

**Increasing Access to Community Health Services
with Oldham's Bangladeshi and Pakistani
Communities**

A Report into End of Life Preferences amongst Oldham's Bangladeshi and Pakistani Communities

by
OAK Community Development

September 2015



About Us

OAK Community Development specialises in working with the BME and faith communities. Our aim is to empower individuals, families and disadvantaged communities with the skills, confidence, networks and resources they need to tackle problems, grasp opportunities and achieve; thereby creating a better, prosperous and inclusive society



OAK COMMUNITY DEVELOPMENT

Earl Business Centre
3rd Floor
Dowry Street
Oldham
OL8 2PF
T: 0844 504 7111

Contents

- Executive Summary.....4
- 1. Introduction.....5
- 2. Methodology & Approach.....8
- 3. What We Found.....9
- 4. Conclusion.....21
- 5. Recommendations.....22
- 6. Acknowledgements.....23
- 7. References.....24
- 8. Appendix.....25

Executive Summary

This report is a compilation of key findings into the end-of-life preferences of Oldham's Bangladeshi and Pakistani communities. The study was undertaken by OAK Community Development during April 2015 and July 2015 with members of the Bangladeshi and Pakistani community living in Oldham. A summary of the key points are as follows:

- Pakistani and Bangladeshi residents make up a nearly quarter of the current population of Oldham and this is set to increase within the next ten years. It has a youthful and diverse make up but also a growing number of people who will be reaching 65 and over. Most of the Bangladeshi and Pakistani community are concentrated within the Oldham District wards.
- The carer's experience of the end of life care service was overall positive with the majority stating they were treated with respect by all of the staff involved in delivering end-of-life care.
- A sizeable number of patients/carers said they were not offered access to specialist help and support if it was required.
- Emotional support and spiritual support scored much lower compared to other areas of overall support that were assessed.
- More than half of people surveyed had talked about dying matters with someone in their family, a relative or a friend.
- The views of a good death experience of Oldham's Bangladeshi and Pakistani community differed from the national picture. The aspects of dignity and privacy, spiritual support, and being with family were considered to be the most important.
- The majority preferred to die at home, but this differed in practice as most people died in hospital.
- The lack of knowledge and accessible information about services such as hospices and specialist types of support meant that Oldham Bangladeshi and Pakistani people were unlikely to engage with or refer themselves on for help. It also meant they were less likely to choose hospices as a place to receive end-of-life care.
- GPs, Imams and family members were seen as the best places to go for advice and support on end-of-life and dying matters.

1. Introduction

Whilst there are many examples of good end-of-life care being provided in various settings, studies suggests there still exist too many inequalities in the care that different groups of people are receiving at the end of their life. Between 2012 and 2013, on average, 7% of new people accessing palliative care were described as non-white, while a total of 14% of the population in England is reported as being of a non-white ethnicity. ⁽¹⁾

Research around the quality of end-of-life care for people from BME backgrounds is limited, thus impacting on the quality of care they receive. A study by Marie Curie Cancer Care stated that people from BME backgrounds will soon make up a significant proportion of people over 65. It highlighted the fact that the end-of-life care needs of BME communities are varied, growing and despite examples of good practice, overall are not adequately understood or met. ⁽²⁾

In a 2011 survey, 43% of bereaved people said they thought that care for their loved one in the last three months of life was excellent or outstanding. But 24% said it was fair or poor; it was felt too many people aren't getting high-quality care at the end of their life. ⁽³⁾

Studies have also suggested that palliative and end-of-life services can further help to improve quality of care by allowing more people to choose where they die,⁽⁴⁾ and in the majority of cases, the preferences of the BME community are similar to the general population, which is to die at home.

This report commissioned by the Oldham Pennine Care NHS trust aims to get an insight into the end-of-life care preferences of the Bangladeshi and Pakistani residents living in Oldham with a view to help palliative and end-of-life care providers develop more high-quality, culturally appropriate care, promoting equity of access and utilization.

2. Methodology & Approach

A variety of methods were adopted to gather information for the research study. This included questionnaires, focus groups and face-to-face interviews. Two separate questionnaires were undertaken with the target audience. A post-bereavement questionnaire aimed at those who had experienced caring for someone during the end of life, and a second end-of-life preference questionnaire was provided for the wider community to help get insight into their end-of-life preferences.

