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^{*} We have used the term BAMER (Black, Asian, Minority Ethnic and Refugee), as a collective term throughout this report when referring to the ethnicity of the client groups involved in this work. At the time of writing this report, we understand there are ongoing discussions with the Governments' Race Disparity Unit (RDU) around the use of this term. We will continue to follow any Government guidance as to how to refer to people's ethnicity in any future work we do.







Background

The Impact of Bereavement during Covid 19 particularly on BAMER Communities

Healthwatch Bolton

Healthwatch Bolton is an organisation set up by the government to listen to the views of patients and the public about their experiences of using local NHS health and social care services. Healthwatch Bolton uses the information it gathers from the public, to present to the people that make the decisions about what health and care services are provided for the people of Bolton. From this information, Healthwatch Bolton makes recommendations to improve services. So, the more diverse voices that Healthwatch hears, the more health and care services can be shaped to meet the needs of everyone.

The Flowhesion Foundation

The Flowhesion Foundation was established in 2017 to engage constructively with Black, Asian Minority Ethnic & Refugee (BAMER) communities to ensure that they are able to live better, feel better and achieve more. The Foundation's centre for BAMER research specialises in undertaking timely pieces of BAMER research to shine a light on issues that will subsequently influence policy and practice.

About This Project

In Bolton, Healthwatch has been working with the local community, to ensure it hears more of the voices that are not usually heard. There are many barriers to people having their voice heard and the Healthwatch engagement team has been exploring these and finding ways to improve. From the community engagement work, intelligence has been picked up from the community as to how the Covid 19 pandemic has been affecting lives. One of these issues has been that of bereavement and how this has impacted on people. During the Covid 19 pandemic it has not been possible to have the same freedoms due to restrictions to keep people safe. This has meant that people have been finding it difficult to be with family members when they have had to go into hospital and even more difficult when a loved one has died. This has affected all parts of society but, in particular, people from BAMER communities. This project focus is in response to the disproportionate effect of the COVID-19 virus on ethnic minority groups*.

Healthwatch Bolton commissioned The Flowhesion Foundation to use their expertise and language skills to interview people from BAMER communities. The project explored how the pandemic has affected normal practices of dealing with bereavement and the impact of this. The project also explored if there are any barriers to accessing bereavement services and support services to ensure people do not experience any inequities when accessing these. Services need to be culturally appropriate to ensure people do not miss out on support. The project is in line with our workplan priority of mental health.

*Ref: Beyond the Data - Understanding the impact of Covid 19 on BAME Groups - Public Health England 2020.







Methodology

A survey was launched using Survey Monkey which was advertised on social media/newsletters and on Healthwatch Bolton's website. Twenty pre-defined questions were asked. In addition to this, The Flowhesion Foundation carried out thirty semi-structured interviews which were undertaken between October 2020- March 2021 with members of the south-Asian community in Bolton aged between 18-65. Each interview lasted between 30-45 minutes each.

Given the sensitive nature of the questions and topic, The Flowhesion Foundation offered its free bi-lingual counselling service for participants who felt it was required for them.

Credentials

The interviews were overseen by Imam Abdul Hafeez Siddique CEO of the Flowhesion Foundation. Abdul holds an M.Phil. in community cohesion and an MA in social work from The University of Manchester.

