Sands Surveys of Parents and Families from Black and South Asian Communities: Full Report

Background

Introduction

Sands is committed to reducing inequalities in both the access to maternity care and high-quality bereavement care and support services for pregnancy loss and baby death. Communities that can find it difficult to engage with maternity services (often due to barriers within and around those services) are also those that are more likely to receive poorer care, have worse outcomes and be less likely to access bereavement care and support. This is exemplified by the fact that babies from Black and South Asian communities in the UK are twice as likely to die as White British babies.

Sands' Bereavement Support Services directorate (BSS) were keen to explore the experiences of families from the Black and South Asian communities in the UK to better understand how to support families from these communities in the most effective manner. The directorate has already introduced two new roles to focus on engaging with and supporting both communities and this survey represents an initial exploration of parents' and families' experiences to inform this expanding area of activity.

Methodology

Two separate surveys were created, one for each community. The survey focusing on the Black community was co-created and disseminated with Black Mums Upfront, a London-based collective that works to highlight and champion experiences of black motherhood, and the survey of parents and family members from the South Asian community was co-created with Shetal Joshi, one of Sands' trustees. The surveys were created and managed on the platform Typeform and used a combination of multiple-choice answers and free-text responses to gather different levels of information about experiences of pregnancy loss and baby death. All responses were anonymised upon analysis. A mixed methods approach was employed with descriptive statistics, thematic analysis and close reading being combined to compare experiences of parents and family members both within and between the two communities.

Results and Analysis of the survey of people from the South Asian communities

Demographics

There were 82 respondents for the survey of people from the South Asian community and 131 for the survey of people from the Black community. In both cases the vast majority of respondents were bereaved mothers (94% for the survey of people from the South Asian community, 97% for the survey of people from the Black community), and only one respondent (an aunt) was not a bereaved mother or father.

The geographic representation of both surveys is weighted heavily towards London and the South East and the Midlands (see Fig. 1). Comparing the two, the survey of people from the Black community had a significantly higher proportion of respondents in London and the South East, whereas the survey of people from the South Asian community has greater representation from the Midlands. This probably reflects the baseline population demographics for these communities across the UK, but the involvement of Black Mums Upfront as a London-based collective may also have contributed to the London and South East dominance for the survey of people from the Black community. It is also important to note that the Northern Ireland, Wales and Scotland are greatly under-represented compared to England.

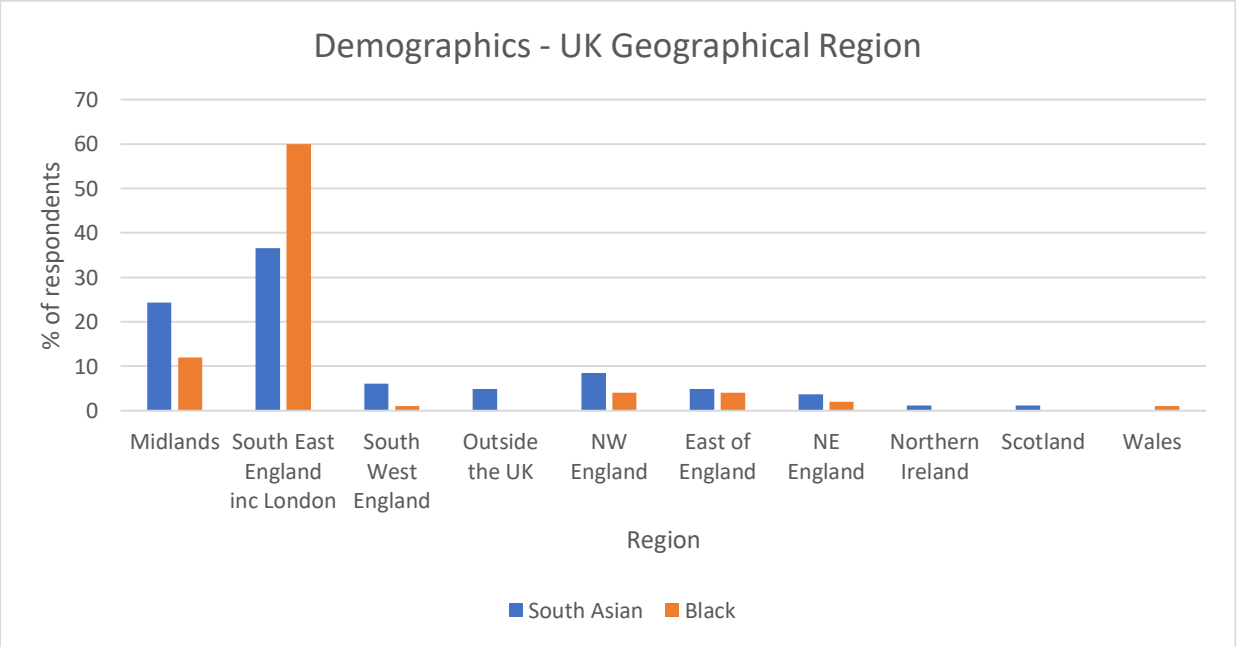

Figure 1: Bar chart showing spread of survey respondents across UK regions

Ethnicity, race and religion were recorded in different ways for the two surveys, reflecting the different cultural complexities present in the Black and South Asian communities. Respondents to the survey of people from the South Asian community were given options for ethnicity that combined country of origin and religious group, e.g. 'Indian Hindu' or 'Pakistani Muslim', whereas respondents to the survey of people from the Black community were given options for ethnicity based more on race and cultural origin, e.g. 'Black British' or 'Black African'.

There were a range of ethnicities recorded across both surveys (see Figs. 2 & 3), representing the variety of different groups that constitute the overarching communities and demonstrating the

complexities inherent in such seemingly singular labels. However, in both surveys a particular ethnic identity was more prevalent compared to the others: for the survey of people from the South Asian community 'Indian Hindu' is the most common (see Fig. 2), whilst for the survey of people from the Black community the most-represented group is 'Black British'.

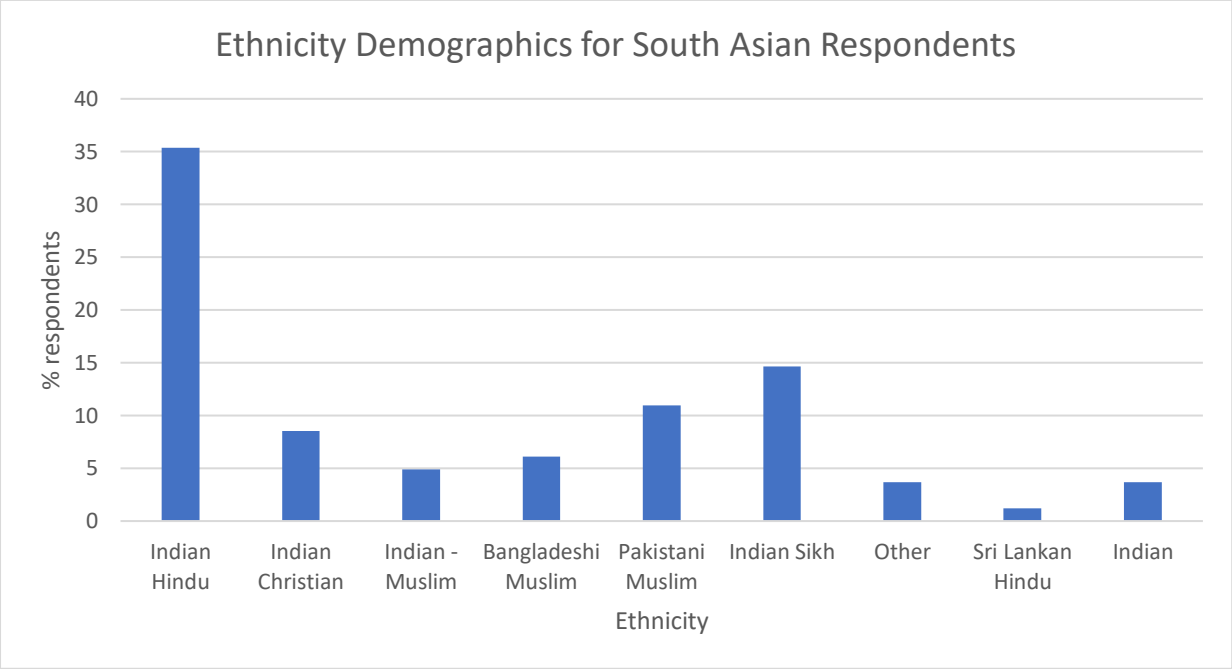

Figure 2: Ethnic identities of respondents to survey of people from the South Asian community