A PR campaign was organized to recruit respondents to take part in the research. Leaflets and posters were designed in English, Urdu and Bengali to ensure broader appeal and accessibility for the target audience, and these were widely distributed in the community.

Outreach and engagement activities were undertaken, including meeting people on the streets and in their homes, setting up information stalls at local events and community venues, making announcements after Friday congregational prayers in mosques, and through general word of mouth. In addition, an online survey was produced and promoted through email, social media and group networks.

Printed & Online Survey

Two survey forms were developed: a post-bereavement form provided by the Oldham Palliative Care Team targeted at persons who had cared for someone during their end-of-life stages within the last 24 months, and a more general end-of-life preference questionnaire produced by OAK CD aimed at getting the views of the wider Bangladeshi and Pakistani community.

Volunteers were recruited to assist staff in getting the forms completed. Prior to going out on the streets, they attended workshops and briefing sessions. In total a sample representative of 110 questionnaires was completed: 52 post-bereavement questionnaires and 60 end-of-life preferences questionnaires.

To make the survey more accessible, an online version was created and promoted via leaflets, posters, emails, text message and Facebook. The response was limited as compared with actual on-street completion.

Focus Groups

Three focus groups were held with residents of Werneth and Westwood: a focus group with women only, a focus group for men only, and a mixed focus group of men and women.

Interviews

A combination of face-to-face interviews and telephone/text interviews were conducted with some of the respondents who had filled in the post-bereavement and end-of-life preference questionnaires to help tease out further information and get an insight into why they had selected certain answers. The focus groups lasted between an hour and half, but flexibility was given to the respondents so they could freely put across their points.

The interview approach taken to consult with professional stakeholders varied between face-to-face interviews and telephone.

3. What We Found

3.1 Trends, Background and Makeup of the Respondents

Oldham Population Trend

Oldham's population is currently at 227,312 ⁽⁵⁾ and is made up of the following groups: White, 77.5%; Pakistani, 10.1%; Bangladeshi, 7.3%; and Other, 5.1%.

The BME population accounts for nearly a quarter of Oldham residents, 22.5% in total. It has a younger population, with 22.4% of 0–15 years age compared to the national average of 18.9%. The ages between 16–64 is about the same as the national average of 62.1%, but it has a relatively lower than national 65+ age group of 15%.

By 2023 the general population is set to increase to 236,000 ⁽⁶⁾ with a projected increase of 20% for over-65 age, 40% increase in over 75, and 50% increase in over 85. There will be a significant increase in the BME population who are ageing 65+.

Age, Gender & Place

The Pakistani and Bangladeshi community mainly reside in the parts of West Oldham covering the wards of Alexandra, St Marys, Werneth and Coldhurst. The community is increasingly moving out into other areas such as Royton, Chadderton and Hollinwood.⁽⁷⁾

Our respondents mainly came from the wards of Werneth & Coldhurst; 36% came from OL8 areas, 40% from OL9, 6.5% from OL4, 16.3% OL1 and 1.2% from other parts of Oldham.

The majority of the respondents were females, which accounted for 65% of respondents. Males who responded were 35%.

70.49% of respondents were from the ages of 25–44, 16.39% were aged between 45–64, and 13% were between 16–24. Less than 1% did not state their age.

The ethnic origin of the respondents were approximately equal; 47.54% were of Pakistani heritage and 45.9% of Bangladeshi heritage, with the remaining 6.56% made up of African, Mixed Race and Whites.

The main mother tongue languages spoken were Urdu, 18.03%; Punjabi, 23%; Sylheti, 41%; Mirpuri, 5%; and Other, 11%.

The faith and beliefs of the respondents were mostly Islam and Muslims. 98% stated they were Muslims, 1% Christian and 1% who did not give any faith.

In terms of their economic status, 30% were employed full-time, 26% were employed part-time, 5% were self-employed, 27% were unemployed, 10% were students, and 2% gave no response. (8)

3.2 The Carer's Experience

The post-bereavement questionnaire was used to gather the views and experience from the carer's perspective. This was a person who had looked after or cared for someone during their illness in the end stages of life. The key findings were as follows:

The most common type of relationship of the carer to the person looked after during end-of-life care included parents, son/daughter and other relatives such as granddad/grandma, uncle, or aunt.

