



MUSLIM
WOMEN'S
COUNCIL

Dealing with Dying, Death and Bereavement

2021/2020 **MWC Think + Do Tank Report**

Background

The way we do research to inform policy isn't working. Today, most community based/'led' research is done through collaborations between large science or specialist research institutes partnering with local organisations beyond their institutions. Whilst this is an attempt to enrich the quality of research and of bringing wider social benefits, it still lacks the true representation of the communities they are trying to help. Where such partnerships are formed the experiences are not always productive or conducive to drawing on the knowledge and expertise of all participants, as they remain the subject not the co-authors of the research.

There is a need for a process that places these individuals and communities as the authors of research that considers the issues they face; and develops practical responses and recommendations from the ground up. There is a need for a radical shift and movement in how authentic data and insights are collected from women of Black and Minority Ethnic backgrounds.

In response MWC have developed an approach that focuses on the delivery of authentic and appropriate research to create better policy and practice that drive practical solutions that address women's health and wellbeing.

Think + Do Tank

With the support of Wellcome Trust, Smallwood Trust & Friends Provident Foundation, we hope to reverse the current trend of Muslim males and non-Muslims researching and advocating on behalf of Muslim women, especially regarding issues of health, wellbeing and bioscience.

Our approach will straddle the 'Think + Do Tank' between both policy and beneficiaries (Muslim Women) and will offer authentic insight and appropriate solutions, as it will be led by the beneficiaries. We focus on the relevance, credibility, legitimacy and utility of the research we do, ensuring that we position our research for use.

We focus on Muslim Women from Bradford and surrounding areas. Within this group there is a climate of misogyny and patriarchy fuelled by public stereotyping and male-dominated interpretations of women's roles and positions. In short, society is denying these women their ability to think and act independently or contribute to the creation of health, wellbeing and bio-science policies and practices that affect them and their community.

For example, Muslim women have not been engaged as contributors to research and policy reflective of them. It seems that most research is a male bastion, which undermines their effectiveness and puts them at a disadvantage and impacts on how they research and present the needs of women. This project will be women led and women governed, therefore putting these women at the heart of the research.



This Report

There have been significant challenges for Muslim women following the death of their spouses, which have been exacerbated during COVID.

The situation does not allow a process of death in which families and communities can be involved in a way they would normally hope or expect to be. This report focuses on the experiences of Muslim women at this difficult time.



Dying, Death and Bereavement

We spoke with a sample of 25 women over the last 6 months that used our helpline, to support them through the various aspects of dying, death and bereavement. We looked at and discussed the moments in the process of death, and what strategies could be mobilised to support Muslim women and other communities through these specific phases.

- Hospital admission
- Disposal and release of the body
- Funeral rites and rituals
- Managing bereavement

We held 6 discussion groups with these women to openly discuss their lived experiences of managing death during this time.

A good death in the Muslim community is one where “you are surrounded by family members, by those who love you, those who are reciting for you, encouraging you to recite, let those be your final words.”

Muslim women, who already feel alienated within their community and society, felt further isolated by the pandemic. Coupled with fake news and rumours, there were significant feelings of mistrust regarding medical information and staff, manifesting in families thinking their loved ones were being experimented on. They felt that burial rites should not be delayed and were grateful for accessing technology that allowed prayers for the deceased to be held together.

Experiences and Thoughts

Hospital admission



‘This was a time of confusion and distress’

‘We felt shame that we had Covid in the house’

‘We had nothing prepared, no understanding of what to do & when’

‘I suddenly had to manage the home, access welfare support, and caring responsibilities’

‘The fear of not being able to visit family members in hospital is preventing some families from admitting their ill relatives to hospital.’

‘We did not know or understand the hospital chaplaincy services’

‘We were shocked by how quickly my husband deteriorated, I wished I kept him home’

Disposal and release of the body



'There was a lack of support or explanation of what was happening'

'We felt that we had to get our mother home as we did not want her cremated'

'I felt alone and had no one to turn to'

'I did not know what I could or should do'

Funeral rites and rituals



We did not know if we would get to see the body or what kind of funeral we could have'

'I felt that having a small funeral was better as it felt more intimate and personal'

'I had so many arguments with my husband's family as they did not think mine and my children's needs were important'

'I was surprised and not ready for the cost of the funeral'

*'I was grateful for MWC who helped me through **understanding my rights, finances and connecting with my family through WhatsApp**'*