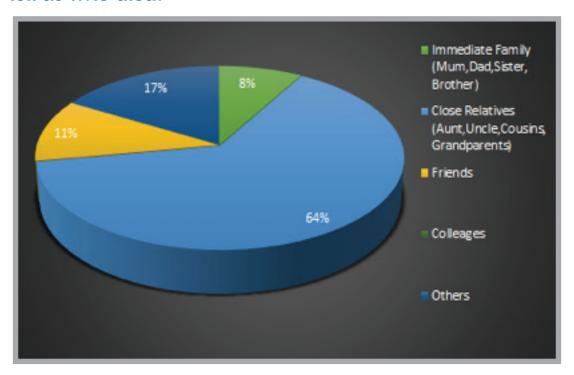




Summary of Findings

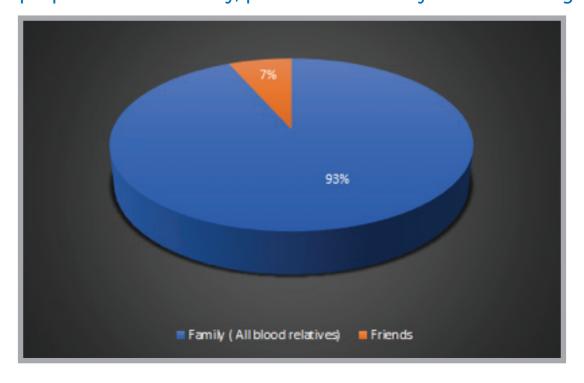
Question 01

Please tell us who died?



Question 02

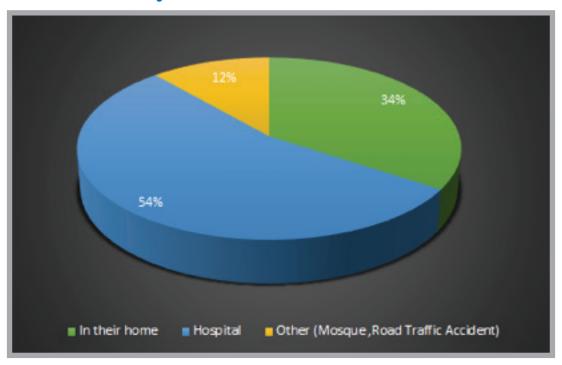
For the purposes of this survey, please tell us who you are focusing on?





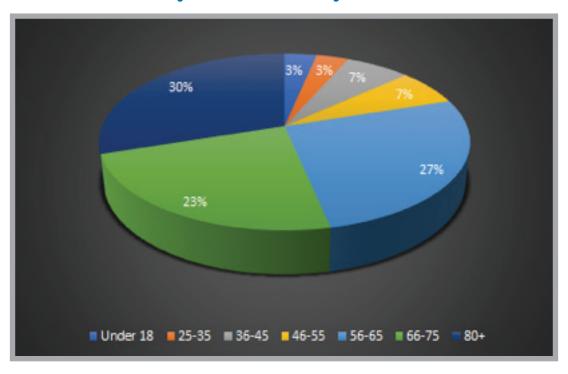


Please tell us where they died?



Question 04

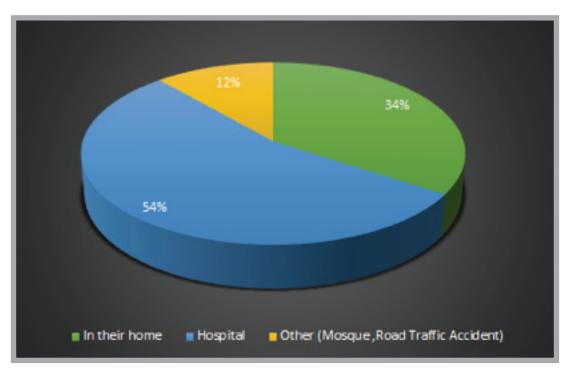
Please tell us how old they were when they died?





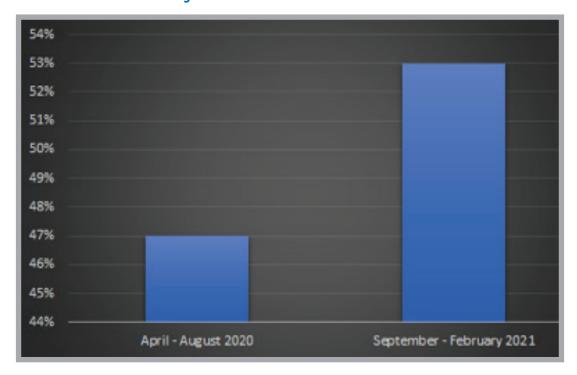


Please tell us the cause of death?