Carers felt it was their duty and an act of love to help look after their family and relatives during illnesses or times of need. Others commented that although sometimes it was challenging, they nevertheless felt the experience was rewarding.

"We don't see it as a burden but it is a way of pleasing our Creator."

"It is part of our culture and faith to look after our parents and relatives."

A range of people were involved in the caring of the patient with the GP being cited by more than 62% of respondents as the key person, followed by specialist palliative care nurse at 35% and district nurse at 19%. Other key people included family members, hospital staff/nurses, and other doctors.

A vast majority of carers felt the person they were caring for was treated with dignity and respect by all of the staff who were involved in looking after the patient.

During the focus group, issues around better communication, understanding of culture and knowing the needs of the dying person were mentioned to improve the overall experience of affording dignity and respect to the patient and family.

“One of the nurses took interest in finding out about me and our culture; I couldn’t explain a lot but she looked after me well.”

Similarly, 87% carers felt their role as carers was acknowledged by staff, as compared to 13% who didn’t feel their role was acknowledged. The need for better information, communication and support was often cited by carers who felt they had to sacrifice much time and sometimes money to look after the patient but received little or no help.

“Just family help, no resources to access or available.”

Although the majority, 65%, stated they were offered access to specialist support and information if requested, there was a significant number, 34%, who said they had not been offered any type of specialist support. Language and communication was often a barrier to asking for or receiving support and information.

“I wasn’t sure about how to ask or if it was right to do so.”

With regards to the overall level of support given from all teams providing end-of-life care, the results varied for different aspects. The table below shows the results. (9)

How would you assess the overall level of support given in the following areas from all teams providing end-of-life care?							
	Very Good	Good	Fair	Poor	Very Poor	Does Not Apply	Don't Know
Relief of pain	10.5%	36.8%	36.8%	0.0%	0.0%	0.0%	15.8%
Relief of symptoms other than pain	7.9%	39.5%	36.8%	0.0%	0.0%	0.0%	15.8%
Emotional support	5.3%	18.4%	50.0%	5.3%	0.0%	0.0%	21.1%
Spiritual support	2.8%	27.8%	44.4%	2.8%	0.0%	0.0%	22.2%
Support to stay where they wanted to be	2.6%	42.1%	44.7%	0.0%	0.0%	0.0%	10.5%

We can see that most of the highest scores were in the Fair and Good categories. Emotional support and spiritual support were the two areas where respondents gave a score in the poor category.

The highest score for the Very Good category was 10.5% for relief of pain care, followed by relief of symptoms other than pain at 7.9%. In the Good category the highest score was relief of symptoms other than pain, with 39.5%. Relief of pain scored equally in the Good and Fair category at 36.8%

The highest Fair score was 50% for emotional support, followed by 44.7% for support to stay where they wanted to be and 44.4% for spiritual support.

The highest score for Poor category was for emotional support at 5.3%, followed by spiritual support, 2.8%. There was no score in the very poor category.

Therefore, in summary, emotional support and spiritual support scored the lowest in terms of overall support received; it was mainly average and leading towards poor, whilst the relief of pain and relief of symptoms scored the highest for overall support given, ranging from Fair to Good and some Very Good.

“Whilst I was in hospital I didn't feel comfortable to pray.”

“Nurses and doctors always seemed in a hurry, had no time.”

3.3 Attitudes and Perceptions of Death

Death and dying is seen as an inevitable part of life for all, regardless of the type of community, culture or faith you belong to. Getting people to talk about death and knowing their views and perceptions of death and dying can help in their readiness to die, the degree to which they fear death, their expressions of grief and mourning, and the nature of funeral rituals. In Oldham, the Pakistani and Bangladeshi community mostly belong to the Islamic faith and their views and perceptions of death and dying are guided by the concepts and beliefs of Islam.

Comfort level of talking about death

Talking about death is normally considered a taboo subject in society. We are generally reluctant to discuss matters of death. In our survey we found that more than half of people had talked about 'dying matters' with someone. Family members

was the category chosen by 85% as to who they had talked to, followed by friends, 11%, and local Imam, 2%. (10)

Exploring the reasons why those who had not talked to someone about dying matters had not done so, it was about equal between those who did not feel comfortable talking about death and those who just did not get round to doing so. Only a small proportion, 4%, were not concerned about it.

