

A discussion with South Asian groups on their understanding of end of life care services in Kirklees

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Executive Summary

Low referral rates from South Asian communities prompted the Kirkwood Hospice to work in partnership with Healthwatch Kirklees to explore the awareness and understanding of end of life care services among South Asian communities in Kirklees

"End of life care means when someone has a terminal illness and there is nothing more that the doctors can do so you end up getting care at home"

"People get sent to a hospice when they have cancer and are terminally ill. They are given morphine so that they are knocked out and don't feel any pain"

"I Hope I never have to go into a hospice, I hope my children would want to care for me at home"

"They don't understand our culture and what our needs are"

"If a person has to stay in the hospice then then the hospice should have facilities like a bidet in the wash room, a prayer room and access to an Imam"

"The hospice should promote their home help services, I would not go into the hospice, but I would take help that they can provide in my home"

"The services should be promoted via mosques, Teapot Chapel mosque is quite good in Huddersfield, they would be happy to help"

"I knew someone who had to go into a hospice, I used to visit them regularly. I was amazed at how clean the hospice was, even though I was a visitor I was offered food which was very good of them"



1. Introduction

End of life care (EOLC) is care and support for people who are in the last months or years of their life. Good EOLC enables people to live in as much comfort as possible until they die, and make choices about their care. EOLC includes provision of psychological, social, spiritual and practical support. Depending on the needs of the person, different health and social care professionals may be involved for example; hospital doctors, GP, hospice staff or complementary therapists.

End of life care includes palliative care. Palliative care focuses on maximising quality of life, by managing pain and other distressing symptoms. Palliative care involves psychological, social and spiritual support for the patients and their family/carers. Palliative care may be required at diagnosis, at certain times during an illness, when death is anticipated and in bereavement (Department of Health, 2008). Specialist palliative care is provided by hospices and other services such as Macmillan and Marie Curie nurses.

In the UK, South Asian patients are less likely to access end of life care services than their White counterparts. The diverse and ageing population of Kirklees makes this a cause for concern.

Kirklees is a mix of urban communities and rural areas. The number of people living in Kirklees is predicted to rise from 430,200 in 2010 to 482,600 in 2030, i.e. by 12%. By 2030 it is estimated that 1 in 5 people will be aged over 65 years, of whom 1 in 6 will be aged over 85 years.

Kirklees has an ethnically diverse population including people of Pakistani, Indian, Irish, Afro Caribbean and black African origin. The small Afro-Caribbean population is mainly located in Huddersfield. Over 1 in 8 people are of south Asian origin, Pakistani and Indian primarily.

Between the years 2008-2010 there was an average of 3,696 deaths a year in Kirklees, 64% were aged 75 to 85 and 33% were aged 85 or over. The remaining 3% were aged under 75. After falling slightly over recent years the number of deaths is predicted to rise to over 4,000 by 2033 (YHPHO, 2012).

The most common underlying causes of death and most commonly mentioned contributory causes that are demanding of end of life care in Kirklees are; cardiovascular disease, cancer, respiratory disease, Alzheimer's and renal disease.



2. Why are we focussing on South Asian communities and their access to end of life care services?

The Kirkwood Hospice provides palliative care services: in-patient care, spiritual care, complementary therapies and family care. Between 2014 and 2015 clinical activity figures from Kirkwood Hospice show that 92% of referrals were from White British and 8% were from other backgrounds. Low referral rates from South Asian communities prompted the Kirkwood Hospice to work in partnership with Healthwatch Kirklees to explore the awareness and understanding of end of life care services among South Asian communities in Kirklees.

The aim of our engagement was to understand why the local South Asian communities in Kirklees are not using the Kirkwood Hospice services and identify appropriate ways to improve access to end of life care services by exploring:

- Palliative/ end of life care as a concept
- Perceived barriers to accessing end of life care services
- What would the local South Asian community in Kirklees like the hospice and end of life care service to offer
- In what ways they would like information about the hospice and palliative/ end of life care services.



3. What did we do?

We held four discussion groups; two with women aged over 45 and two with men aged over 50 years old. We also carried out an online survey. In total we engaged with 61 people. We attended groups that already met regularly so that our work was not the main purpose of the gathering, the topic of death can be taboo in some cultures which means that if we had dedicated a session just to this topic, people may not have felt comfortable with attending.