Question 06

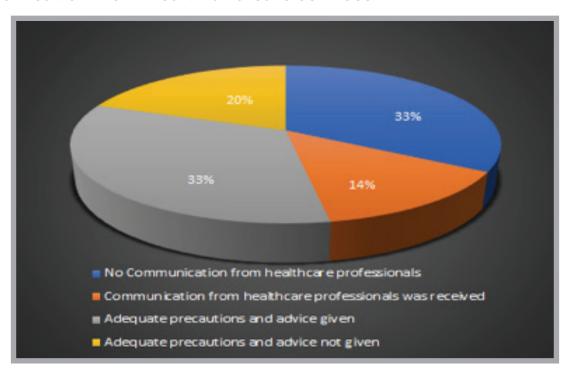
Please tell us the date they died?







Please tell us what happened when they died and how was the communication from health and care services?



33% of people responded that the communication between themselves and the healthcare professionals was not adequate and that they did not get the information they required at the time. On the latter 33% of people said that there were adequate precautions taken and advice given but the communication was poor.

(Participant 16, Asian, 25-34)

"Wrong information given, advised it was COPD (Chronic Obstructive Pulmonary Disease), but then passed away as a result of Covid, they weren't giving a lot of information."

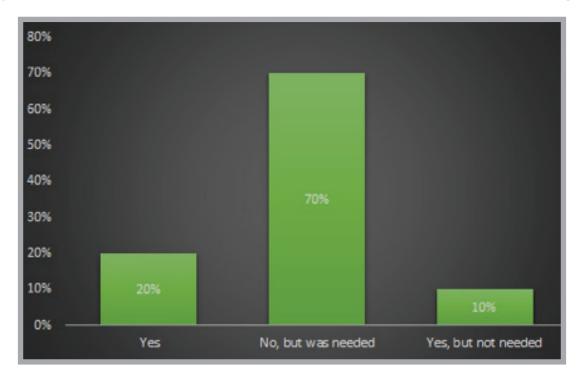
(Participant 14, white Asian, 25-34)

"He was poorly, and the ambulance took him to hospital. When he got to hospital within a couple of hours, we got a phone call from the hospital to say he's passed away. But his heart was still breathing when he left home. They only released the body 2 days after."





Were you provided with bereavement services, such as counselling?

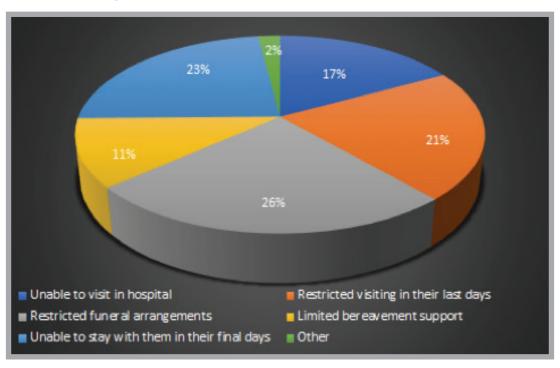


The evidence shows that 70% of people were not provided with bereavement services (such as counselling), but they felt it was needed. 10% of participants stated that although they had access to bereavement services, they felt they did not need the services.





As your loved one was approaching the end of life, did you experience any of the following?



In the above pie chart the 'other' option was chosen by 2% of the participants. They stated that not being able to be present with family and friends at the time of death, made the experience more difficult as there was no closure from the death.

(Participant 8, Pakistani 35-44)

"I was unable to fly out before he died to spend time with him and as a result could not attend the funeral"

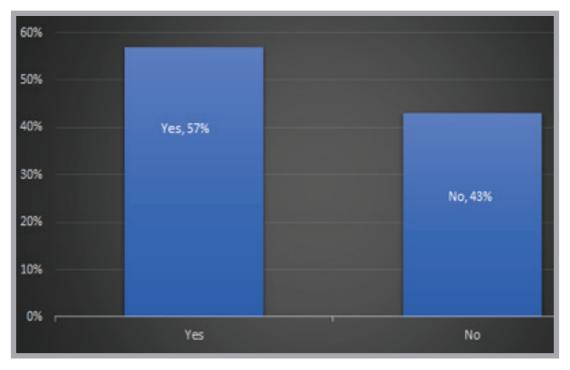
(Participant 16, Asian, 25-34)

"They weren't allowed to see him even though they said he was not in a Covid ward"





Were you satisfied with the care your loved one received at the end of their life?