Views of a good death

What constitutes a good death may differ from person to person or culture to culture. We decided to take the 12 principles widely accepted as principles for a good death and see how they compared to the Pakistani and Bangladeshi people living in Oldham.

There were some interesting differences amongst the Pakistani and Bangladeshi community about what they felt was most important in having a good death experience as compared with national picture. A study carried out by Demos for Sue Ryder to identify what was most important to people at the end of life found in order of priority that being pain free, surrounded by loved ones, having dignity and privacy and being in familiar surroundings were considered to be the most important to people for having a good death experience. (11)

Which of the following would be most important to you regarding how you spend your final days?

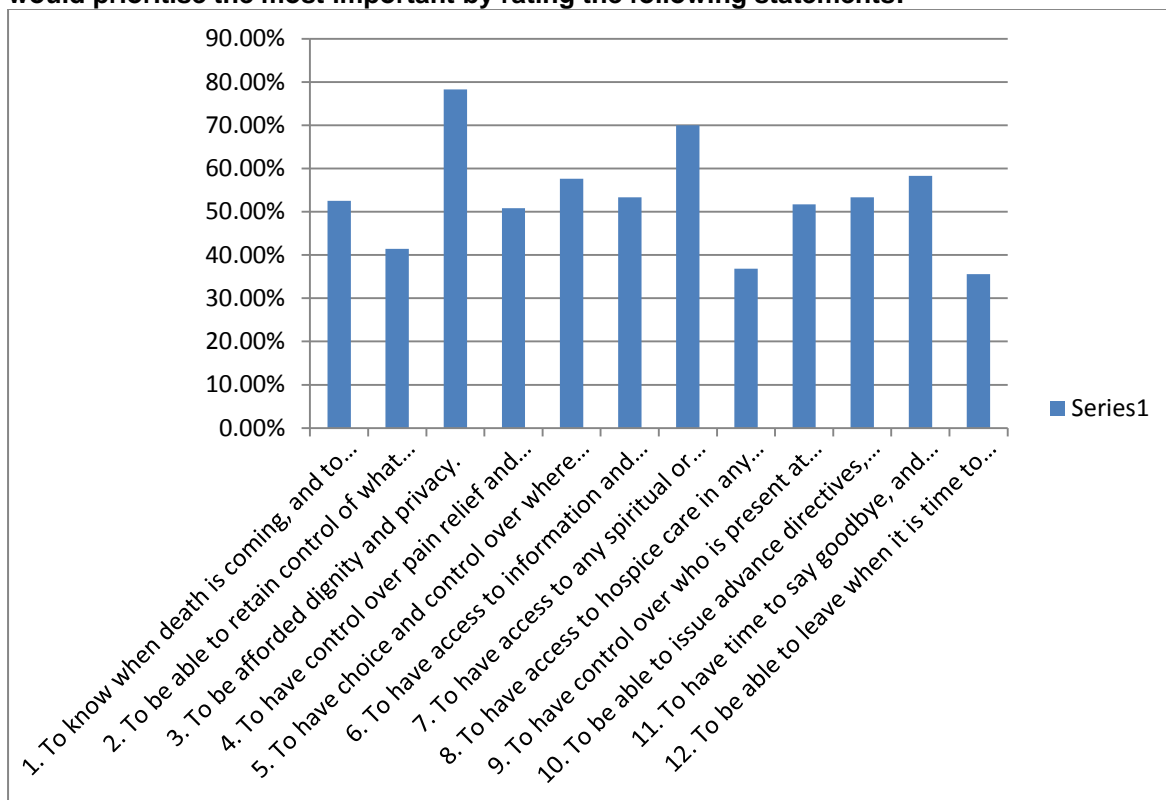


Source: Sue Ryder, A time and a place: what people want at the end of life, July 2013.