Managing bereavement



'We could not visit, cook and care for the bereaved due to social distancing guidelines'

'I felt so lonely and isolated'

'I have no family here, they are all in Pakistan...So when I spoke to Muslim Women's Council I felt better'

'I feel guilty, depressed and sad not being able to give my mother the correct ritual procedures'

'I was almost left with nothing. No house, no money, nothing'

Recommendations

- Better support for Muslim women to ensure their rights are recognised and met.
- Use of digital or telephonic technology can also be used to facilitate the witnessing of wills and other legal processes.
- Having a dying wishes form, especially with the COVID situation as things can go from bad to worse very quickly.
- Better understanding of what happens with the following processes – receipt of a green certificate, release of body, passage to funeral parlour, process of burial or cremation of body, funeral directors and religious leaders.
- Use of technology bringing mourners together after death, particularly for those unable to attend funerals.
- A telephonic or text-based support line could be provided for the bereaved, with understanding of religious and cultural practices.
- Guidance regarding how to deal with HMRC and other legal agencies.



Muslim Women's Council Response

We created a helpline that offered support regarding bereavement, which was underpinned by various online resources regarding how to deal with the trauma of losing a loved one.

We also, pre-COVID, offered coffee mornings that brought women that were grieving together to support each other, along with a professional bereavement counsellor. Once restrictions are lifted, we aim to continue this service and develop it further in line with group needs.

We are looking to work with more faith-based and BAME wellbeing & bereavement counsellors to provide more relevant support for local Muslim women in the future.



Case Study

Ms S, a 39-year-old White British convert to Islam, contacted our helpline a few months after the suicide of her 18-year-old son, after searching for bereavement support online.

The COVID-19 lockdown and subsequent remote learning meant that her son lost his social life and it became harder to get help, leading to him getting increasingly depressed. They found it impossible to get a GP appointment for mental health support. After her son's death, Ms S severely struggled with the arrangements and having to limit numbers attending the funeral due to COVID restrictions.

When our staff member spoke to Ms S she was very frustrated as she felt that everything else apart from COVID was being ignored. She said suicides and depression have increased, domestic violence has increased, cancer is still here and so are all the other illnesses. She felt the lockdown was causing more damage. She was experiencing high levels of stress, causing body rash. We encouraged Ms S to pursue a doctor's appointment to help with her rash and stress, and we referred her to some reliable online resources about depression, suicide, grief, and death in Islam. Ms S found most of the online resources very useful. We regularly called Ms S to keep in touch, as she was on leave from work due to the grief and stress of losing her son.

Ms S feels the government needs to massively invest in mental health services, and extra resources in the NHS to catch up on all the missed medical appointments, cancer screenings, and so much more, and to treat people as individuals and actual humans, not just numbers.

Ms S said that losing her son has changed her perspective on life, and she feels that more provisions are needed such as support groups, bereavement support, and particularly suicide bereavement support as she feels that suicide carries a heavy stigma and is very difficult for loved ones to deal with, especially in the Muslim community.



Case Study

Mrs M, a 56-year-old nursery nurse of Pakistani origin, contracted COVID soon after the lockdown first started in March 2020. She contacted our helpline after seeing it advertised on our social media pages, as she was looking for a Muslim organisation to turn to. Her older sister had recently died after contracting COVID and she was struggling with how to cope with her grief.

She felt at a loss and was finding it difficult to look ahead, and had to deal with rifts and tension in her family due to the loss of her sister. She had contacted another support line but felt they did not understand the cultural and religious aspects of death from her perspective.

We supported Mrs M by discussing death from an Islamic perspective, and how to support her family and deal with her grief. Mrs M was also struggling with health issues ever since her COVID diagnosis, so we encouraged her to make an appointment with her GP, who subsequently diagnosed her with long COVID.

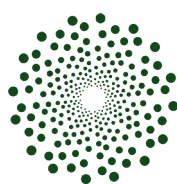
Mrs M said she gained comfort from speaking to us regularly, as she felt there were not a lot of faith-based support services in the community. Mrs M felt she could speak to us about any issue without being judged or misunderstood.

Mrs M has since been able to mend some relationships in her family, and although she still has days when she struggles with her health, she is looking to get back to work soon.

For future support, Mrs M feels there need to be more wellbeing support services that are faith-based and understand the cultural nuances of BAME communities, so that they can provide effective help to those in need.



**Report created by the Think + Do Tank
participants supported by the MWC team.**



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