We developed 8 key questions (see appendix 1) to explore participant's knowledge of end of life care services, where they expected to receive end of life care, what would influence their decision, barriers, what they would like and ways of locating information. Following introductions, an explanation of the purpose of meeting



with the group was given, with an emphasis on wanting to listen to their views and opinions. The reasons for note-taking were also explained and assurances given that all comments would remain confidential and anonymised if used in the report.

In the first half of the discussion we asked the participants questions to understand what they knew about the current provision of end of life care services, where they expected to receive end of life care, their knowledge of Kirkwood Hospice and if they had any experience of using the Kirkwood Hospice services.

In the second half of the discussions we gave participants information about the role of a hospice, the services provided by Kirkwood Hospice and where the hospice is located. The participants were then asked if they would consider using any of the hospice services, what they would like the Kirkwood Hospice and end of life care services to offer and how they would like to find out about services provided by the Kirkwood Hospice.

Focus groups, requiring recording and transcribing of the discussions, were not thought achievable as gaining consent for recording and transcribing can be an intimidating factor in some cultures (Lund & Denicolo, 2012). Data analyses was undertaken by reading through the notes made during the group discussions and identifying themes. Reoccurring themes from our findings have been presented in this report.

4. What did we find?

4.1 What does end of life care mean to you?

The majority of participants did not know about or understand the meaning of end of life care or palliative care services, however once broken down and explained in simple terms, it was met with general approval. Since there is no equivalent of the word 'palliative' in many South Asian languages the participants struggled with the concept of 'palliative' and 'care'.

The most common responses to our first questions of what end of life care means to people were; 'when you are terminally ill and nothing more can be done', 'when there is no hope that you will recover or be cured' and 'the final care you need before you die'.

"It means when someone has a terminal illness and there is nothing more that the doctors can do so you end up getting care at home"

"It is when the doctors have told you that there is no cure"

"The care you receive whilst dying"

A small number of participants did demonstrate knowledge of end of life care, usually from personal family or friend experience.

"Being looked after, helped and supported, with dignity and compassion"



4.2 Do you know which services provide end of life care?

Common responses were:

- Dewsbury Hospital
- Huddersfield Hospital
- Local GPs

4.3 When the time comes, where do you expect to receive end of life care?

The majority of participants said that they expected to receive end of life care at home or in a hospital. Only one person stated they expected to receive end of life care in a care home.

4.4 What would influence your decision about the place you would receive end of life care?

“I would like to be around my family and those closest to me”

“I want to be around family and in a place that is clean and comforting”

“I want to die in my own home”

The majority of participants said that they would want to be at home with their family when they receive end of life care. For others it was important to be at home as they wanted to be in a place that is familiar, comfortable and clean.

4.5 Have you heard of Kirkwood Hospice and do you know what a hospice is?

In general, the level of awareness about end of life care services and Kirkwood Hospice was very low. Many participants held the view that a hospice was a place where people were “sent to” when they are terminally ill or have nobody to look after them.

“It’s a place where old people go to die”

“You get sent to a hospice when you are close to dying and nobody is around to look after you”

“It’s a place where people with cancer go to die”

“People get sent to a hospice when they have cancer and are terminally ill. They are given morphine so that they are knocked out and don’t feel any pain”



Some knew about Kirkwood Hospice - although very few had been there. 'It's a place where people with cancer go to die' was a frequent comment.

Very few were aware of where the hospice was located, those that did had personal experience.

"Is it not a department in Huddersfield hospital, the one where terminally ill people go?"

Some respondents had heard the name 'Kirkwood Hospice' but were not able to say what services it provides. Out of the 61 people we engaged with, not one had any knowledge of the in-home hospice services.

4.6 Do you have experience of using the hospice services?

Although only a small number of participants had experience of using the hospice service the comments they shared suggested they had positive experience.

"I had a friend who towards the end of his life was in a hospice, the care he received was fantastic"

"I knew someone who had to go into a hospice, I used to visit them regularly. I was amazed at how clean the hospice was, even though I was a visitor I was offered food which was very good of them"

"My family friend went to a hospice when he was close to dying, he only stayed there for a week before he died. It was okay, the family didn't talk much about the hospice or say what it was like. I think it was just a like a care home with a built in hospital"

4.7 Would you consider using any of the hospice services for yourself or family member?

The main perceived barriers to accessing the hospice services were lack of awareness of available services and cultural/religious concerns.