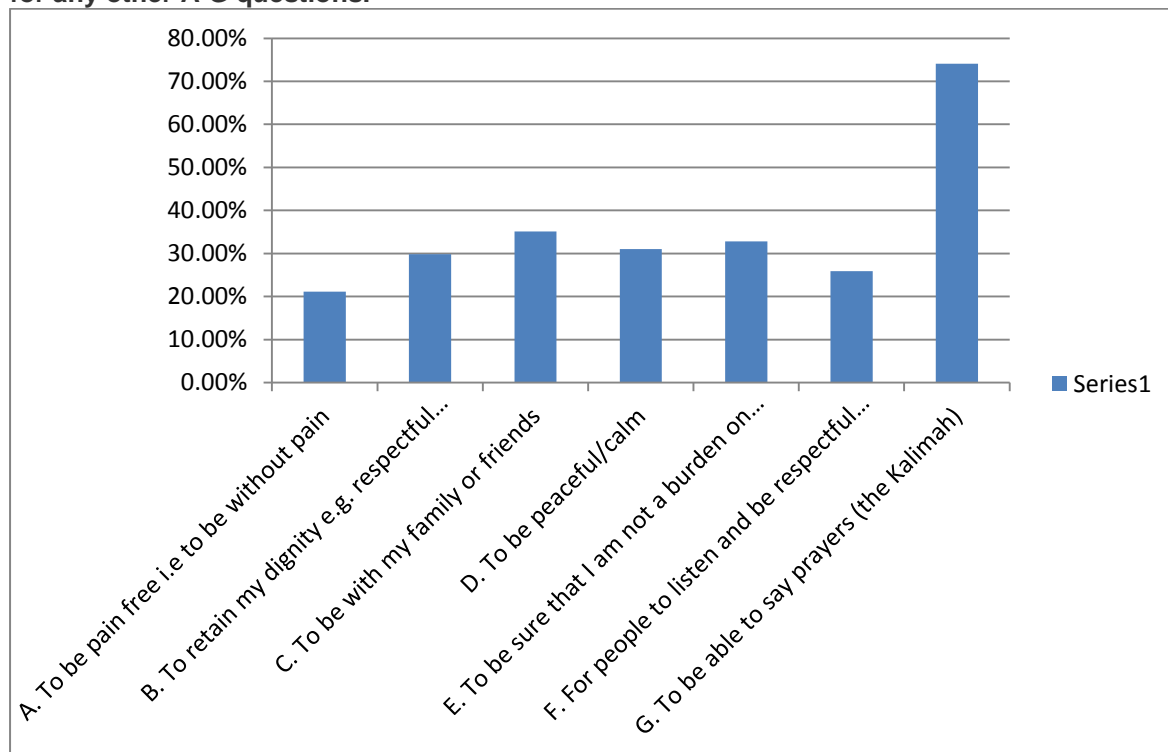
In contrast, the Pakistani and Bangladeshi community considered the four most important things for them to having a good death experience were to be afforded dignity and privacy, access to spiritual and emotional support, to have time to say goodbye and control over other aspects of timing, and to issue advance directives which ensure wishes are respected.

In another similar question that was asked where respondents had to prioritise about what would be most important for their end-of-life care when the time of death comes, the spiritual dimension and family were chosen as the most important. These were chosen above categories such as being pain-free and for people to listen to their wishes.

In your opinion, what makes a good death experience? On a scale of 1 to 5 where 5 is the most important and 1 is least important principle of having a good death, please select how you would prioritise the most important by rating the following statements:



When the time of your death comes, what would be the most important thing for your end-of-life care? List the following in order of preference starting from the 1st most important thing. Please mark 7 for most important and 1 for least important. Please note you can choose one number for one question only; e.g., if you choose 6 for question B, then you cannot select 6 for any other A-G questions.



Dignity and privacy

Dignity and privacy is generally considered a high priority by most people; however, in the case of the Pakistani and Bangladeshi community in Oldham, the category ‘To be afforded dignity and privacy’ was seen as one of the most important aspects in having a good death experience. The aspect of dignity and privacy is an essential part within the life of a Muslim. This probably reflects why it was selected as a top priority. Muslims believe that all human beings have been conferred a special status by God.

**“We have bestowed dignity on the progeny of Adam and conferred on them special favours, above a great part of Our creation.”
(Holy Quran, Chapter 17, Verse 70)**

In Islam, it is not permitted to violate the dignity of any person regardless of their status and background. Physical modesty plays an important part in the dignity and privacy sphere of Islamic ritual life and Muslim culture. There is specific guidance and rules in Islam around gender and mixed gender relations, the issue of seclusion with the opposite gender, and what parts of the body can be exposed and to whom.