57% of people responded with yes and claimed that they were happy with the level of care and that their loved one was in the best place.

(Participant 5, Indian, 45-54)

"She was in hospital, the best place for her. She was in good care"

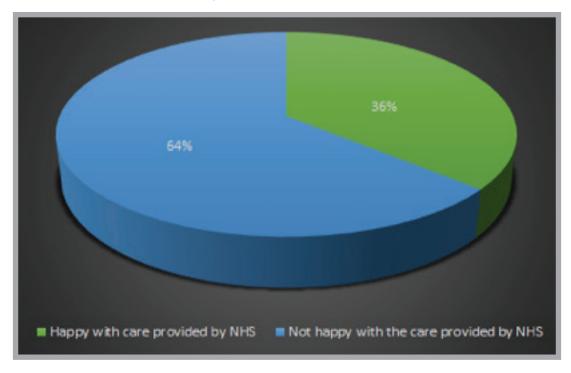
(Participant 3, Pakistani, 35-44)

"Ambulance came as fast as they could but it wasn't enough"





Continued, if not please can you explain the reasons?



We found that when asked about the satisfaction of the level of care provided, 43% of people responded with 'No'. The following comments give a flavour of why people were unhappy:

(Participant 6, Bangladeshi, 35-44)

"Because nobody was with her and grandmother did not speak English, did not know what communication took place"

(Participant 18, Pakistani, 35-44)

"There wasn't a lot of communication, couldn't visit him in hospital a lot of time was wasted"

(Participant 16, Asian, 25-34)

"They gave wrong information to them, weren't allowed to see her parents, different information everyday"

(Participant 28, Other Asian background, 45-54)

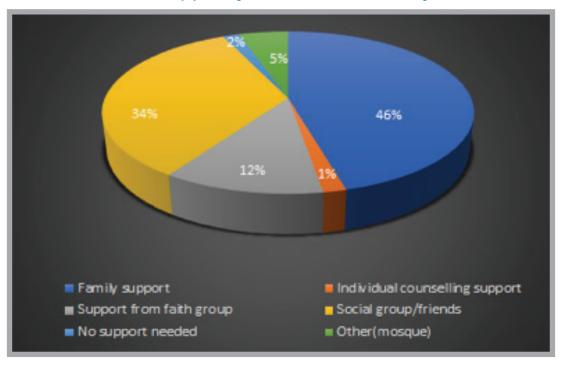
"Was tested positive for covid but was told to stay home. My aunty might have survived if they were able to go into hospital straight away"





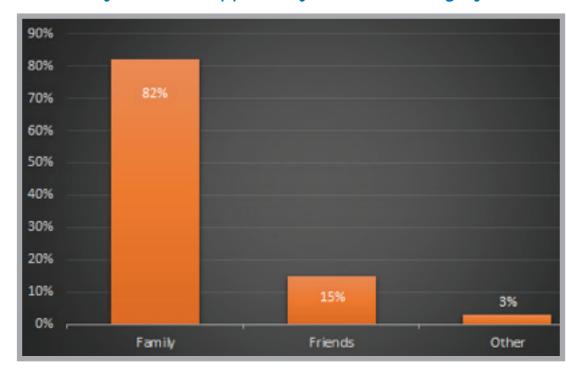


Please tell us about the support you have had since your loss?



Question 12

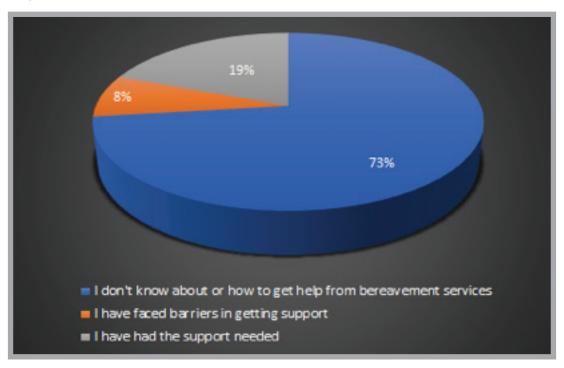
What or who do you think supported you most through your loss?