"No- They don't understand our culture and what our needs are"

"I would not want to stay in the hospice. I don't think the staff there would understand what my needs will be towards the end of life. I need halal food, a prayer room and would want to listen to the Quran whilst I am towards the end of life"

The majority of the participants said they would only consider using the hospice services if they were delivered in the home.

“I would consider using their services if they can provide them in my own home, but I wouldn’t want to go to Huddersfield or stay there. If they can provide support at home, then I would take it”

“If the hospice can provide support in the home then I would take support and use the hospice services, but I don’t want to stay or spend my last few days in a hospice”

A number of participants also discussed how they ‘hoped’ and ‘wanted’ their children to care for them.

“I want my children to care for me, I wouldn’t want to be sent to a hospice and left to die”

“I hope I never have to go into a hospice, I hope my children would want to care for me at home”

Fear and misconceptions of the hospice was also voiced, although not everyone shared this. One participant discussed how if he went to a hospice he was worried about being be given too much morphine.

The hospice staff should be aware that not everyone wants to be given so much morphine that they are no longer conscious, I also wouldn’t want my death to be hastened even if I was in pain. I would want to spend my last few hours looking at my family and loved ones. I want to be aware of where I am when I die. I think the best place for me would be my home, with the people that understand my needs and an environment that is clean and pure

4.8 What would you like to see the Kirkwood Hospice and end of life care services offer?

Below are the key themes we identified from the group discussions:

4.8.1 Support services at home

Participants indicated that people from South Asian backgrounds may prefer home care services as these would be in line with their cultural background of looking after relatives at home.

“Services that can come out into your home and provide care and support”

“The hospice should promote their home help services, I would not go into the hospice, but I would take help that they can provide in my home”

This includes services such as being supported to be able to die at home, home visits for help with pain relief and most importantly support for the carers.

“More support for people who want to die at home. Support for carers so that they can care for the patient in the home”

Day care services where participants can meet up with other people with a similar illness were viewed positively, as this would give the ill patients a chance to share their experiences and also give their carers some respite.

“If the hospice had a group of people with the same illness, who could maybe meet up at the hospice to share their feelings then that would be beneficial, but I would not want to stay in the hospice overnight”

4.8.2 Staff diversity

Participants felt that there was a need for more staff from South Asian backgrounds who they could relate to, and feel confident that their cultural/religious needs will be understood.

“The hospice should employ BME workers who we can relate to. If I saw an Asian worker at the hospice, then that would give me confidence that they will understand my needs. I would not want to spend my last days in a place where I couldn’t relate to anybody”

For older community members, language was also seen as a barrier. Participants felt that it was important for the hospice to have staff/volunteers who can speak South Asian languages, as it was important for them to understand the care they are receiving.

4.8.3 Location of services

Participants living in North Kirklees felt that there should be a hospice in North Kirklees closer to Batley and Dewsbury. Many participants felt that the current location of the hospice is too far and were concerned that if they chose to stay there then their families would struggle to visit them.

“I would like a hospice that is closer to where I live, Batley. Huddersfield is not a place that I visit and would be the last place I would want to die in”

“The hospice should have another branch in North Kirklees, I wouldn’t be comfortable going to Huddersfield. It is too far and my family would struggle to visit me”



4.8.4 Culture and religion



Some participants were concerned that the hospice may not be set up for people from South Asian backgrounds and had concerns over whether the hospice was culturally and religiously appropriate.

Most participants discussed the importance of prayer and washing facilities (bidets) for patients and carers. Muslim participants also expressed the need of having access to an Imam, halal food and a bidet in the washroom.

“If a person has to stay in the hospice then then the hospice should have facilities like a bidet in the wash room, a prayer room and access to an Imam”

There were also discussions around the need for items needed for prayer, including copy of the Quran, a sign for the direction of Mecca and prayer mats.

Participants felt that staff needed to understand the praying and time of death rituals and be able to help if required. For Muslim participants it was important that at the time of death someone could encourage them or read the Kalima Tayyab (the testification of faith in Islam) to them, they would also want their feet in the direction of Mecca.

