BME CANCER VOICE

Exploring the Needs of Black & Minority Ethnic (BME) Cancer Patients and their Carers

Report written by

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Commissioned by Black Health Initiative (BHI)

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Executive Summary

NHS England commissioned BHIs – BME Cancer Voice to explore the reasons why BME cancer patient and carers have reported poorer experiences of cancer services in England. Since 2000 NHS surveys have identified BME cancer patients report poorer experiences of cancer care than white cancer patients.
To explore this further BME Cancer Voice carried out a number of qualitative focus groups and ran a large deliberative event ran to explore the experiences of cancer from BME cancer patients and carers perspectives.

The key themes are identified below where consistent across all ethnic groups worked with which includes: Irish, South East Asian, African Caribbean, Chinese and African.

Aftercare & Support

• Patients and carers to have access to a holistic needs assessment before hospital discharge to ensure adequate support is in place after surgery/treatment.
• Patients and carers to have access to psychological support services to deal with the effects of cancer.
• Access to appropriate and culturally sensitive support groups which meet the needs of all cancer patients.
• Consistency of access to culturally appropriate wigs and toned prosthetics in a timely manner on a par with products for white patients.

Improvements in professional to patient / carer communication

• Primary care professionals to listen to the patient when they think something is wrong and act accordingly.
• Providing access to trained (cancer specific) translators.
• Ensure all patients receive adequate and timely information about tests and investigations in formats they can easily understand.
• Providing discharge information in accessible formats to meet the needs of all cancer patients.
• Health care professionals to communicate better with each other so patients have confidence and trust in the professionals knowing about their needs, so they do not have to keep repeating the same information to different healthcare professionals in the same setting.

Accessible information

• Patients to have access to written information that is appropriate and on time.
• Provide high quality verbal information to make choices and ensure informed consent.
• Provide information which is culturally sensitive and accessible.

1. Background to BHI & BME Cancer Voice

Black Minority Ethnic (BME) Cancer Voice was first established in 2010 by Paula
Lloyd Knight then Associated Director within the National Cancer Action Team (NCAT), as part of a wider NHS led BME Cancer Patient Experience Programme in response to the wide variation in cancer patient experience between BME and white cancer patients.

In March 2013 NCAT was abolished as part of the wider NHS reforms and BME Cancer Voice became part of the charity Black Health Initiative (BHI), headed by Heather Nelson CEO. Since 2013 BME Cancer Voice has published a BME Cancer Patient Information Survey providing insight into the information requirements of BME cancer patients and their carers.

BME Cancer Voice seeks to provide a platform for the experiences of BME cancer patients to be heard and increase the current evidence base on the BME cancer experience through community based research.

2. **Introduction**

Since 2000 NHS cancer patient experience surveys have identified that cancer patients from BME communities report a poorer experience of cancer services and care than white cancer patients. NHS England commissioned BHI - BME Cancer Voice to explore the experiences of BME cancer patients and carers to gain insight into their experiences of NHS cancer care services.

3. **Methodology**

A mixed methodological approach was used, which included; a community development approach working with ethnic specific community organisations to run focus groups, a large deliberative facilitated event and one to one interviews.

3.1 **Focus Groups**

3.1.1 **Irish Specific Focus Group**

A focus group which consisted of 12 Irish and Irish heritage cancer patients and carers took place in Birmingham on the 17th September. The group consisted of 11 females and 1 male. The group shared their experiences of cancer services provided largely in the West Midlands which were very mixed.
3.1.2 Experiences in Primary Care

3.1.3 Carers

The general experience of carers in the group was from caring for their husbands. Most shared the view that their husbands rarely visited their GP, even though they suspected something may be wrong. The carers shared their experiences of having to persuade their husbands to attend the GP. In most cases they were referred on to secondary care but all died within 12-18 months of diagnosis with advanced cancers.

3.1.4 Patients

A number of the participants who were patients shared their experiences of primary care, this experience was mixed, some were told nothing was wrong and had to return several times to their GPs before being referred to secondary care. Only one member of the group felt empowered to challenge the GP and insist on a referral.

“I found a lump in my breast and went to the GP, the GP stated “Women have lumpy breast” so thought everything was ok. 12 months later I was still having problems and my breast started to bleed, so went back to the GP, but this time I saw a female GP who referred me straight away to hospital. But because of the time taken to diagnose me, it had spread to lymph nodes”.

3.1.5 Experiences of Test & Investigations

Both patients and carers recounted their experiences only a minority of patients received information that told them what to expect at the hospital including the type of clothing to wear. Participants were not informed they could bring someone with them for support.
3.1.6 Experiences of Treatment

All of the members felt they had received good cancer treatment at the hospitals and praised the doctors and nurses looking after them. They generally saw this period of their journey very positively.