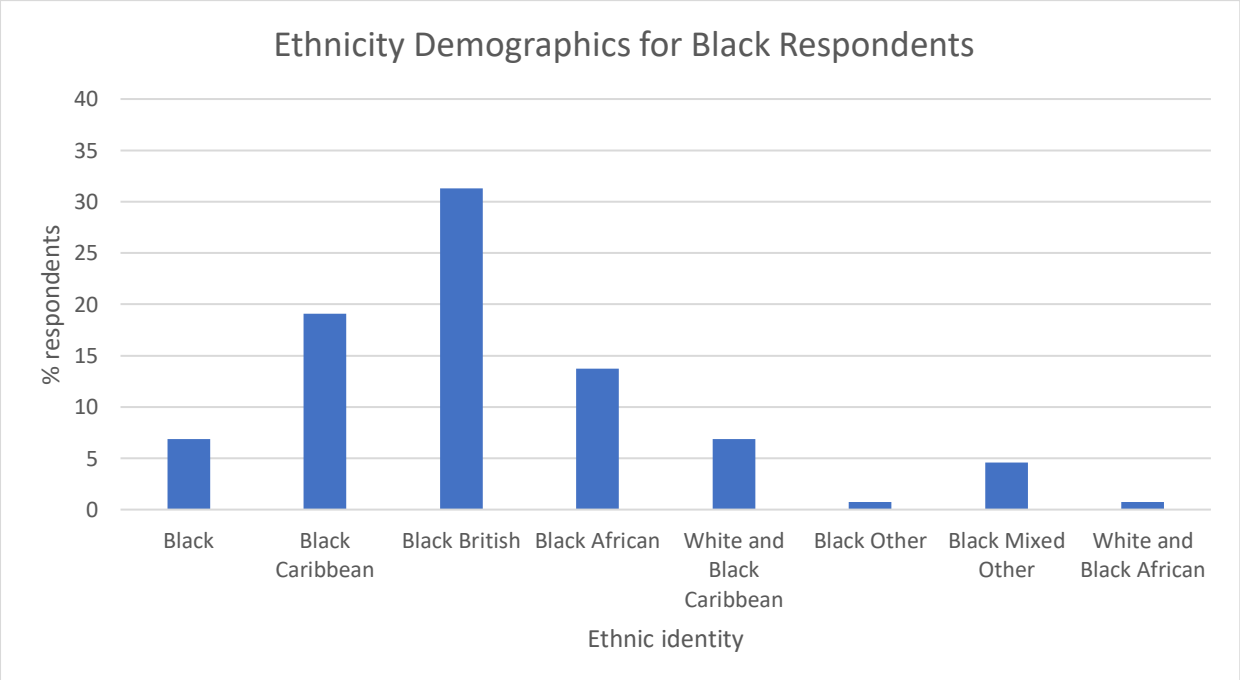

Figure 3: Ethnic identities of respondents to survey of people from the Black community

Pregnancy Loss and Baby Death Experiences

Respondents to both surveys were asked about the type of pregnancy loss or baby death experience that had happened to them and how long it was since this experience had taken place. For both surveys, the time since the experience had occurred was quite similar with 70% of respondents for the survey of people from the South Asian community having had their experience within the last 5 years, compared to 56% for the survey of people from the Black community. When examining experiences in more detail it will be important to note whether any differences in support might correlate with changes in care over the past decade or more (see 'Changes in Bereavement Care and Support over time' section).

The figures for type of pregnancy loss or baby death experience differed somewhat between the two surveys (see Fig. 4), with experiences of stillbirth and neonatal death being more common amongst the South Asian respondents whilst experiences of miscarriage are more strongly represented in the survey of people from the Black community. This difference grew when looking at pregnancy loss and baby death before 17 weeks gestation: in the survey of people from the South Asian community this experience applied to 23% of respondents, whereas in the survey of people from the Black community the figure was 47%. Whether this reflects any wider trend is unclear, especially given the very small sample sizes for these surveys, but it is important to bear in mind when examining the communities' experiences in more detail, especially from the perspective of Sands offering support and perceptions of Sands as a charity that focusses on neonatal death and stillbirth.

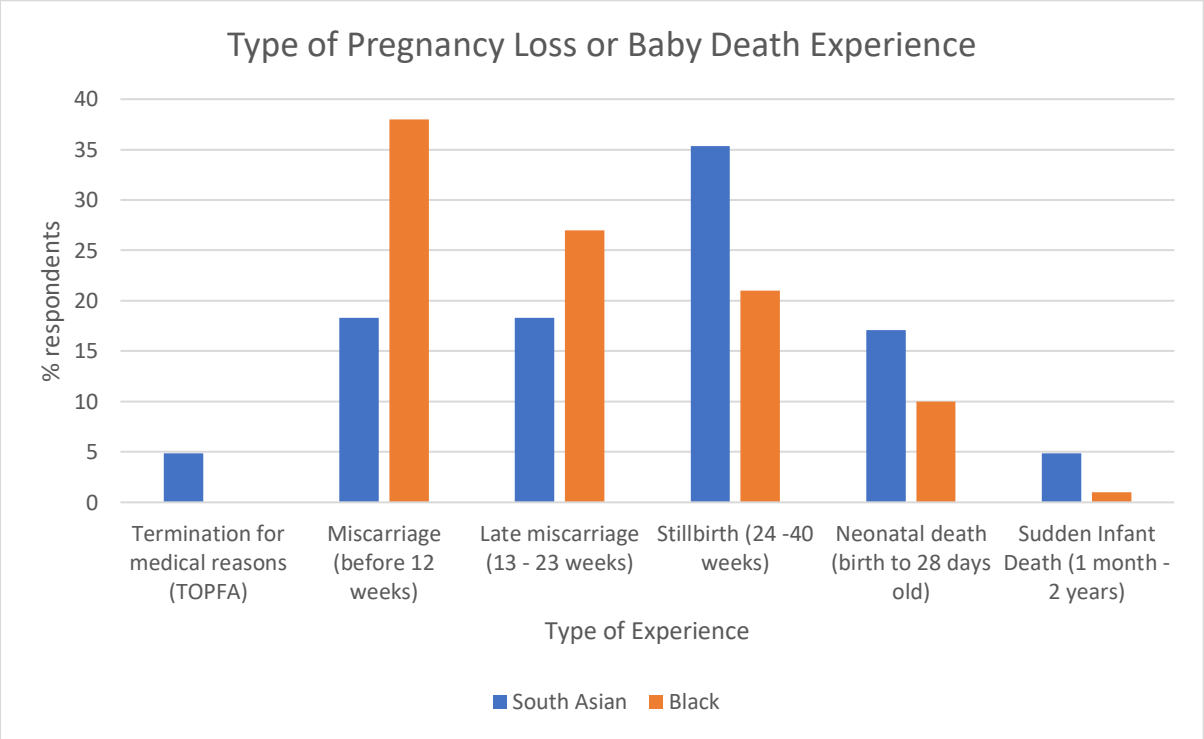

Figure 4: Comparison of the pregnancy loss or baby death experiences of respondents between the two surveys

Support for Bereaved Parents and Family Members in a Healthcare Setting

This section covers a series of questions that considered respondents' experience of receiving bereavement care and support in a healthcare setting, or by a healthcare or associated professional in the community within a healthcare context. This covers the time period in which the pregnancy loss or baby death happened and the short-term support surrounding that event, including who offered support and where, whether memory-making was available and how this was undertaken, and whether other sources of support were signposted, such as Sands.