“When the time of death approaches, we would like a man reading the kalima to a man, and a woman for a woman”

“The hospice should provide halal food, have an imam who can help recite the verses of the Quran. It is very important as a Muslim that people around you are aware of what needs to be done and read when you are dying”

4.8.5 Hospice and joint working

Muslim participants also felt that families should be assured of the hospice’s links with hospitals, local mosques and Muslim burial services in order to ensure that it fully understood the importance of rituals after a patient has died and will be able to support them.

“We want to see a seamless approach from hospital to hospice. There should be no gaps in between, the patient should have clear records. Anything that reduces the risk of having a post mortem”



4.9 How would you like to find out about the services that are provided by the hospice?

Participants were asked how they would like to find out about services offered, responses have been categorised into the following sections.

4.9.1 Building awareness of services

The majority of participants stated that Kirkwood Hospice could raise awareness of its services and the quality of care available by giving out more details about services offered, e.g. support for families and carers, counselling, complementary therapies and specialist nurses who visit patients at home.

Some participants also thought that it was important to communicate the differences between a hospice and a hospital in relation to room sizes, facilities and visiting times.

Participants also felt communities, GPs and local support groups needed to be clearer on referral routes to Kirkwood Hospice.

“I had never heard about Kirkwood Hospice until today. I think it is very important that our community is better informed so that they do not have to struggle alone”

“GPs, Social workers, local community groups should help promote the hospice services”

Key Learning:

Participants felt strongly that people from South Asian communities would definitely use these services if they knew they existed. It is important to reach out to communities on an ongoing basis to inform people about the range of services available from the hospice.

4.9.2 Promoting services within South Asian communities

Participants suggested that a hospice staff member should visit local community organisations to bust myths about what people think a hospice is. This would be advantageous as people would remember the hospice and what it does and would feel comfortable asking questions or requesting information.

“Someone from the hospice should come and explain the real services it provides and bust myths that the hospice is just a place for people with cancer”

“Imams should be approached, somebody from the hospice could promote their service after Friday prayers, as hundreds of people attend on a Friday. It's the best time to get your message across”

It was also suggested that listening to someone from the South Asian community with experience of using the hospice services would encourage others to consider using the services.

“If it’s possible then I would like to hear the experience of a Muslim person who has experience of using the hospice services. This would give me confidence and reassurance that a hospice is a suitable place that can cater for my needs”

Participants also felt that a DVD, available in several community languages shown to community groups would be an excellent tool to showcase the hospice and its services.

“Hospice should create a video of what their hospice looks like, with stories from people who have already used it. If I saw an Asian person in the video then I would be more interested”

“The hospice could create a DVD which we can watch at home or maybe our community centres could show it to their groups who come in for different classes”

The South Asian Muslim participants suggested that the hospice should use the influence of local mosques and Imams to promote their services. Local South Asian TV channels, radio and magazines were also mentioned as important ways of reaching out to the South Asian community.

“Kirkwood Hospice could promote their services via all these new BAME channels, most will be willing to help with advertising the services, they may even be happy to let someone from the hospice go on their talk show to explain what services they provide. So many elderly people sit at home watching these channels, they are very influential”

“The services should be promoted via mosques, Teapot Chapel mosque is quite good in Huddersfield, they would be happy to help”

“Advertise the services in the Paigham and An-Nisa magazine”

“Advertise the hospice services on radio- maybe do a radio interview where people can phone in live and ask questions. I listen to the radio so this method would really help me understand more”

4.9.3 Arranged tours/visits to the hospice

Participants said that they would like to visit the hospice as a group, and were keen to take messages back to the community that dispelled their current myths about the hospice.

The participants supported regular hospice tours, arranged by the hospice.

“I would like to visit the Kirkwood Hospice and see what kind of service they provide”



Key Learning:

Overall, participants felt that the best way to raise awareness of Kirkwood Hospice is through word of mouth and face-to-face meetings. Participants liked the idea of Kirkwood Hospice staff attending their groups and mosque gatherings and of community members being invited into the hospice. This would give them the opportunity to understand the Kirkwood Hospice services and to ask relevant questions.

4.9.4 Referrals by South Asian Community Groups and Health Professionals

Some participants said that they would be more likely to use the hospice service services if they were referred by local South Asian community organisations or other health professionals.

“I would consider using the hospice service if I was referred by someone I knew, a professional like my GP or someone from the Milen day care centre”

Key Learning:

Local South Asian groups and health professionals such as GPs and Social workers are held in high regard and people will listen to their advice. GPs and Social Workers play an important role in providing information about the hospice and end of life care services. There is a need to ensure that local South Asian groups and health professionals understand Kirkwood Hospice’s services and refer patients from South Asian backgrounds.