The term 'Awrah' is used for the covering of the private parts, which is different in extent for men and women.

We further explored this with respondents by asking them what they meant by being afforded dignity and privacy. The most common responses were:

"To have respect for my body."

"Not exposing my body to others."

"It is about treating me with respect and courtesy."

"Being able to say my prayers."

"Prefer to have same-gender doctor/nurse examine me."

"I would like the NHS to have respect for my beliefs."

"Having time to myself."

"Keeping myself clean is important...good hygiene."

"Having a good appearance when I die."

Spiritual support – to be able to say prayers

The saying of the Kalimah (declaration of faith) and prayers was selected to be the most important priority. This may seem quite odd to the general public, where spiritual support (saying the prayers) is considered by Muslims to be more important than being pain-free, having family and loved ones nearby and other aspects. However, to fully appreciate this, we need to understand it from a Muslim perspective. Dying, similar to many other faiths, is seen not as the end but as a transition into a new phase. For Muslims, dying is considered an end to this temporary world and a move to a more everlasting one.

The end moments of a person's life are therefore seen as very important for Muslims as it can signal the position of the person in the next life. In a tradition (saying) of the Prophet Muhammad (Pbuh):

"He whose final words are: 'Laa Ilaaha Illallaah' (i.e., 'None is worthy of worship except Allah') will enter Paradise."

And in another saying: ***"Verily, deeds are but by the way they end."***

Therefore, when the time of death comes, matters like having somebody there to prompt the dying person with the Kalimah *Shahadah* (bearing witness that there is no true God but Allah and Muhammad is verily His Servant and His Messenger) as a final statement of faith is vitally important, as is the presence of someone at the bedside to recite chapters of the Noble Qur'an and to die in a position facing the holy mosque in Makkah. To die in a holy place (e.g., Madinah, Makkah, or a mosque) or in a holy time (e.g., during Ramadan or on a Friday) are also considered to be important factors for the dying person.

Pain relief

Control over pain and other symptoms is generally required by most people. Muslims perceive suffering as atonement for one's sins and as a test and trial from God so they can earn Paradise. They believe that if a patient feels pain and shows patience, he will be rewarded more by Allah and will be more pure. This interpretation helps patients and family members cope with diseases. However, it does not belittle the fact that every effort should be made to relieve suffering. This may also explain why pain relief was lower down the scale of importance.

Being with family and loved ones

Being with family/relatives and loved ones was another category that scored high in terms of what was important to respondents during the end-of-life stages. Members of the Pakistani and Bangladeshi community tend to be part of larger extended families often spanning three or more generations. The family is seen as an important institution within society and the culture gives significance to family values with supporting structures.

Pakistani and Bangladeshi people typically define themselves by the group to which they belong (tribe, cast, and places) rather than by their status as individuals. The culture gives respect and esteem to elders, and this increases with age. Elderly parents are respected on account of their life experiences and their hierarchic position within the family unit.

To visit the sick and, in particular, sick relatives is considered a virtue that one is greatly rewarded for. Hence, being able to look after someone who is sick or go and visit and pray for them is something that is highly encouraged in Islam and within the Muslim culture. The opportunity to attend to the needs of one's parents in their later years is viewed as a gift from Allah that can earn entry into Paradise.

It is therefore important for the dying person to be with family and loved ones and have time to say goodbye and give any final advice or directives.

“I have a large family and it is important to me that I see all of them before I die.”

“I want to know that my family will be all right and secure after I have gone.”

3.4 Views about Preferred Place of Death

All research suggests that home is the preferred place of death, but the hospital remains the most common place of death in England. The proportion of deaths that are in hospital is falling, and was less than half of all deaths in 2013.

The preference from the Pakistani and Bangladeshi community from the end-of-life preference survey showed it was higher than the national average with an overwhelming 87% who stated they would prefer to die at home. However, in the post-bereavement survey, there was a slightly different picture, with 55% of respondents saying the patient-preferred option was to die at home; hospital, 12%; and relative's/friend's home, 25%. In addition, 8% chose Other, which included going abroad back to their birth land in Pakistan and Bangladesh.