Across both surveys, experiences were similar across the board when it came to being offered immediate bereavement care and support, despite the differences in pregnancy loss and baby death experience highlighted above. Most striking is the difference in support offered for parents and family members who experienced pregnancy loss and baby death before 17 weeks gestation, with 53% of South Asian parents and 48% of Black parents receiving no support at all, compared to afterwards, where only 14% of South Asian parents and 23% of Black parents received no support (see Figs. 5 & 6). This corresponds with the figures for the proportion of parents who received support from a healthcare professional in hospital, which are significantly higher for experiences after 17 weeks gestation, probably reflecting the fact that pregnancy losses and baby deaths before 17 weeks are less likely to occur in hospital, or in parts of the hospital away from a maternity unit. However, the lack of short-term support for these parents is still a major cause for concern, especially given the relative lack of support offered in the community (see Figs. 5 & 6).

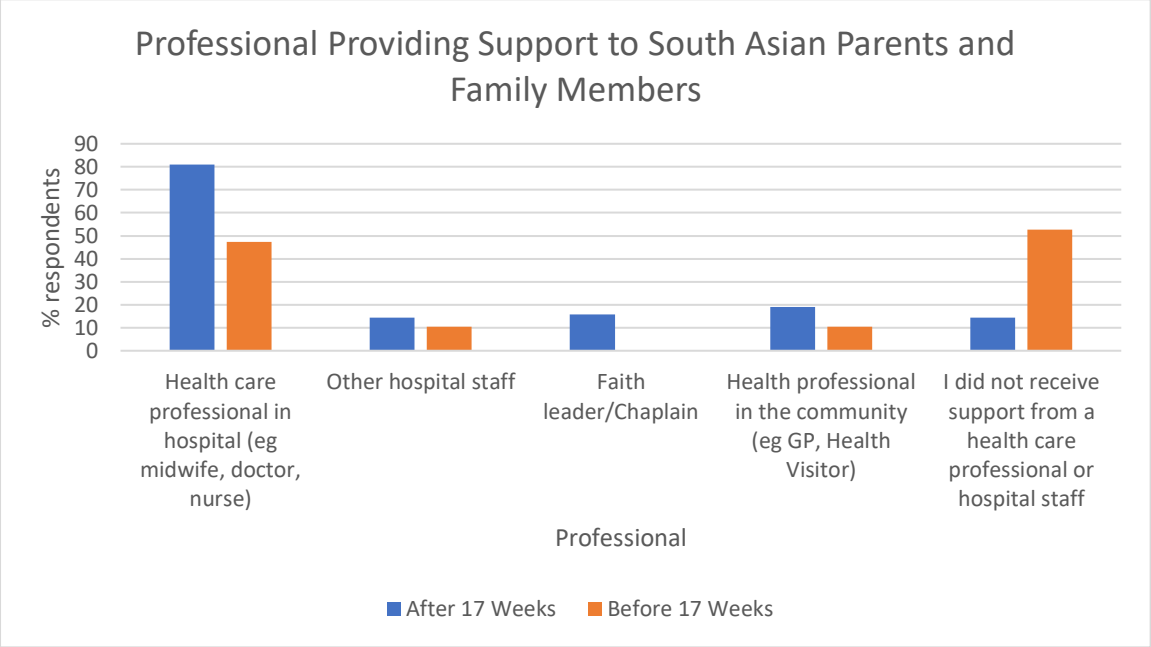

Figure 5: For the survey of people from the South Asian community, whether bereavement support was offered to parents and family members and who provided this support

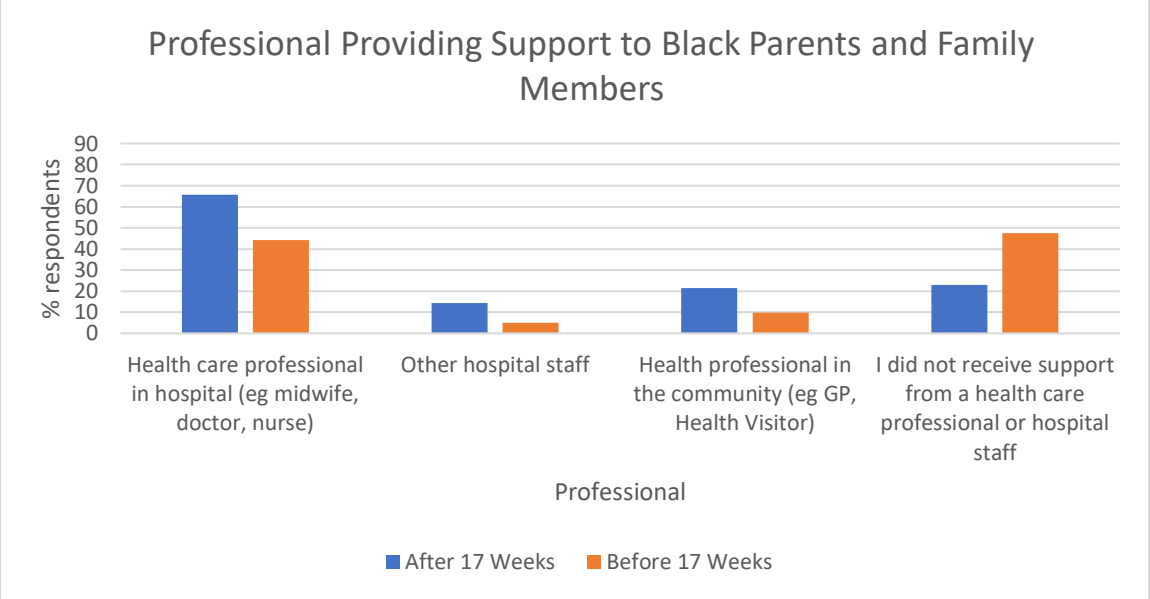

Figure 6: For the survey of people from the Black community, whether bereavement support was offered to parents and family members and who provided this support

These differences in support provision for pregnancy loss and baby death experiences before and after 17 weeks gestation remain consistent across both communities when looking at the types of support available to parents who were offered some sort of support by a healthcare professional. The kinds of information and signposting offered during this initial support were consistent across both surveys and followed a very similar trend in support provision for pregnancy loss and baby death experiences before and after 17 weeks gestation.

On average, professionals were equally able to provide clear explanations where death had occurred before or after 17 weeks but were half as likely to be supporting and understanding to parents when death occurred before 17 weeks. Similarly, the proportion of parents who felt as if the support they received was not clear, supportive or informative was five to six times greater for those who experienced pregnancy loss or baby death before 17 weeks. The following quote sums up the variability in experience for different types of pregnancy loss and baby death:

> *"I've had three losses - one late miscarriage, one neonatal death and one early miscarriage and I received support for the first two in hospital but nothing outside of that really. For my early miscarriage I received no support."* – Black parent

All of this highlights a potential need for further training and support for healthcare professionals in this area, emphasising the need for both clear, empathetic and consistent communication especially when dealing with parents and family members who have experienced early pregnancy loss. It should also be noted that Sands information was only ever given to parents who experienced pregnancy loss or baby death after 17 weeks (although only for half of parents across both surveys), with those having losses before 17 weeks being signposted to other organisations.

