Addressing the barriers to accessing palliative care amongst the South Asian community in Wolverhampton

Background

Uptake of palliative care services amongst Black, Asian and Minority Ethnic (BAME) communities in the UK is significantly low. A 2013 study by Calanzani, Koffman and Higginson reported that religious beliefs, family tradition, barriers in communication and an overall lack of knowledge and information about the services available were all contributing factors.

In concurrence with national findings, Wolverhampton palliative care provider and charity Compton Care has observed low uptake of its services amongst the BAME community, most notably from the South Asian community. Despite the City of Wolverhampton having one of the highest BAME populations outside London (35.5%) of which 17.5% are of South Asian descent1, an average of just under 3% of Compton Care patient’s are from a Sikh, Muslim or Hindu background2.

To gain further insight and address the inadequacies faced by this group, Compton Care successfully secured funding from the National Big Lottery Community Fund in November 2018 to deliver the CCUES Project (Complex and Incurable Conditions: Understanding the views and Experiences of the South Asian community in Wolverhampton). This project would capture the views, thoughts and experiences of Wolverhampton’s South Asian community with the aim of achieving an improved understanding of the needs and wants of this community group. Compton Care would then formulate recommendations to improve awareness of and engagement with its services amongst the UK’s South Asian population. These recommendations could then be shared with other palliative care providers across the country.

The Study

Lead by Compton Care Senior Research Associate Dr Karan Jhutla and supported by an Expert Advisory Group comprising representatives from the South Asian community and key service providers, the study captured the views of 596 people (of which 184 were Sikh, 82 were Hindu, 48 were Muslim, 34 were White British, 1 Polish and 247 were unassigned but of South Asian descent).

Through one-to-one conversations, focus groups, roadshows and attendance at various events four key themes emerged:

1. Communication: Language barriers, particularly faced by older people whose first language is not English, caused difficulty when it came to seeking information about services. One participant quoted: “It’s hard to pick up the phone when you don’t know English” (Sikh male, 45). Furthermore, it was suggested that translated literature would only provide half the solution and that personal contact programmes with culturally competent staff would be of huge benefit: “during a time of distress, the last thing you want to do is read what’s on a leaflet, and I think it’s that personal touch that makes a huge difference.” (Sikh male, 45).

2. Lack of awareness and understanding of services: Many of the South Asian community were not aware of the palliative care services available to them, with some having no knowledge of Compton Care. For those who had heard of Compton Care the association was that it is ‘a place you go to die’ or believing it to be a care home “where white older people go” (Hindu male, 57). Many were unaware that support could be accessed in the home and assumed that the service would come at a cost.
3. **Stigma:** When community members were asked what they consider the main challenges for using palliative care services, stigma remained a common answer: “they (the community) can’t be seen to put a loved one into care.” (Muslim female, 33) at the fear of “people pointing fingers that we couldn’t care for our family member.” (Hindu female, 55). Consequently, it was repeatedly reported that “the community needs educating to show there’s no shame in accepting outside help.” (Sikh male, 45).

4. **Intergenerational differences and conflict:** Evident from the study were the intergenerational differences within the South Asian community. For elder members there was the expectation from their children to care for them should they require it: “We have cared for our children all our lives, they should care for us” (Muslim female, 45) and that despite being made aware of services available many suggested “I won’t need a service like that because I still live with my children” (Sikh male, 75). However younger members of the community spoke of a shift in focus: “The younger community now is more focused on doing things themselves. Things have changed so fast they. You do need to start educating communities, and its about how you’ve been brought up. People shouldn’t be afraid to used services” (Hindu male, 33) and “It’s all changed now. People still think that we live in large families, but that’s not true.” (Sikh female, 52).

**Discussion & Recommendations for Compton Care**

This study has highlighted the value of undertaking community engagement events and activities with the South Asian community. Providing information in various language formats is one thing, dedicated face-to-face engagement initiatives are required in order to properly embed messages and learning. It is recommended this is achieved through:

1. **To continue with community engagement activities to maximise reach:** To go into the community visiting places of worship, existing community-led groups, specialist South Asian services and facilitating roadshows.

2. **Ensure literature are culturally appropriate and disseminated appropriately:** Ensure service literature uses appropriate language and cultural translations and identify appropriate channels for distribution.

3. **The introduction of a South Asian Community Engagement Worker:** a bi-lingual worker dedicated to identifying, maintaining and strengthening links with relevant organisations to engage and support the South Asian community. This will include developing relationships with key clinical, medical and healthcare groups to further explore inequalities of care.

4. **Champions and Ambassadors:** With extensive training, ambassadors and champions can be empowered to provide support members of the South Asian community who are living with, or supporting someone who is living with an incurable condition.

5. **Family-centred personalised care:** “Included in personalised approaches to care should be the individuals cultural, religious and spiritual wants and beliefs (Jutla 2013).” Though it is important to reduce language and cultural barriers, the project findings remind us that ultimately compassion and empathy must remain at the heart of care provided.

6. **To host an annual open day targeting the South Asian community:** To invite members of the South Asian community to visit and tour Compton’s on-site facilities and learn about the services available to the community within the home setting. Tour and supporting information to be delivered in various community languages.

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