The difference in responses may be due to the fact that those looking after someone or receiving care themselves in the end days of life have first-hand experience of what was involved, the issues and challenges they faced, and the problems they had to deal with caring for someone at home. Therefore, the latter preference is probably more realistic. We know that in practice the BME community have a higher tendency to die in hospital than other groups, and although the preference is to die at home, perceptions and other factors help decide otherwise. Some of the reasons from respondents were:

“We feel there will be better treatment options at hospital.”

“I think it helps to speed up the process of the funeral...getting coroner to issue death certificate.”

“Because of privacy and space. At home there's going to be constant visitors or come from large family so you just don't get time to rest.”

The top four reasons for preferring to die at home were:

- To be with family and loved ones
- To feel more comfortable
- To have more privacy.

When asked if they would still like to die at home if there wasn't sufficient support, the responses were about equal: 57% said yes and 42% said no.

Almost 14% said they didn't mind where they would die.

Other preferences included dying at holy places such as Mecca and Madina, and dying in their birth/homelands of Pakistan and Bangladesh.

Hospices & Care Homes

The survey result showed that no one chose hospice or care home as their preferred place to die. We tried to find out why this was the case. Some of the reasons given in the survey and during the focus group discussions included:

A lack of knowledge and information. Many people were simply unaware of the hospices and care homes and the services they provide:

"What is a hospice?"

"Didn't know we had a hospice."

"I thought hospice was a nursing home for the elderly."

Views of perception of care. Another major reason was that respondents felt they would not receive the quality of care they would need in the hospice or care home. Previous headline stories of the mistreatment in care for elderly at nursing homes was associated with the care in hospices.

"I don't want anyone treating me unfairly."

Adequate and specialist staff not available. The perception was that adequate and specialist staff would not be available in hospices. Therefore, treatment would be lacking.

Cultural and religious reasons. The Pakistani and Bangladeshi community has a strong family-based supporting structure where family members and relatives see it as their duty to care for and look after parents and relatives. Sending them away to a hospice or a care home would be considered as shirking their responsibility and may be viewed as going against their faith teachings. There was also an issue of honour and pride which would be damaged by other members in the community having a negative view of the family.

Language and communication barriers. The ability to communicate the needs to a carer or specialist was seen as very important and respondents felt they would not be able to do this in a hospice.

Privacy and the ability to say prayers. Having sufficient privacy and being able to do prayers was also a common concern stated by respondents.

Not feeling comfortable. The perception was that facilities will be lacking, as well as there not being with someone from their own background who they could talk to.

Would rather be with family and loved ones. There was the preference of being at home with family and loved ones.








3.5 Best Person/Place for Advice on EOL Matters

This question tried to explore who would be the best or most convenient person or place to go to for further information and advice on end-of-life matters. Imams, GPs and family members were considered to be the preferred choices. However, during the focus group discussions and meetings, we found the choice depended on what the respondent understood about end-of-life matters.

In general, if it was about funeral and burial arrangements including inheritance and religious issues, then the Imam was identified as the best person.

For care and medical treatment, the GP was considered to be the best person.

And for general issues, the family and elders were identified as the best person.

20. If you did not choose hospice care home, nursing home, what were the reasons? (You may choose more than one)			
			Response Percent
1	Not aware of them		24.14%
2	Don't feel I will get the right care		24.14%
3	Language & communication barriers		20.69%
4	Cultural barriers		13.79%
5	Is not seen as something positive in the community.		13.79%
6	Not being able to practice faith – do your prayers		31.03%
7	Other (Please state below)		6.90%

21. Who do you think will be the best person to go to for advice on end-of-life matters? (You may choose more than one)			
			Response Percent
1	Your local doctor (GP)		32.08%
2	Nurse/health visitor		11.32%
3	Family		37.74%
4	Friend		15.09%
5	Imam/priest		58.49%
6	Other		1.89%

4. Conclusion

The research has attempted to survey the views of Oldham's Bangladeshi and Pakistani residents about their end-of-life preferences and experiences. There were some limitations as to the scope and breadth of study, such as a relatively small sample and perspectives from the wider profession. It may be that carrying out a larger study may reveal more in-depth and further insights.

The report has highlighted some areas that would require the attention of palliative care. Whilst most people were generally appreciative of the support provided by palliative care teams and NHS staff, there are areas which have been identified to impact on providing the required level of high-quality support.