If you have wanted to, but not been able to access any support, please tell us why this was?



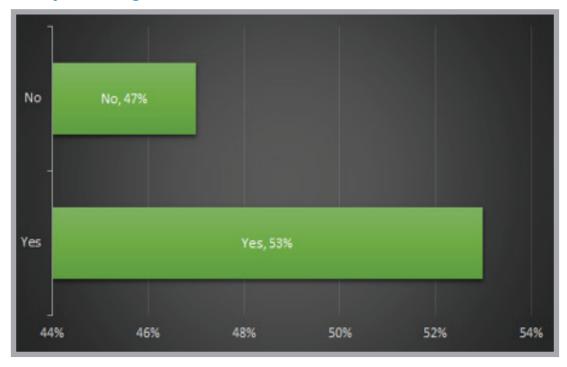
The data collated states that 73% of participants did not know they could get help or access help for bereavement services. This could indicate that support for bereavement is either not being made available, is not easily accessible i.e. people are not being informed of such services, or the information is either not being provided, advertised adequately or understood by people who are bereaved.

There are many barriers within the BAMER community for accessing help, as language and societal structures can become a barrier, these services should be available for the wider community in an easy accessible form.

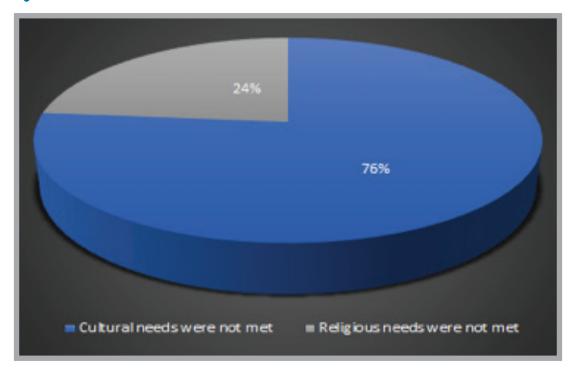




Do you feel your religious and cultural needs were met or understood?



If No why?



The above pie charts represent that although 53% of participants felt that these needs were met, there is still room for improvement in these areas. As 76% of participants stated that their cultural needs were not met and that 24% of participants believed that their religious needs were not fulfilled.

In respect of BAMER communities their religious and cultural needs are that they are present with family and close friends when someone is bereaved, and that is how they attain closure on these occasions.





(Participant 3, Pakistani 35-44)

"Couldn't be with loved ones and siblings while grieving. It was hard to process"

(Participant 8, Pakistani, 35-44)

"Because I was not able to attend the funeral and hold a wake, I was not able to get full support from family and friends. I did not get the closure that I needed."

(Participant 14, White Asian, 25-34)

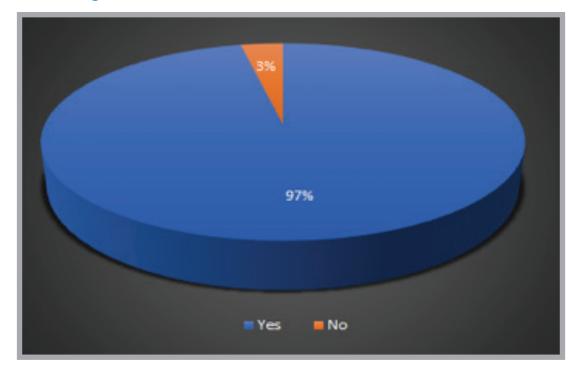
"We were not allowed to attend the funeral. We have a big family, restricted funeral arrangements. Did not feel like we could mourn the death of a loved one."

