



Bengali Community Focus Group Report Macmillan Cancer Support and Healthwatch Southwark

Date of focus group:

Thursday 15 October 2015

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Acknowledgements

Healthwatch Southwark would like to thank the Bengali women for contributing to and participating in the discussions and also to the Bengali Women's Group in Southwark who arranged the venue and catering and publicised the focus group.

Disclaimer

Please note that this report relates to discussions that took place on the 15th October 2015. Our report is a summarised account of what was contributed at the time.

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Background

Healthwatch Southwark is a champion for patient and public voice. We want people's voices to count towards improving services. We know that some groups are 'seldom heard' and therefore we aim to engage with these communities in a targeted manner. We want to find out about their experiences of using services and the challenges they face.

In 2014, Healthwatch Southwark worked with Bengali women to discuss healthcare behaviours, experiences and challenges. Key topics were GP access, long-term conditions, coordination of care pathways, cultural needs, mental health, information and feedback. The key issues arising from this were a need for interpretation and more sensitive communication, better support for those with long-term conditions, non-medication treatments for mental illness, and ways to feedback on care experiences.

When Healthwatch Southwark was approached by Macmillan Cancer Support about evaluating their materials for different communities, we were keen to work with the Bengali community again. After discussing this with the leader of the Bengali Women's Group, we found that cancer has affected many people in the local community recently and therefore this would be a timely and apt discussion.

Aim of the focus group

In this focus group, Macmillan wanted to explore the different ways the Bengali community access information - where they get it from and in what format and language. The main objectives were to understand what currently happens, and what could improve this e.g. materials available in their own language, in different formats and available in different settings. Macmillan also wanted to evaluate some specific materials they have developed for the Bengali-speaking community, to ascertain if they were useful, and also ways that they could be improved.

Methodology

Macmillan wanted specifically to hear from people who had a past experience of cancer, personally or as a carer or relative of a patient. Attendees were recruited through Bengali Women's Group based at the Rockingham Centre in Southwark. We were advised that Bengali women generally feel more comfortable speaking up openly in an all-female setting. Women were thanked for their participation with a meal and shopping voucher.

The session was held on Wednesday 15th October 2015.

Findings

1. About the attendees...

In total, nine women participated in the focus group, all with experience of cancer (themselves or in a caring capacity). One attendee, also a medical professional, translated for those that could not speak English, as well as contributing her own experiences.

Eight of the nine women (not the translator) completed a short survey so we could know a bit more about them. Those who could not read English were assisted to do this.

Ages ranged from 43 to 77. Two people had a diagnosis of cancer and six had cared for someone with cancer (either past or present).

All of the women said Bengali was the language they spoke and their preferred language, though in addition to the translator, at least three spoke some English during the session. Five said they could read Bengali only, and three women could read both Bengali and English (of whom two had no preference and one preferred English). However, it later emerged that one older woman could read neither language and was helped to understand the materials by the translator - it was unclear whether this was because of poor eyesight.

Some of the women arrived slightly late but five were present from the start.

2. Getting information about health and illness

When asked where they get information about health, most people answered with respect to their cancer diagnosis or that of a relative, but were prompted to branch out into health generally. There was consensus that the GP would be the first port of call for health information. If people were unable to understand English, they relied on relatives to translate information.

A lady who speaks and reads English said, *“I read a lot on the internet. Also the GP surgery had leaflets.”* When at the hospital with her sister who had cancer, she saw the Macmillan support number and called it. She also said, *“My sister had chemo with a lot of side effects. We got information in hospital from the doctor [verbally].”*

Another said she got information (translated by her sons) from doctors in the hospital when her husband was diagnosed with cancer, having been referred there for a different problem. But for general health concerns she would go to the GP.

The other three present at this point said they would visit the GP first, with one commenting, *“We know the GP so if we have anything at all we go to him.”* The translator added that people would go to their GP first for a wide range of health issues including the minor.

When asked to give examples of where they would like to see information, all of the women said their GP, but they also agreed that the local mosque and other community hubs would be good places - *“Someone in every family goes to the mosque and can tell them... it is like a community centre for us”*. One said it would be good to have material sent directly to their home, and another suggested email for the younger generation.

3. Getting information in one’s own language (Bengali)

3.1 The importance of getting information in Bengali

There was agreement amongst all attendees that getting information in their own language was very important, particularly for *‘the older generation’*. All agreed that many Bengalis cannot go to the hospital alone as they need an interpreter. There is a *“culture of responsibility and duty”* around helping the sick and translating for others especially relatives, so people do not mind doing this.

3.2 Experiences of information provision in Bengali

None of the group had ever been given any written information about health in Bengali. When asked if they had ever seen any available for them to pick up themselves at the GP, they all said no or weren’t sure.