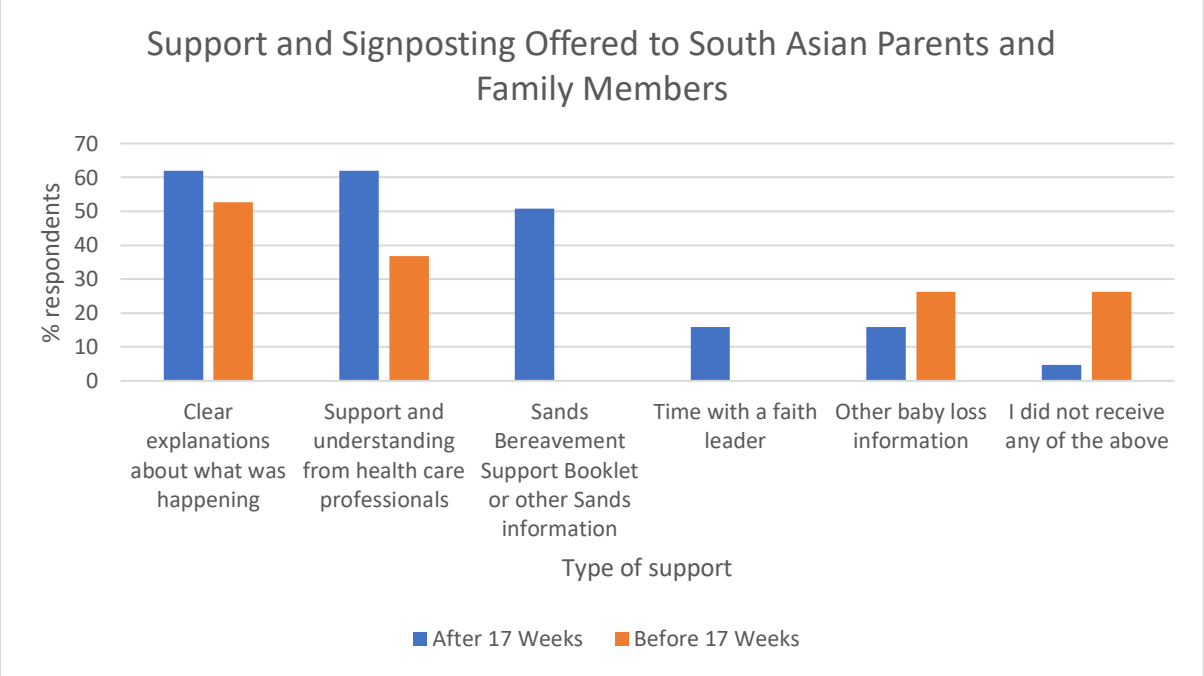

Figure 7: For South Asian parents and family members who received support from a healthcare professional, the types of support and signposting offered

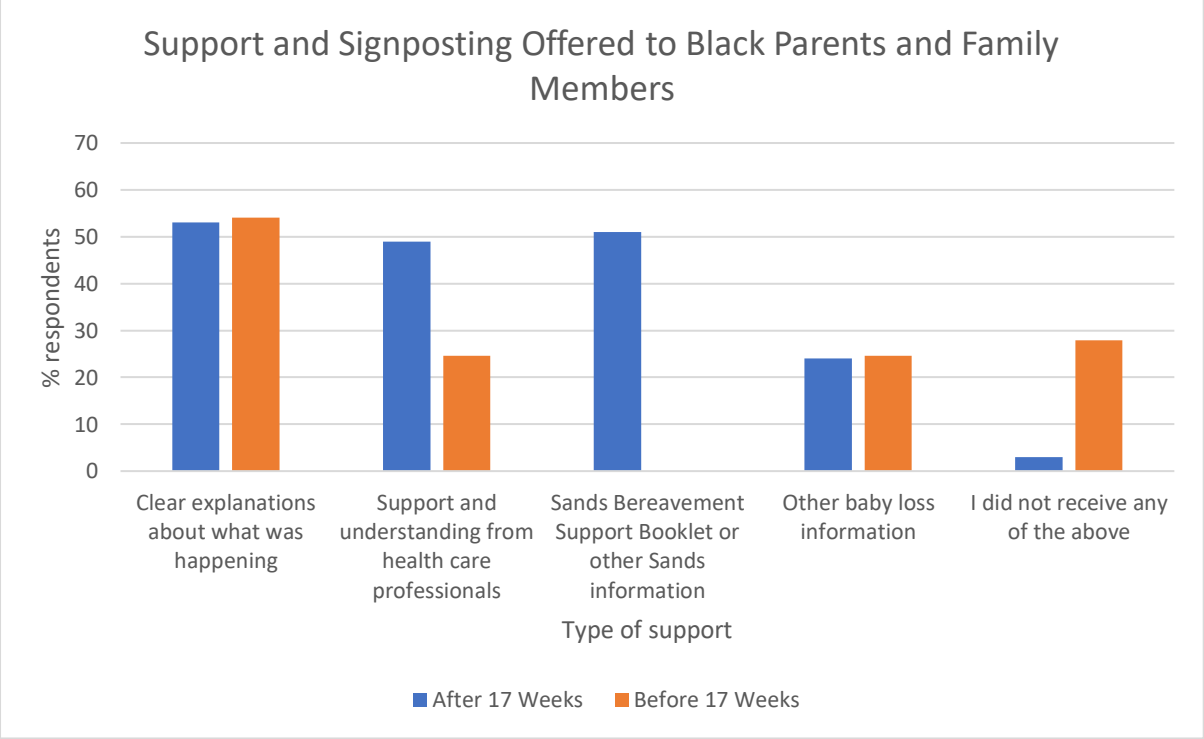

Figure 8: For Black parents and family members who received support from a healthcare professional, the types of support and signposting offered

Supporting Memory-Making Activities

One of the most important and valuable forms of bereavement support that can be offered to parents at the time of pregnancy loss or baby death is memory-making. The opportunity to carry out

memory-making activities - such as taking photos of the baby, making hand- or footprints casts, being given a special certificate or a memory box – is part of high-quality bereavement care and support. Although memory-making activities are more readily associated with later pregnancy loss and baby death experiences (primarily stillbirth and neonatal death) by parents and professionals, offering appropriate memory-making support, such as a special certificate, is still encouraged for miscarriages. This set of questions explored whether memory-making activities were offered to parents and family members and what type of activity were available, along with their experiences of the communication around memory-making and of carrying out the activities.

Once again, there is a very similar pattern across both survey groups with a consistently large disparity in experience between pregnancy losses and baby deaths before and after 17 weeks gestation (see Figs. 9 & 10). A minority of parents who experienced pregnancy loss or baby death before 17 weeks were offered time in a bereavement suite (although this does not necessarily mean that any memory-making activities took place), but almost no other form of memory-making support was offered to these parents. Healthcare professionals may assume that memory-making is not possible for early pregnancy losses, a feeling that is also reflected in some parents' perceptions:

"I suffered a miscarriage so this [memory-making] *does not apply"* – South Asian parent

As noted in the previous section, parents who had pregnancy loss and baby death experiences before 17 weeks gestation often did not receive support from a healthcare professional at the time, in part due to the settings in which such loss may have occurred. This means that memory-making support is also not immediately available, or left up to parents caught in the midst of such traumatic experiences:

"I took a photo of the baby when he came out of me in the a&e toilets" – South Asian parent

In these situations, the availability of subsequent support is all the more vital, including opportunities for some form of memory-making (perhaps a special certificate), yet lack of follow-up support was a common theme amongst respondents across all types of pregnancy loss and baby death:

"I just went home and had to deal with the loss by myself." – South Asian parent

Even in situations where immediate support was available, there was a sense amongst some respondents that missed opportunities for memory-making, sometimes due to the fact that they did not know that it was possible or available, could be a source of deep regret later on. Linked to this, across all types of pregnancy loss and baby death, was the importance of clear communication around memory-making and the understandably conflicting emotions that it can cause in parents during an extremely traumatic time:

"I didn't understand at the time why I would want to remember such a tragic experience… I wish someone had told me" – South Asian parent

A common theme across all responses from Black and South Asian parents was the importance of healthcare professional support and encouragement around memory-making during this difficult period and how valuable this proved to be later on:

"Allowed me to create memories which I would otherwise have not thought of myself" - South Asian parent

"The hospital had an experience bereavement midwife who explained all about Sands and also gave me the items of photos and footprints before I left the hospital. She was very understanding." – Black parent

"I was too traumatized and unwell to take photos with my son or comprehend everything that was happening and am forever grateful to the nurses that took a photo, footprints and lock of hair." – South Asian parent

Another common theme amongst parents offered memory-making activities was the therapeutic benefit that they could bring at the time, not just sources of future comfort. In some cases this stemmed from the fact that healthcare professionals had thought to offer this support, which may not have otherwise occurred to parents, whilst others found a cathartic release in the undertaking of the memory-making activities:

"It made me feel cared for and validated my feelings. It made me realise that I just had a baby and it was stillborn before that I was in denial" – South Asian parent

"Memory making gave me something else to focus on other than the pain of grief." – Black parent

With this in mind, it is also important to note that some parents, although finding the memory-making activities valuable, would have liked to have been more involved in them were possible, or have had more time to carry them out:

"The memory box was initially difficult to look at, but I am beyond grateful that we were given the option to have one and only wish that I was given the opportunity to help put the box together." – Black parent

Although support for memory-making was generally viewed positively by parents from both communities, there were slight differences between the two. Whilst Black parents made no mention of cultural or community taboo or discouragement around memory-making, some South Asian parents noted that such feelings within their communities prevented them from undertaking memory-making activities:

"I felt it was a taboo in my culture to celebrate a stillborn by taking pics" – South Asian parent

This was further borne out in a question on the survey of people from the South Asian community asking about parents' experiences of looking through memory boxes or photos with their family and friends, which some parents found difficult or impossible due to lack of understanding or community beliefs and taboos:

"Yes but it was a taboo subject and still is" – South Asian parent

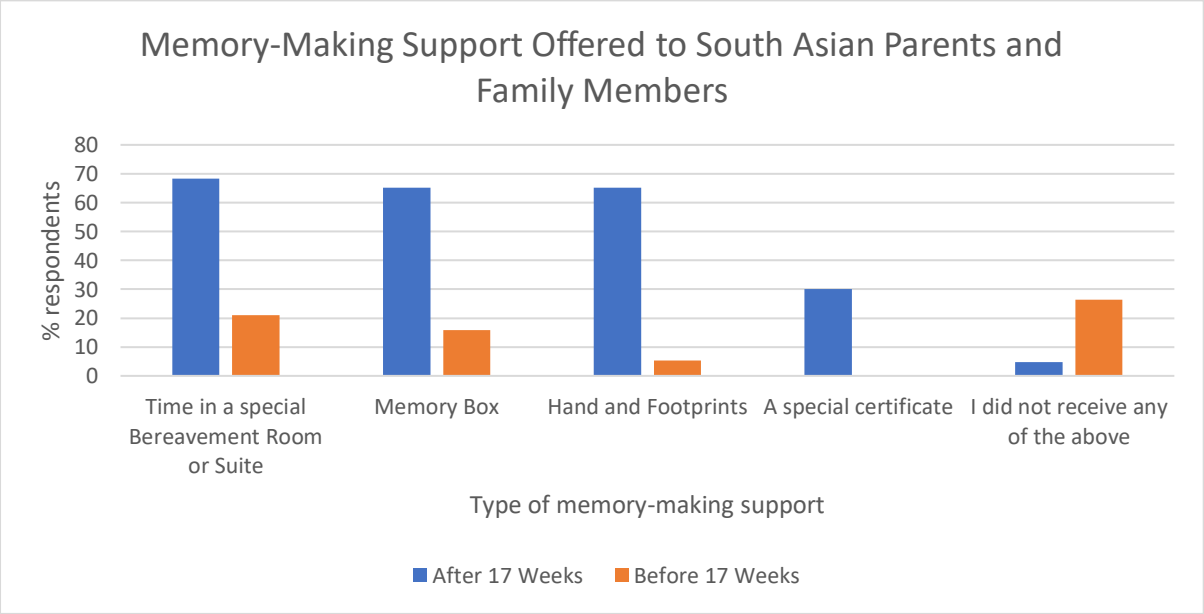

Figure 9: For parents and family members who received support from a healthcare professional, this chart shows the types of memory-making support offered

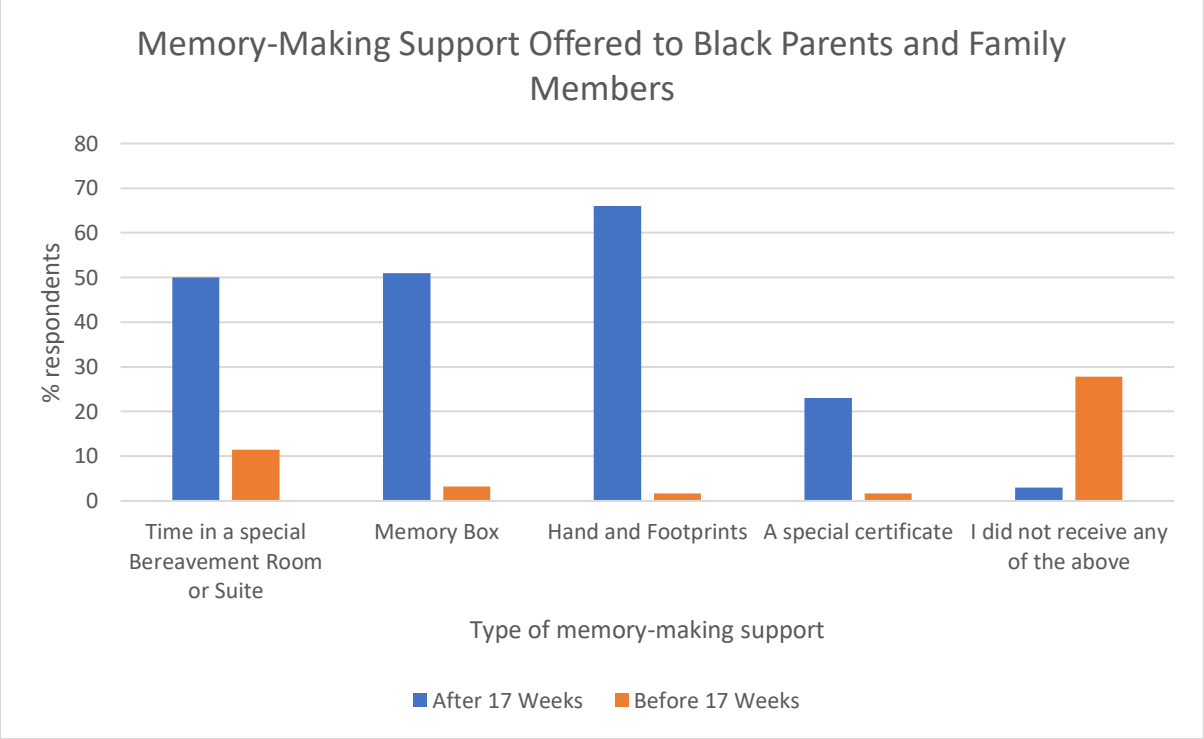

Figure 10: For parents and family members who received support from a healthcare professional, this chart shows the types of memory-making support offered

Bereavement Care and Support Provided at Home

The bereavement care and support available to parents and family members when back at home, away from a healthcare setting, is again remarkably similar across both communities surveyed (see Fig. 11).

For most respondents the primary source of support was their partner, followed by siblings, friends and then other family members. Many respondents across both surveys spoke of the invaluable support provided by family and friends, especially in time period surrounding the experience of pregnancy loss or baby death, with many citing this as the most effective and valuable support they received:

"My family and friends were amazing. One friend was pregnant herself but still was there physically and emotionally. Sometimes them just being there, holding my hand was enough." – Black parent

It is not surprising that family and friends constituted the core support network in most cases, but the individual experiences' of respondents from both communities show that this is often a more complex picture with relationships changing over time along with the degree of support offered. A common theme that emerged from the free-text responses around experiences of support at home is a sense of initial support being strong but then fading over time as friends and family members move on whilst the parents continue to grieve, or that friends and other family members are simply unsure of how to continue being supporting long after the experience of pregnancy loss or baby

death has occurred. Over time this could lead to support becoming restricted to very close family members, or often just the bereaved parents themselves:

"[Supported by] *Only my husband and older kids. Our families and friends didn't really talk about my son or know how to. It felt like no one remembered him except us"* – South Asian parent

"I felt like I needed to pretend to be OK quicker to make them feel better. I wasn't allowed to feel my emotions just pressure to move on and not dwell." – Black parent

Whilst family support was invaluable for many, the most effective and helpful support came from those who had undergone a similar experience, be they family members, other members of the community or individuals in support groups. Conversely, those without such experience, often despite the best of intentions, simply did not fully understand or know how to support bereaved parents or family members, especially in the long run. For parents in this situation, the ongoing support available from groups and organisations was particularly valued:

"It was nice to meet other parents who had also lost their children" – South Asian parent

With these points in mind, it is surprising to note that of the parents who did receive information about Sands from a healthcare professional, only a small proportion of them went on to access Sands support when at home (17% of respondents to the survey of people from the South Asian community and 13% of respondents to the survey of people from the Black community). It is not clear from the survey responses from wither community why this is the case, although the fact that Sands support was often highly valued when accessed shows that increasing support uptake is an area to focus upon. It should be noted, however, that some parents experienced this support differently as time went on:

"I had to go out and find sands myself. But it was the best thing I did I was able to speak to you I other women who went through what I had been through and made some lasting friendships and we even supported each other with subsequent pregnancies" – Black parent