5. Limitations of the work

Whilst the findings appear generalisable and have congruence with previous work carried out by other organisations, communities and groups who did not engage may have other concerns. Some of the larger group discussions may have not given enough opportunity to quieter or shy participants who disagreed with the general consensus to voice their opinions.

The age and gender of the interviewer would have had some influence on the data we collected. Being younger than the participants, culturally some participants did not feel completely free to discuss sensitive and taboo subjects in the discussion groups.



6. Changes contributed by Kirkwood Hospice

Kirkwood Hospice was formed from the local community in Kirklees in the 1980s; it has been supported very generously since by all parts of the community and continues to work very hard to meet the needs of local people through the services it provides. As population needs change over time, so should the hospice be flexible in meeting those needs.

In general the ethos of palliative care and the end of life care that Kirkwood Hospice provides is to maximise peoples' quality of life within the limits of their illnesses using a holistic and personalised approach, we work hard to understand the individuals we care for, who they are, what their needs are and what preferences they have in relation to the care and support they receive.

Our services have been developed over the last 28 years to be as flexible as possible to accommodate the needs of people and their families no matter what their cultural or ethnic background.

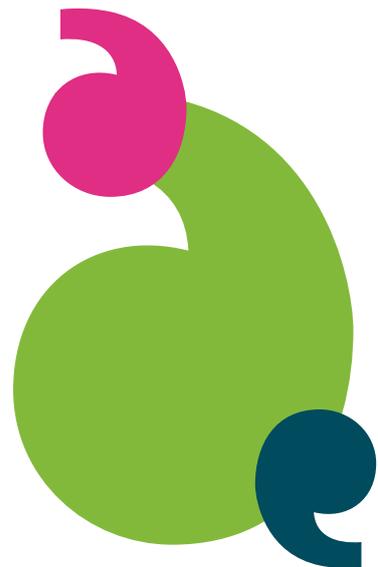
As a Hospice we are committed to reaching more people within our local communities that could benefit from the services we provide. We were delighted to have been involved in this study with Healthwatch Kirklees and intend to take action as a result of the findings.

The findings of this study confirm that there is more that we need to do to develop the understanding in South Asian communities about the services we provide. Some of the perceptions that are evidenced in this report are common for all cultures within our community. While this is the case we need to do more to engage with South Asian communities in particular. This will involve developing the publicity of our services to be clearer about what we do, making the information more accessible, and finding effective ways of getting our messages heard.

We will promote and improve access for representatives of different communities to be involved with the Hospice, as representatives on our board of Trustees, as volunteers and employees and also as services users, the purpose being to increase the number of people who can advocate for Hospice care.

We will help users of our services who are happy to share their experiences to document their stories in different ways, and in different media. We have already had some success in doing this during 2015 and we will work hard to develop diverse stories, encouraging people from different communities to be involved.

Finally, one particular theme that came out of this report was the wish that people had for being supported to be cared for at home. Less than one third of the people





that we care for will need an admission into a Hospice bed, far more are supported to remain in their own home. This is a significant part of the support that Kirkwood Hospice offers to people and therefore we need to prioritise how we help people to understand this. Kirkwood Hospice is not a place, but a model of care for people towards the end of their lives, a flexible model of care that focusses on the needs of individuals and those that care for them no matter what their individual characteristics.

Michael Crowther C.E.O of Kirkwood Hospice



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- Indian Muslim Welfare Society (IMWS), Batley
- Milen-Care Batley Asian Elderly Day Care
- Pakistani Association, Huddersfield



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Additional Healthwatch Reports can be downloaded at
<http://healthwatchkirklees.co.uk/our-work/listening-to-you/>



Appendix

Focus Group Questions

1. Do you know which services provide end of life care?
2. When the time comes, where do you expect to receive end of life care?
3. What would influence your decision about the place you would receive end of life care?
4. Have you heard of Kirkwood Hospice and do you know what a hospice is?
5. Do you have experience of using the hospice services?
6. Would you consider using any of the hospice services for yourself or family member?
7. What would you like to see the Kirkwood Hospice and end of life care services offer?
8. How would you like to find out about the services that are provided by the Kirkwood Hospice?



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