One lady who speaks and reads English said, *“I never saw any booklet in Bengali about cancer...but the ones in English are so nice and simply explain things, and a bit supportive as well. So it would have been nice to have this in Bengali in the past.”* She said that she would find it more comforting if the information was in Bengali.

3.3 Experiences of and barriers to getting health information in the past

Most people had experiences of translating for or being translated for by a relative:

- One woman whose husband had cancer had her sons translate information for her and she is happy for them to do this as they are *'educated'* and work in healthcare themselves.
- Another's daughter translates for her. Her daughters are very supportive. In fact they have previously told medical staff that they don't need an interpreter and don't need written information.
- One woman translated for her sister who has cancer. She said when her mother also had been diagnosed, it was *"heart-breaking"* having to tell her herself what was happening, and she would have preferred support to do this.

On the whole people were happy with the information they have been given verbally via family members who interpret for them. However, it was later clear that the leaflets in Bengali gave them new information and that perhaps people are not always aware of the detailed information they could be missing out on. Other comments also arose later which pointed to occasions when things could have been better:

- One woman said that she had used the Language Line service but had not properly understood what was being said.
- One lady described having talked to a Bengali doctor in the hospital about some tests she needed for possible cancer. Despite him speaking her language, she did not quite understand what he was telling her and he didn't have the time to write it down for her and said it would have been sent to her GP. She later forgot the information she had been told. In this scenario some written information in Bengali would be very useful for her to take away and refer to.

4. Evaluation of Macmillan's materials

4.1. Ovarian Cancer symptom awareness leaflet

See the Macmillan website for the Bengali/English version:

<http://be.macmillan.org.uk/be/p-22408-early-diagnosis-flyer-ovarian-symptoms-bengali-translation.aspx>

The group were shown and given time to read Macmillan's two-sided leaflet on symptoms of ovarian cancer. Initial feedback was that the information was *"simple, short, good"*. When asked if they could understand what the symptoms were, it became apparent that some of the words had not translated clearly.

An example of this was 'lower stomach and back'. In English this means the 'lower back', but in the Bengali version it is not clear which part of the back as there are different words for different parts of the back.

The women explained that written Bengali is different to spoken Bengali. They felt some of the language in the leaflet is not 'easy' Bengali. For example, they explained that there are many different words for 'breast' and the one chosen will not be easily understood. Likewise the word used for 'ovaries' is not an easy word. It seems that the terminology used in the leaflet will not be the words that people are familiar with in this context.

Some explanations were given on how to improve the factsheet:

- More 'colloquial' Bengali words needed
- In some cases having the English word in brackets would help as people actually use English for certain medical terms - examples given were 'cancer', 'lung', 'district nurse' and 'Macmillan'.
- In some cases a short explanation would be useful. Not everyone had been educated in science; one lady said that 'people from the villages' wouldn't necessarily understand the meaning of words without an explanation. Examples given were 'ovaries,' 'infection' and 'diagnosed'.

When asked if seeing this information would encourage people to see a doctor if they had symptoms, the participants said *"Sure, definitely"*. The women clearly understood the green box explaining that it was not wrong to 'bother' the GP with one of these symptoms. They said reading the leaflet would *"reassure"* them about going to the doctor and having written material would help prepare them for discussions with the doctor.

A lady that could read both English and Bengali said *"I get satisfaction from reading in my own language"*.

4.2. End of life fact sheet

See the Macmillan website for the English version:

<http://www.macmillan.org.uk/Documents/Cancerinfo/Foreignlanguagefactsheets/EndoflifeEnglish.pdf>

and the Bengali version:

<http://www.macmillan.org.uk/Documents/Cancerinfo/Foreignlanguagefactsheets/EndofLifeBengali.pdf>

The group were shown and given time to read Macmillan's fact sheet on end of life. Initial feedback was that the information was *"useful"* and that the topics covered sounded suitable and logical. However, the same issues highlighted above were raised regarding use of language.

The group reflected on their experiences of loved ones approaching end of life. One lady said that family give a lot of advice about what to do approaching end of life and what to do after, and it can be overwhelming. She spoke about her family's negative attitude towards a hospice, even though she felt it was the best place for her loved one. The lady said a booklet such as this one would make it easier to know what to do in that situation.

The most striking message in the booklet was the need to 'plan ahead for the end of life'. Even though a sensitive issue, the group felt that the booklets had "*sensible*" and "*acceptable*" information. One lady said that the information in the booklet covered what she thinks about herself.

There were many comments about the importance of Islam in the Bengali community and the strength and calm this brings people. The messages in the booklet were felt to be appropriate for this context. One person mentioned that it would be good to reassure people that they can talk to, for example, their imam.

