15,000 British Muslims were facing financial hardships and received support from National Zakat Foundation, many were directly impacted by Covid-19. A Covid-19 recovery scheme was also introduced in 2021 to support those at risk of losing their homes (14).

Section 5. Information sources and needs

This section describes the sources of information people used during the pandemic to find out more about Covid-19 and their health.

Identifying trustworthy information

Many participants such as Dunia felt unsure where to turn for information about Covid-19 or the latest guidance.

"Mostly the information comes from people. The information spreads from one another, apart from that I don't know any proper channel which gives information." Dunia

Some participants felt that the amount of information produced, and the clarity of information provided by the government and NHS became less clear as the pandemic went on.

"I think we had information about the covid, when it was at its height. But I feel it's different now. I think that's quietened down much more. People are more vaccine and how people are being affected. But not much is spoken about the actual covid itself. And how best to take care of it if you haven't had covid." Zainab

Shezheen felt the information for the clinically vulnerable, like her father, could have been better.

"I feel like when they lifted the actual restriction and sent letters to say that the extremely vulnerable should carry on shielding themselves… I feel like the government didn't emphasise this in the news. You know, we just got one letter saying that. And because of it I think family or visitors behaved more like the restrictions have been lifted. The pandemic is passing. But it wasn't the case. And I think my dad had the Delta. There wasn't enough information to say that there is a serious strand going around. And the people who are extremely vulnerable there is a very high risk. And it should have been isolating more." Shehzeen

The lack of information was particularly distressing for families when it concerned their loved ones illness. Participants felt uncertain about what to do about their relatives distressing symptoms, and were unaware of the support available to them.

"Yes, a voyage of discovery, 100%. I didn't know half of this existed, neither did my siblings. It's only because my sister's … literally been on the phone for days. He's a cancer patient, heart patient, loads of issues and different specialists that she had to deal with. And then the social care part came recently. And she said there's actually people that can help. They can come to your house and see you. And they can assess this and do this and that and the other. And they're the ones who made the decisions. So, we were unbeknown to these facilities. So, yes, that's good that we managed to achieve it. It's taken a long time." Rayyan

However, others like Zainab felt well informed, gathering information from a variety of sources including community groups, the NHS and via technology.

"There was the news and there was the NHS itself who was sending information to our doorstep. There was the Muslim/Asian nationwide. Then there were some community programmes about Muslim doctors who took certain initiatives and speaking about various aspects of covid that affect them in the community, particularly the women." Zainab

Some participants had suggestions about how information could be better distributed through their community and appealed for more information in languages such as Urdu and Punjabi to make it more accessible.

"More could be provided, I think. And if the NHS provided better leaflets and maybe better online. Or even news itself in a better way. Maybe use WhatsApp messages or some kind of media messages where they could post in Urdu or Punjabi or in a different language where they could get languages out in different languages." Rayyan

Recommendations: Information sources and needs

Organisations delivering or commissioning health and social care services should:

- Proactively work with local community groups and organisations that work with British Muslims to raise awareness of existing palliative and end of life care services and sources of support for people living with terminal illness in the local community, supporting people to access these services when needed.
- Work with local communities and organisations that work with British Muslims to ensure that literature, guidance and materials about palliative and end of life care services are representative and reflective of the cultural needs of all groups, including British Muslims.

Good practice examples:

Diabetes UK in collaboration with Muslim Council of Britain produced guidance in English, Arabic, Bengali and Urdu on how to fast safely if choosing to fast while living with diabetes (15).

NHS commitment to improving care for people living with long term conditions

Person-centred coordinated care has been recognised by the NHS and House of Care model developed to improve care and services for people living with long term conditions and multimorbidity. A further essential element is continuity of care which included informational and management continuity where people and family/carers have access to information about their conditions, draw up care plans in collaboration with service providers and know how and where to access services when they need them (16).

Conclusions

As shown in this research, Covid-19 impacted the physical and mental wellbeing of British Muslims with palliative care needs and the people who are important to them. Some participants described observing the accelerated physical decline of people living with chronic conditions and neurodegenerative diseases due to delayed access to healthcare, medication, and reduced social interaction and movement. Older and more vulnerable groups, such as those living with dementia, faced barriers to accessing health and social care services, including language barriers, digital exclusion and challenges adjusting to telephone and video consultations. Many participants felt unsure where to go for information during the pandemic. A lack of information concerning their condition and illness, or the health of their family member, was particularly distressing. People did not know what to do about distressing symptoms and struggled to get information about the sources of support for their condition available to them.

For the participants in this research, family members played central roles in supporting people with palliative and end of life needs. However, they faced significant emotional and practical burdens in doing so. Services must adopt both person and family-centred care approaches to care that encompass the dynamics and norms of individual families to ensure patients and families are supported in a way that meets their own unique needs. Future research should explore how culturally competent care, and culturally competent discussions around advanced care planning can be delivered.

In order to improve end of life experiences, Marie Curie believes that everyone with a terminal illness or palliative care needs should be offered a conversation about their needs, wishes and preferences for their care. These conversations should include addressing support for their mental and physical health and wellbeing, financial and practical support, and support for their social relationships and religious needs. Services must adapt to better meet the needs of diverse local communities, including British Muslims, and those providing health and social care services must ensure that individuals and those who are important to them are placed at the centre of decision-making.