"Initially the Sands support group really helped, talking to other bereaved parents. Later on we stopped going as we found it quite sad and stopped us from moving forward" – South Asian parent

Support through any means – face-to-face, online or by phone - was seen as helpful by both communities and those who accessed it were often keen that it should be made more accessible to others and better signposted, especially for those support communities not part of an organisation like Sands:

"It meant the world. I also wish someone had told me in those early days to get on Instagram and follow baby loss. The support from this network of loss parents was just incredible" – South Asian parent

"Very helpful to know there was always someone at the end of a phone if I needed to talk" – Black parent

For those bereaved parents and family members who were not supported by their families or communities, or were unable to access support from organisations or groups, the experience could be particularly lonely and damaging. As seen in the experiences of memory-making, there was a slight difference here between the communities with a few South Asian respondents mentioning a total lack of community and family understanding or support, whereas Black respondents experiences were generally positive and did not single out stigma from specific communities as a problem:

"I had little support just family which I didn't open up to as much, which lead me towards postnatal depression and anxiety" – South Asian parent

"No I had a backlash from in-laws and wider community" – South Asian parent

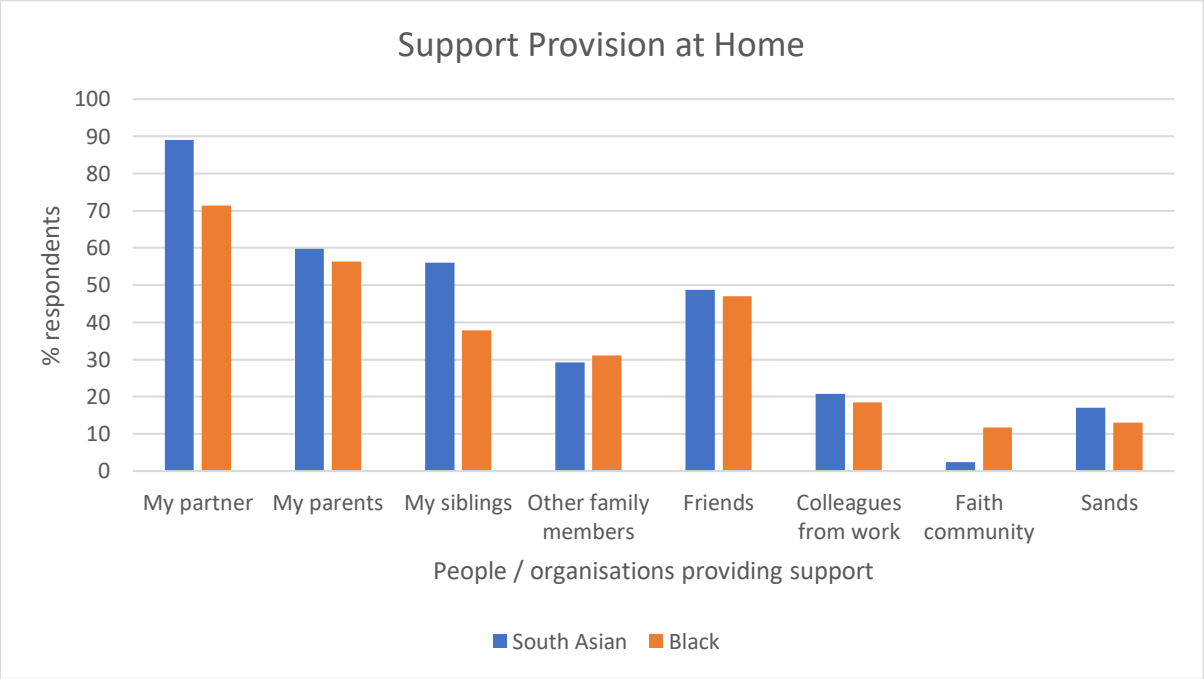

Figure 11: Bereavement support available to parents and family members at home

Improving Bereavement Care and Support for Parents and Family Members

This final section considers how bereavement care and support could be improved for Black and South Asian communities, taking into account their experiences in healthcare settings and at home and specifically asking parents what would have been the most effective type of support for them. Again, the range of responses was extremely similar across both communities (sese Fig. 12). In many cases this boils down to ensuring that some of the positive experiences for parents of good practice are consistently available to all, with many of these being factors that have often been mentioned before. A commonly cited example is ensuring access to a bereavement suite or similar private space:

> *"A separate room to make phone calls to family and friends. My husband had to go into the corridor to make the phone calls while he was crying and upset himself"* – South Asian parent

"Just a chance to sit in a room with someone else as I was on my own and instead went and sat in my car and cried whilst googling miscarriages" – Black parent

Another common theme across both surveys is improving follow-up care from any immediate support given in a healthcare setting to making sure that support continues once parents are back home, especially mental health support such as counselling. Across both surveys, some respondents thought that such support would be most effective if the person or group providing it reflected and understood their community and experience:

"A call or bereavement check in with a professional. Being referred to a support group. Anything, not just a leaflet." – Black parent

"it would have been good if there had been some form of follow up to check if we'd had some grief counselling" – South Asian parent

"Counselling from a black person especially would have been so valuable." – Black parent

This links in with the fact that the most important factor for parents and family members across both communities was being able to access support from individuals who had similar experiences of pregnancy loss or baby death; in both surveys this factor was seen as twice as important as whether those individuals came from the same community as the bereaved parents or family members. Although there were slight differences in the choice of how to access such support, whether online, over the phone or in person, the fact that such support should be available and clearly signposted was the crucial point:

> *"Being given easy access to support groups local to me - I would love to speak to other mums that have gone through this and I'm just not sure where to find them"* – South Asian parent

"I feel the support that helped me the most was by talking to someone who understood […] what I have been through. Basically a person who has too lost a baby." – South Asian parent

"A support group that had women who had experienced what I had." – Black parent

Alongside this was the theme of better tailoring the initial bereavement support received from healthcare professionals to meet the needs of the bereaved parents, with some respondents noting that whilst it was good the support was offered it did not necessarily reflect their experience or situation:

"Not to generalise miscarriage but offer support tailored to that individual." – Black parent

This is also highlighted by the 5% of all respondents (across both surveys) who chose not to access bereavement support, citing the fact that the support available to them did not reflect their experience of pregnancy loss or baby death or did not reflect their community. This theme of reflecting a particular community was seen by parents in both surveys as something that help make bereavement care and support more relatable, which might make the experience of the person providing support feel more similar to their own. Some also noted that whilst they found support groups helpful, they would have felt more comfortable and engaged more with such support if it better reflected their communities and situations:

"I wish that I could have had black midwives or a black bereavement midwife just for that extra relatability" – Black parent

"Sands was helpful I would have loved if there was a Sands for Black women or more black women on the online community telling their stories" – Black parent

"I found it difficult to attend Sands group because I was a single and only black mother" – Black parent

"Baby loss is Taboo in the Sikh community only few of us speak openly so it would be great if a leaflet could be made of social media platforms where support can be found" – South Asian parent

"I have always believed baby loss across all communities is a taboo subject but more so in our Asian communities and finding people to talk to within the communities would be so beneficial" – South Asian parent