(Participant 24, Arab, 35-44)

"The religious side was met. However, the cultural side was not because we were not allowed to gather"

Question 15

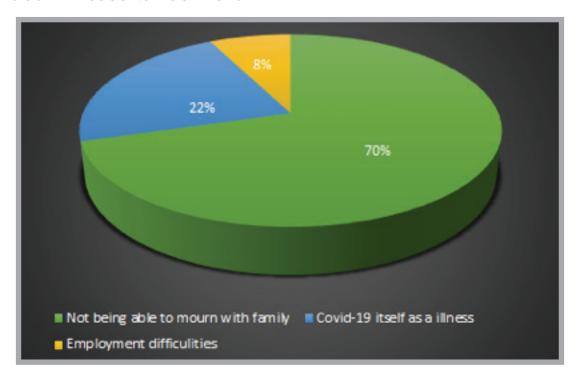
Do you think Covid-19 has made your experience of losing a loved one more distressing?







Continued... Please tell us more?



In this section it becomes apparent again that the participants are finding it hard to deal with the situation because they are not allowed to be present and mourn with family. 97% of participants responded that Covid 19 has had a major impact on how they dealt with the deaths and 70% said that was due to the fact of being away from family.

(Participant 28, Other Asian background, 45-54)

"We couldn't visit aunty in hospital, couldn't get information from doctors, it was all limited, the whole family were in hospital so it was a very hard experience"

(Participant 12, Somalian, 25-34)

"We couldn't share our grief with family and felt we had no support. I felt like i was left alone to get on with it"

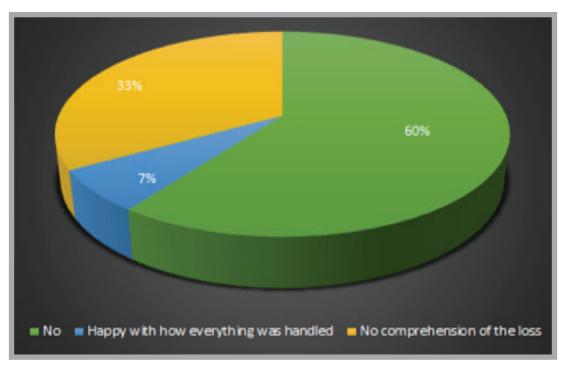
(Participant 2, Pakistani, 35-44)

"Not being able to spend the last moments with them."





Would you like to share any further information relating to your experience?



In the above pie chart, the evidence shows, when asked whether they would like to share further information, most of the participants felt they had stated all that they needed to. But 33% responded - anyone who has not gone through this situation could not possibly comprehend what losing a loved one is like; therefore, they had felt as if they were not emotionally content by the services provided.

(Participant 1, Indian, 35-44)

"Only when someone has had a loved one pass away, can understand what you are going through. Also, I will not be taking vaccination."

(Participant 17, White Asian, 55-64)

"We were not allowed to gather and have a wake, so I did not feel like I was comforted and I could not comfort my family. It didn't feel real."

Participant 21, Pakistani, 35-44)

"It was a very difficult experience, we weren't able to see him face to face, spend time with him in his last days."

(Participant 24, Arab 35-44)

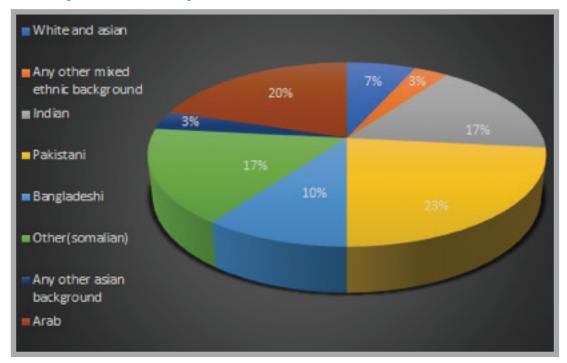
"When something like this happens there should be more done to let family gather, very difficult losing a loved one. It still feels like he's around because it's not sunk in.