What is also clear from this research is that more support is needed for those who do not have the support of family networks. It is crucial that those who are isolated or otherwise vulnerable have routes into the support that they need. Examples of best practice came from the wider mosque community and local people and groups working together. Faith organisations, voluntary and community groups should be supported to develop and lead efforts to equip communities with the connections and knowledge they need to ensure the best possible experiences towards the end of life, which may include connection to their mosque and wider communities.

It is vital that the voices of British Muslims with palliative care needs are involved in the development of new and existing services at a local and national level, to ensure that people can access care that is right for them at the end of their lives.

In addition to ensuring that people from diverse backgrounds are included in the development of health services and policies, the coproduction of palliative and end of life care research, in equal partnership with people affected by dying, death and bereavement, is essential to generate the knowledge needed to reduce inequity in palliative and end of life care. Furthermore, better data around ethnicity is essential in understanding where and why ethnic disparities in healthcare exist. Data must be collected and used in a manner which builds trust with communities and does not reinforce health deficit models or wider structural racism and discrimination (17).

Steps that Marie Curie are taking to support people from different minority ethnic groups

As a leading palliative and end of life care organisation Marie Curie aims to reduce inequities in end of life care and ensure access to high quality care and support for everyone affected by death, dying and bereavement. We are taking steps to address barriers that we see but we acknowledge that much remains to be done before equity in access to palliative care is achieved. Marie Curie strives to provide holistic and patient-centred care and understands the need to work in partnership with patients and families by including them in care planning and decision-making. All Marie Curie staff are required to complete an introductory module about Equality and Diversity. In London, more practical Anti-Discrimination training in the form of sessions and workshops was introduced to staff during the pandemic. This is due to be rolled out across the charity.

Marie Curie caring services during Covid-19

During the pandemic, Marie Curie registered nurses and healthcare assistants continued to provide healthcare and support to the public, including British Muslims. While technology became widely used during the pandemic, Marie Curie continued to provide face to face services to patients and their families, whilst ensuring staff and patient safety by using appropriate personal protective equipment (PPE).

The Marie Curie Nursing Service continued to provide end of life care and after death support to patients and families in their homes during the pandemic and were sometimes present at the time of the patient's death. They provided practical, emotional and psychological support to families in different ways, including contacting out of hours GPs and undertakers for family who were too distraught or unsure how to organise this. Marie Curie also provided a Rapid Response service to support with urgent care during the pandemic. Staff provided overnight care for those patients who needed support for a longer period in their homes.

Challenges experienced by Marie Curie Caring Services during the Covid-19 pandemic

During the pandemic the use of PPE equipment, including face masks, sometimes hindered effective communication. In addition, the pandemic restrictions made it challenging to access interpreters to overcome language barriers. Staff shortages as a result of staff sickness, staff shielding and isolating sometimes impacted the number of patients that could be supported. Furthermore, some elderly patients, and those who were shielding, may not have been able to receive this support.

Marie Curie Staff Network groups

Marie Curie has established a number of staff Equality, Diversity and Inclusion groups. The Marie Curie Muslim staff network arranged an online talk from an Imam in London so that any Marie Curie staff in the charity could listen and engage in an 'Introduction to Islam' session. There are plans to run practical discussion sessions for clinical staff focussing on individual topics, such as: Islamic rites leading up to, and following, death, understanding Muslim celebrations such as Ramadan and Eid and improving communication skills when speaking to patients about religion and spiritual issues.

Learnings from supporting Muslim patients within a Marie Curie hospice

A middle aged, Eastern European devout Muslim gentleman was admitted to the Hospice. As part of his initial assessment his communication needs were assessed. This included finding out his first language to determine whether he needed a translator. He spoke English as a second language and was able to communicate with staff until his condition deteriorated. The patient's religious and spiritual needs were also assessed, and he was introduced to an Imam in the first few days of his admission. Staff established that the patient required a halal diet, which was easily catered for by the kitchen staff in the hospice. The patient identified the relatives whom he wanted to be involved in decisions about his care. These family members were given regular updates about the patient's condition as he deteriorated. When he died in the early hours of the morning, the patient was surrounded by his wife and children and an Imam was present. The staff ensured that documents such as the death certificate were provided quickly in the morning in order to facilitate a same-day burial.

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Appendix

Participant characteristics

	n	**%**
Gender		
Female	5	41.7%
Male	7	58.3%
Carer	7	58.3%
Person with palliative care needs	5	41.7%
Age, mean ±SD (range)	58.8±16.2 (35- 85)	
Ethnicity		
Asian	1	8.3%
Bangladeshi	2	16.7%
British Bangladeshi	1	8.3%
British Pakistani	2	16.7%
Indian	1	8.3%
Pakistani	3	25%
Punjabi	2	16.7%
Country of birth		
Bahrain	1	8.3%
Burma	1	8.3%
India	1	8.3%
Pakistan	3	25%
Switzerland	1	8.3%
United Kingdom	5	41.7%
Diagnosis		
Arthritis	1	20%
Cancer and comorbidities	1	20%
Dementia	1	20%
Heart failure and rheumatoid arthritis	1	20%
Multiple Sclerosis (MS)	1	20%

Years living with illness, median (range)	13 (8-29)	
Years as carer, median(range)	3 (0.25 -12)	
Interview language		
English	11	91.7%
Urdu	1	8.3%
Employment status		
Retired	5	41.7%
IT	2	16.7%
Doctor	1	8.3%
Postgraduate student	1	8.3%
Self-employed	1	8.3%
Unable to work	1	8.3%
Not identified	1	8.3%

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