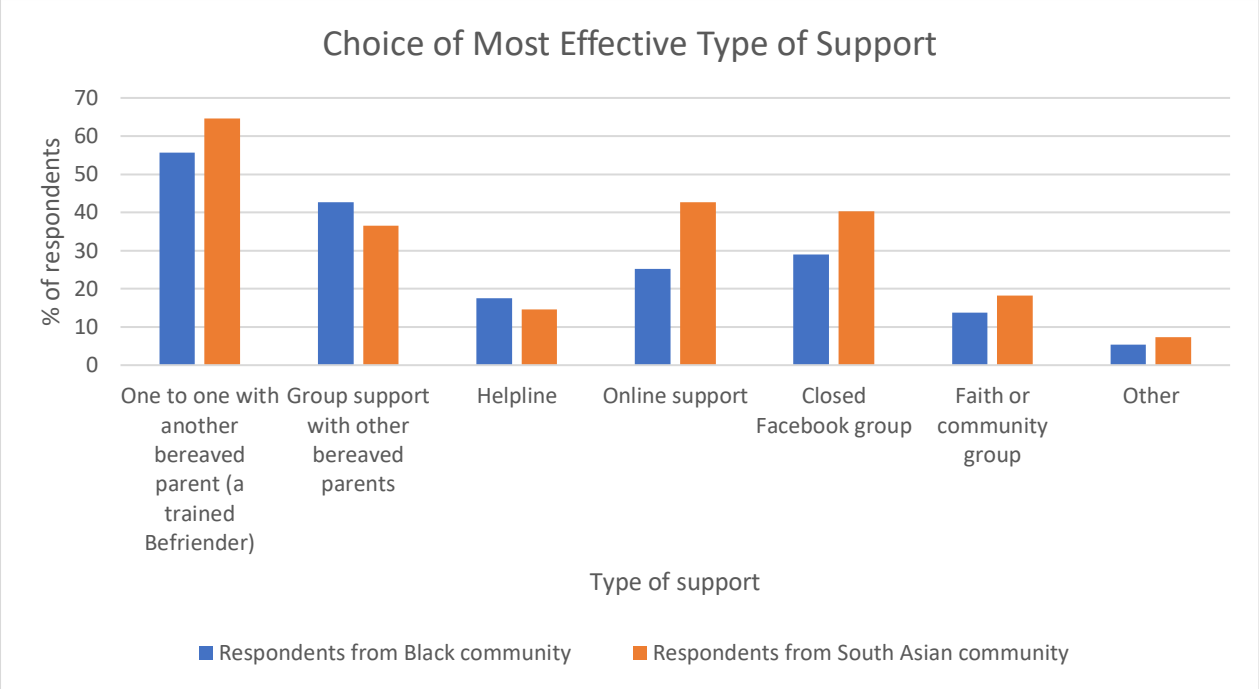

Figure 12: Black and South Asian parents' choices for what would constitute the most effective type of bereavement support in their experience

As seen in the previous sections, there are subtle differences here between the Black and South Asian communities in what constitutes relatability of experience and how such communities are further defined, with the Black respondents identifying more along racial lines and the South Asian respondents along religious ones.

This has been reflected in the co-creation of the surveys themselves; some of the complex cultural and community issues are further explored in the survey of people from the South Asian community via a question around support for funerals and ceremonies which was not present on the survey of people from the Black community. Responses to this question highlighted this as the most important area where lack of religious, cultural and community knowledge and understanding was most keenly felt by bereaved parents:

"Guidance on funeral arrangements or experiences particularly in Asian customs, I had no one to turn to who had experienced this or could give me advice and guidance." – South Asian parent

"I wish someone from my community was able to guide me on what kind of funeral I should have had. Looking back my parents were not much help as their guidance was based on their knowledge from India and not as an Indian living in England" – South Asian parent

This is perhaps the area where support for bereaved parents and family members from the South Asian community can be significantly improved with the implementation of relatively basic measures around community-specific guidance and information provision or signposting.

Changes in Bereavement Support and Care over time

As noted earlier, respondents to both surveys were asked about the type of pregnancy loss or baby death experience that had happened to them and how long it was since this experience had taken place. For both surveys, the time since the experience had occurred was quite similar with 70% of respondents for the survey of people from the South Asian community having had their experience within the last 5 years, compared to 56% for the survey of people from the Black community (see full breakdown in Fig. 13). Examining respondents' experiences of bereavement care and support in relation to the time since that experience occurred makes it possible to get an idea of how the provision of such care and support may have changed over the last decade or more. This analysis was restricted to pregnancy losses and baby deaths that occurred after 17 weeks gestation because the numbers of respondents with experiences before 17 weeks gestation that happened more than five years ago, for both surveys, were too small to allow for meaningful comparisons.

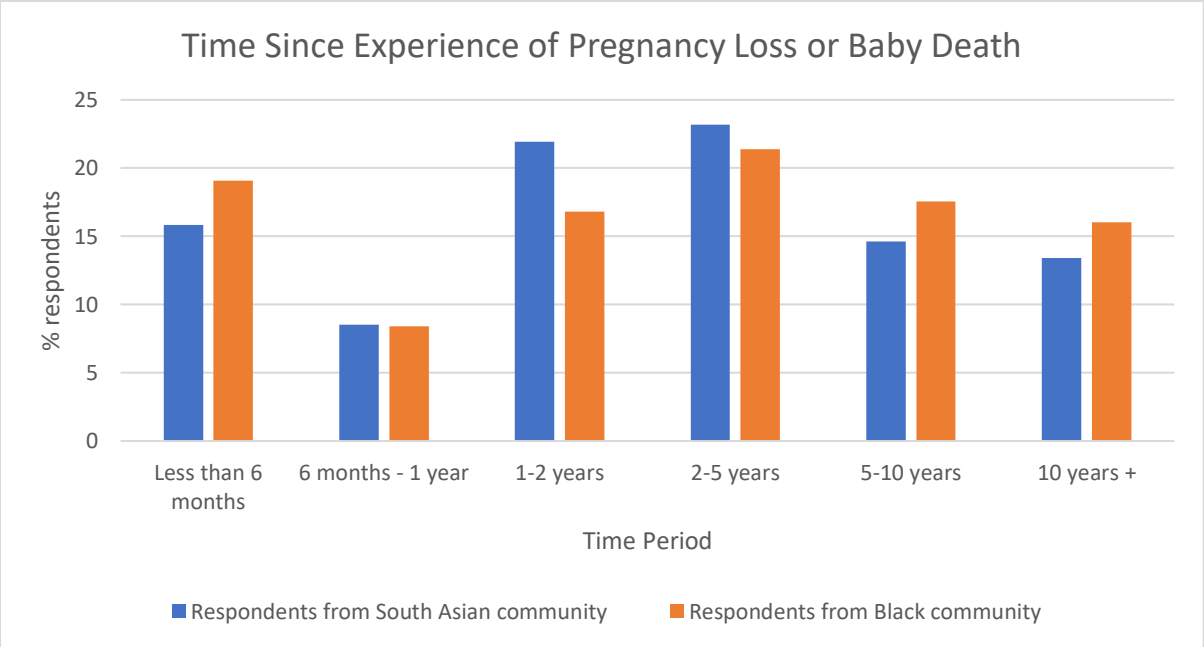

Figure 13: Range of time periods since respondents' experiences of pregnancy loss or baby death

For parents and family members who experienced pregnancy loss or baby death after 17 weeks gestation, the analysis showed an overall trend of improvement in the provision of bereavement care and support over time (see Figs. 14 & 15). For both surveys, there is a 27% increase in the number of respondents being provided with bereavement care and support by a healthcare professional in hospital between the two time periods.

The impact of COVID-19 over the past two years was also taken into consideration and there is very little difference between the figures for the past two years and the past five years, although the graph for the survey of parents and family members from the Black community does show some slight variations. It is also possible that COVID-19 may not have affected the provision of bereavement care and support services in hospital, but may have changed experiences of using these services, as demonstrated in the following quotes:

I didn't get to have a special room as such due to covid and was on the delivery suite with other mums who were delivering – South Asian parent

Due to covid I was told the news my daughter had passed away on my own when I was in triage. This could have been handled more sensitively – South Asian parent

During the pandemic we were not able to get a photographer to come in – Black parent

There was no similarly clear trend across community and charity support, with small improvements in some areas but relative stability in others; for example there is an average 17% increase in family support over time for the survey of parents and family members from the South Asian community, whilst the same sample of respondents saw a 4% decrease in the number of respondents accessing support from charity organisations including Sands.