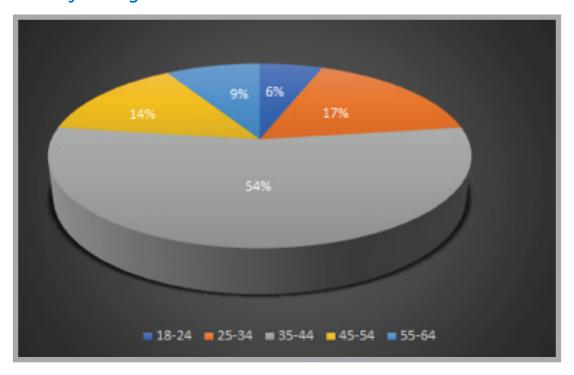


Please tell us your ethnicity?



Question 18

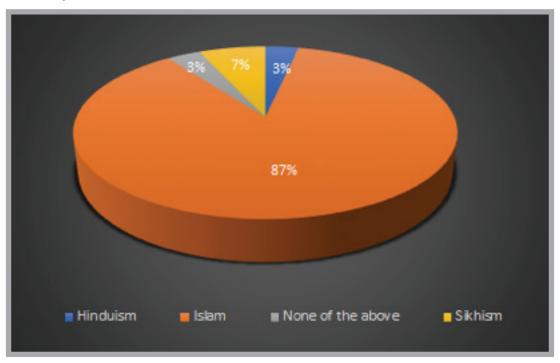
Please tell us your age?





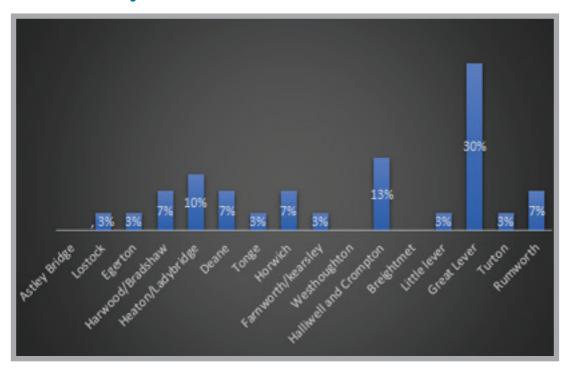


Religious or spiritual beliefs?



Question 18

Please tell us where you live?







Discussion on findings

The participants who were interviewed were giving largely first-hand reflections about their experiences of Covid 19 and bereavement. This is because 64% were discussing their experiences in relation to experiencing the passing of a close relative.

There is a clear indication from the findings that a culturally sensitive and bespoke counselling service would be useful, to help people deal with the trauma, bereavement and other dynamics emanating from a bereavement compounded by covid19 restrictions. 70% of participants felt that this was needed but they were not aware of it. This therefore suggests there is a gap in how services are being advertised across the system given that 73% of participants felt that they did not know how to access support from bereavement services.

There are also a number of findings from the research that point towards the unique manner in which people from south Asian communities' process grief and bereavement within their own internal traditions and practices. For example, 83% saw family as a strong source of emotional support and 47% felt that their cultural needs were unmet. Therefore, there is much learning to be had for health and care services around the cultural needs of different community groups

For south-Asian communities -mourning is a collective process, being at the funeral, washing, shrouding the deceased spending time at the next of kin's home. Evidently all these routines were stopped due to Covid 19 restrictions.

Recommendations

- > Health and care services that are providing end of life care, and support services, need to ensure that they work to include culturally appropriate bereavement counselling services to their clients.
- ➤ Health and care services need to appreciate that BAMER communities are not homogenous and should therefore reach out and engage with them in order to understand how different cultures deal with bereavement and make provision to accommodate the wishes of the families when a loved one is at the end of their life. This is so that families can experience closure of losing their loved one. Covid-19 has made this very difficult, but there is much learning over the past 12 months to make improvements.
- > Services should embed clear messaging and advertising across pathways and at significant points of the patient journey to ensure that families who are bereaved are aware of counselling services that are available.
- > Information about bereavement services should be advertised in different languages and formats that are accessible to different ethnic groups.
- > Faith leaders must be at the heart of promoting ongoing safety messages.

Acknowledgements

We would like to thank all of the interviewees who came forward to take part in this research given, many of whom had recently lost loved ones. Also, thanks to our interviewers, partners and stakeholders who allowed this important piece of research to be undertaken.