The lack of knowledge and information about palliative care, hospices and other forms of support amongst carers and the general Bangladeshi and Pakistani community meant they were unable to make informed choices about end of life. Likewise aspects of what a "good death" as perceived by the wider community are not recognised as being of high importance by many Pakistani and Bangladeshi/Muslim patients. There was some kind of consensus on the importance of dignity and privacy, which can be explained by the Islamic perspective that respects human dignity and privacy and regards each as a fundamental pillar of Sharia (Islamic Law). Secondly, Bangladeshi and Pakistani people by and large value spiritual and emotional support. They also believe that death is closely linked to faith. Therefore, most participants appreciated the importance of access to any needed spiritual or emotional support, which was perceived by carers and respondents to be lacking at times.

5. Recommendations

The following recommendations are made to improve the quality of end-of-life care for Pakistani and Bangladeshi community residents in Oldham and support them to die in their preferred place. We have grouped these into three separate but overlapping areas.

Better support for carers

- Review available support for carers of Bangladeshi and Pakistani heritage.
- Improve communication support for carers and patients; this can be done by making use of more bilingual workers or volunteers, having ready accessible information, etc.
- Provide bespoke training for carers of Bangladeshi & Pakistani heritage. Equip carers with skills and knowledge to do what they do better to support dying at home.
- Identify carers that may be vulnerable or in need and support them earlier on.

Raising awareness, reaching out and engaging with the Bangladeshi and Pakistani community

- There is a need to further strengthen and create new partnerships with the BME community locally to promote and provide information about end-of-life and palliative services.
- Establish partnerships with various community and faith-based organisations and individuals to increase further participation and involvement.
- Increase opportunities for local Pakistani & Bangladeshi people to access training and employment within health and social care services
- Arrange visits to hospices, specialist care places to debunk myths and allay fears.

- Recruit more bilingual workers and volunteers to help overcome language barriers, and provide a better understanding of cultural needs.
- Recruitment and involvement of BME people at strategic levels, e.g., as BME representatives on advisory boards and committees to help inform policy and develop appropriate services
- Provide training for Imams, community advisors and key individuals so they are better placed to support members of the community who may come to them for advice and support relating to end of life matters.

Improving emotional and spiritual support

- Training for staff, carers and volunteers to provide more compassionate care and emotional support - emotional intelligence and relational care including good communication, empathy, and respect.
- Have in place better systems and structure to monitor emotional and spiritual support.
- Improve cultural awareness and cultural competence of staff. Understanding the individual's culture, spiritual and religious needs are key to enhancing the overall experience of care.
- Being sympathetic to the idea of whole family involvement helping with the care.
- GPs and consultants to be better informed about palliative care services for BME communities.

Acknowledgements

We would like to acknowledge and thank all who took part in the research, the interviews and the focus meetings on which the basis of this report was compiled.

Bangladeshi and Pakistani residents of Oldham

Oldham Vision, for assisting with the completion of questionnaires and gathering information from the Oldham Bangladeshi community,

Staff and volunteers, for inputting data and going out to complete the surveys.

Voluntary Action Oldham for their help and support.

Oldham Palliative Care Team.

Imams and the GPs who took part in the meetings.

6. References

1. Source: National Council for Palliative Care, National Survey of Patient Activity Data for Specialist Palliative Care Services, MDS Report for the year 2012-13. June 2014.
2. Palliative and end of life care for Black, Asian and Minority Ethnic (BAME) groups in the UK Natalia Calanzani, Dr Jonathan Koffman, Irene J Higginson King's College London, Cicely Saunders Institute June 2013
3. <https://www.gov.uk/government/publications/2010-to-2015-government-policy-end-of-life-care/2010-to-2015-government-policy-end-of-life-care>
4. Alerson – Barbera and others, 2011, 2012, Barbera and others 2010, Shepperd and others 2011
5. Oldham Census 2011 – www.oldham.gov.uk
6. http://www.oldham.gov.uk/info/200632/profile_of_oldham
7. <http://www.oldham.gov.uk> Oldham District ward profiles
8. Post Breavement survey
9. Ibid
10. Ibid
11. End of life preference survey
12. Source: Sue Ryder, A time and a place: what people want at the end of life, July 2013.
13. Holy Quran
14. Islam beliefs and teachings