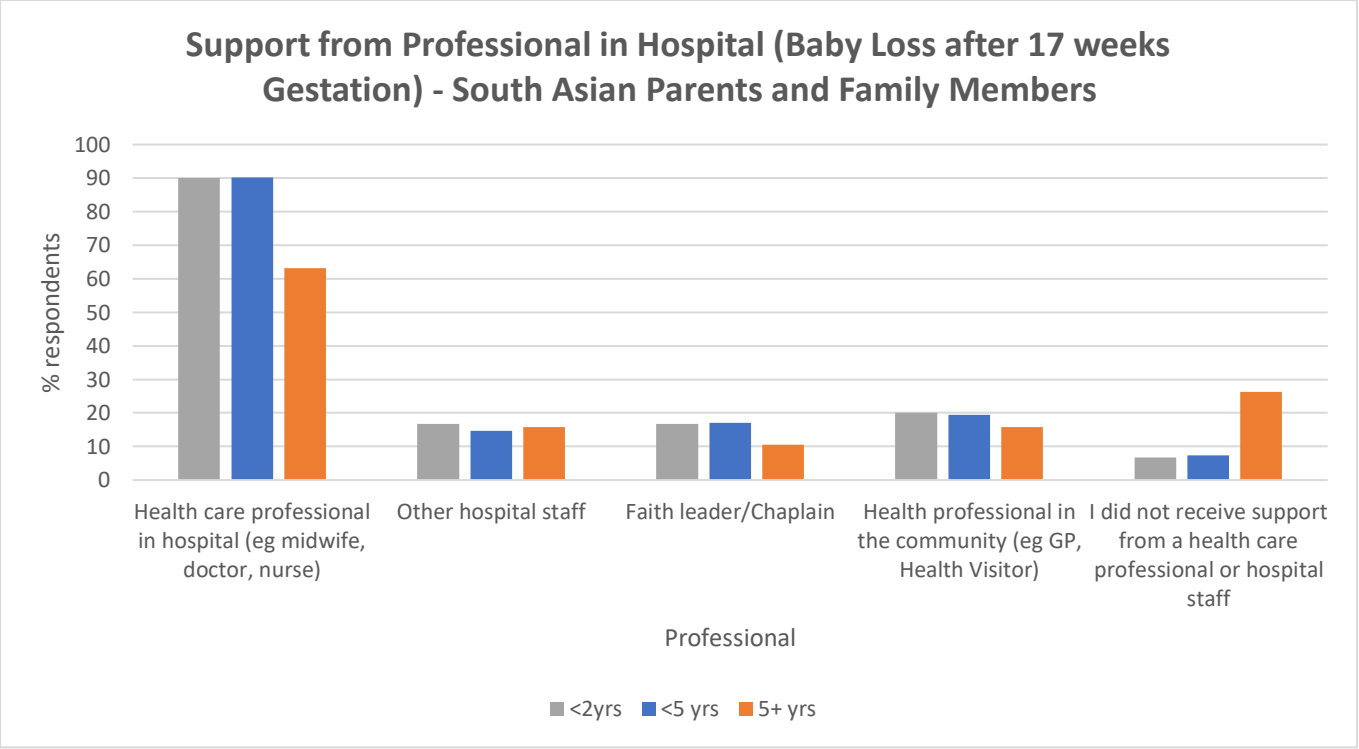

Figure 14: Change in bereavement care and support provision in hospital over time for parents and family members from the South Asian community

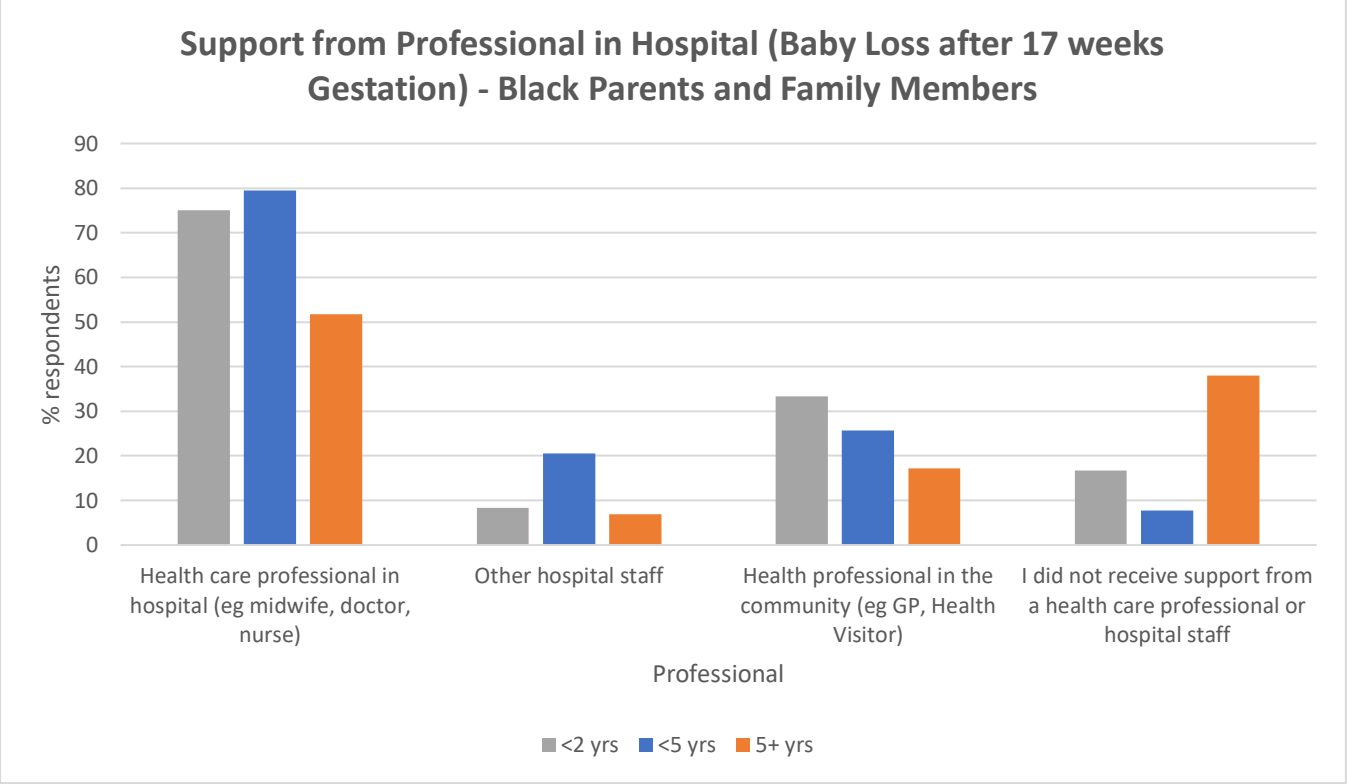

Figure 15: Change in bereavement care and support provision in hospital over time for parents and family members from the Black community

Conclusions

Throughout both analysis clear themes emerged that were consistent across the experiences of bereaved parents and family members from both the Black and South Asian communities. The most striking difference in experiences across the surveys is not between communities but between earlier and later pregnancy losses and baby deaths, with those occurring before 17 weeks gestation being far less likely to be effectively supported compared to those occurring later. This large disparity in provision of bereavement support is seen across all stages of experience, from initial contact with health services to long term support at home and as part of the wider community. It is also clear that provision of bereavement care and support in healthcare settings has improved over time.

Across all survey respondents there were common themes around how bereavement care and support could be improved. The main focus here is on ensuring that support provided by individuals with expertise in and similar experiences of pregnancy loss and baby death is accessible to as many bereaved parents and family members as possible and that it is clearly signposted as early as possible. For both communities, an additional aspect of this was to improve the relatability of such support to the Black and South Asian communities, ideally representing the variety of cultural norms, practices and faiths found within both communities.

Of all the individuals who responded to the surveys, the vast majority were bereaved mothers either from the South East or the Midlands, with hardly any respondents from Northern Ireland, Wales or Scotland. While this survey represents an important step in exploring the experiences of parents and

family members from the Black and South Asian communities, it should be noted that more work needs to be done to include the perspective of bereaved fathers and other family members.

Recommendations

- There is a lack of support for pregnancy loss experiences before 17 weeks - explore the options for Sands' involvement in improving this in line with upcoming strategy shift to include all types of pregnancy loss and baby death
- Of the 50% of respondents who did receive information about Sands during care or support, only 22% of them accessed Sands' support when at home – explore the underlying causes of this gap in more detail
- More specific training for relevant professionals around community-specific support especially when considering arrangements after death such as burials, funerals, services and access to specific advice for a given community or religious group
- More extensive and representative online and face-to-face support provision from Sands and signposting to existing community spaces for bereavement and baby loss support
- This survey primarily represents the experiences of bereaved mothers from the South East and the Midlands, more needs to be done to gather the views of other family members and those in other parts of England and the devolved nations

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