When asked whether the booklet gave them any information they didn't already know - it was hard to say as people hadn't had time to read the whole booklet. One lady noted the part about mouth ulcers and said there was a lot of useful information about the different symptoms someone might have. She told another lady present that the booklet would be very useful to her and offered to read it to her at a community lunch. A couple of the ladies requested that different booklets be sent to the group so that they could learn more about what to look out for and what to expect from cancer.

Overall, the group felt that the layout and format of both information materials were good and "*make sense*".

4.3. Audio on chemotherapy

See the Macmillan website for the English version:

<http://www.macmillan.org.uk/Documents/Cancerinfo/Foreignlanguagefactsheets/ChemotherapyEnglish.pdf>

Bengali version is unavailable.

The group were played the audio CD explaining chemotherapy as a treatment for cancer - what to expect, the side effects etc.

The group understood the information on the audio, but raised the same issue around certain words being used as they were too complex. For example, 'infection' and 'side effects'.

Even though they understood the audio the group were divided in whether they preferred written materials or audio. This seemed to depend on whether they could read Bengali or not.

One lady said she would prefer the written material, as she would *“hear it and then forget”*, while another who could not read seemed pleased and said, *“I like it, I could just put it in the machine and listen!”*

Macmillan clarified that the audio would be given to people on a CD (as well as being online), so they could listen to it whenever they wanted. This seemed to go down well with the group.

Summary

It is very important to the local Bengali community to have health information available in their own language. For the older generation in particular, English may not be understood; even for those who understand English, Bengali can provide more comfort at a time of need.

The group tended to use family members to translate information from health professionals, and experience of using professional interpreters was limited and variable. This resonates with Healthwatch Southwark’s findings from community focus groups. Many were generally satisfied with the translation provided by family members but there were also examples of cases where they had not understood enough. When shown the materials, attendees were pleased to hear that Macmillan were translating materials into Bengali. They felt that this would help people understand information about cancer much better, and they seemed interested in the level of detail available in this way.

The GP seemed to be the first port of call, and so this would be the place they would want to receive information relating to health and illness.

The language used in the written and audio materials would need to be reviewed so that complex words were avoided, and in some places the English word could be used instead and/or a short explanation of scientific terms given. Overall, the format and layout of the written materials were liked.

Getting information in one’s preferred language, whether written or spoken, can have a huge impact on experience and quality of care.

Recommendations

Written versus audio materials:

- Audio materials are helpful to some who cannot read Bengali, while written materials may be easier to refer back to for those who can. Provision of written materials in a community setting means that those who cannot read may be helped by others.
- A CD format would be preferred for audio materials, so that people can listen at home even if they do not have internet access.

Content of materials:

- Clear, simple, structured information is appreciated and should be maintained
- Translations (both written and audio) should use terminology readily understood by lay Bengalis. This can mean:
 - Ensuring that symptoms terminology is clear - for example, there are different words for different parts of the back
 - Using colloquial terminology - for example for parts of the body where there are many alternative terms
 - Sometimes including the English words as well (in brackets?) as these may be the words actually used by Bengali-speakers
 - Sometimes including an explanation for terms, as not all Bengalis have had education in science and it cannot be assumed they will understand.

One possible addition would be a 'dictionary' box giving terms in English and Bengali with a short explanation (e.g. for 'ovary' - 'the place in the body where eggs are made.')

- Materials could also include culture-specific information as well as simply translated materials - for example, a box noting Islamic beliefs around end-of-life and hospice care, death, and where cultural/religious support could be found.

Where to make materials available:

- The GP is the first point of call for many Bengalis with health concerns and this is a good place to make information available.
- It would also be good to have information about tests and treatments available in hospitals for busy staff to give to patients at the appropriate point.
- Mosques and community centres are a good place to provide information which might prompt GP attendance about symptoms, and a place where Bengalis can help each other access the information, especially if they cannot read.

Response from Macmillan

Macmillan would firstly like to thank all those who shared their opinions and personal experiences at this session. We appreciate the time you gave up to speak to us and your commitment to helping Macmillan improve its services. We would also like to thank Healthwatch Southwark and the Bengali Women's Group for arranging the session.

We were very pleased to hear people say the translations were helpful, culturally appropriate and had the right tone of voice. However, we discovered a lack of awareness that such resources existed. There are also some language issues to deal with. Here are just a few of the actions we will take as a result of this session.

- In response to some of the points raised about the difficult language, we now add glossaries of medical words to our translations.
- We will seek to promote Macmillan's translated materials and telephone interpretation service to the Bengali community through GPs, mosques and other local community centres.
- We will continue to promote the translated materials and telephone service to Macmillan cancer professionals working in hospitals. We will also look at ways to reach non-Macmillan professionals.
- We will feed back any specific language/translation issues to Macmillan's translation company to address them.

Macmillan's translated cancer information can be found at www.macmillan.org.uk/translations.

For more information, or if you have any feedback on Macmillan's translated cancer information, please contact Abi on ahowse@macmillan.org.uk.