3.1.7 Experiences of Discharge and Support

Both patients and carers recall this part of their journeys as the “worse part of it”, experiences range from being sent home from hospital a few days after the operation to still having drains in on discharge and wound dressings and being left to fend for themselves.

“No support was offered after my treatment. In fact I had no contact until 3 years after my procedure....Thank God everything was OK.”

“After my breast procedure I was discharged from hospital, only my family looked after me. I was never asked if I needed any help/assistance at home, or even checked upon.”

Participant shared their experience of hospital staff taking for granted that they had support mechanisms at home that would, “kick in once they left the hospital”.

“I had no one to look after me, when I went home as my family was in Ireland, so I just had to get on with it the best I could”.

A number of participants talked about feeling isolated and abandoned once they were discharged from hospital. They were not told about support groups and didn’t want to or felt they couldn’t speak to their families about their experiences or what they were feeling. A number of them said that this was the first time since having cancer that they had actually talked about it. They felt it was really positive to be able to talk and to hear other people’s experiences.

3.1.8 Identified Themes

Access to support and information was identified by both patients and carers’ as one of the main issues that affected their experience of NHS care. All the participants spoke about not being informed about support groups. Many of the participants attended church or were members of the Irish association, although it was a place where they could socialise they didn’t discuss issues like cancer, but felt if they could talk about it with people with similar experiences it would be very positive and help with their healing process.
3.2 Chinese Specific Focus Group

A focus group which consisted of 10 Chinese patients and carers and 2 interpreters took place the 23rd September in London. The group consisted of 3 males and 7 females.

3.2.1 Experiences of Primary Care

The patients and carers shared their experiences of cancer services in London. Their experiences of care had a number of similarities particularly their experiences of primary care. The majority of participants described their primary care experience as poor. They spoke of having to be extremely insistent to get a referral for further tests and investigations.

“I felt something was wrong, my husband went with me. The GP did not take me seriously.”

“The G.P. did not want to make the referral, but because of my insistence and after the physical examination the referral was made. It took 2 weeks for the consultant appointment.”

“I was not comfortable to go the G.P. because of the language barrier. Finding an interpreter was a problem. I had pain on the left side of the groin. I kept delaying my attendance because I had to find a translator. I did not request a translator that would cause further delay. Finding my own translator would be faster. By chance one day a friend went with me. At that time the G.P. did not take me seriously. I insisted on further investigations. The G.P. tried to send me home without doing anything.”
A participant also spoke of describing her symptoms and being given a diagnosis without an examination and told there was nothing that could be done.

“The GP made a diagnosis of fibroids, no ultrasound; he just went on the symptoms. After consistent pain and insistence I was sent for an ultrasound. The appointment took 4 weeks I was diagnosed with cancer”

3.2.3 Experiences of Test and Investigations

Both patient and carers shared their experiences of having tests and further investigations in secondary care. Their experiences at this stage of the pathway were quite mixed. Some received information before their test (in English) others received no information at all, so had no idea of what to expect when attending their appointment, or whether they should have taken along someone for support.

“Before the test I received a letter explaining all the details of the test and facilities at the hospital, all in English. I found it difficult to understand. I had to take it to be translated.”

Language was identified as a significant barrier for both the patients and carers, some were offered translators at the hospital but the quality of them varied with people still not feeling informed.

“The doctor asked me via the translator to sign a consent form I was being told by the doctor that the cancer cells will be removed. The interpreter did not explain fully. I signed without fully knowing.”

At the time of being told they had cancer only one focus group participant out of 10 was told with an interpreter present. The other 9 participants had their diagnosis given to them without interpreters present. Similarly only one person in the group was offered information in another language.

3.2.4 Experiences of Treatment

Most of the experiences of treatment described were seen as poor experiences due to lack of information, not understanding what was going to happen to them, not being told someone could accompany them, and not understanding when they would be discharged. Early discharges left many extremely anxious and confused.

“The day after the operation they wanted to discharge me and I refused as there was no one at home.”
3.2.5 Experiences of Discharge and Support

All participants but one shared a similar experience in that they were not offered support when they were discharged from hospital. A number struggled with information that had been given on discharge.

“After surgery I was told nothing except go to your G.P. for follow up. I wasn’t aware of what the operation was or what the details of the operation were. I was given a report in English and had to take it to the Chinese Cancer Care Association a charity group for an explanation. 6 months later I had a hospital follow up. The doctor didn’t explain to my friend either.”

“They gave me a number for the breast cancer nurse, the clinic is only open on Wednesdays. When I called the number it just rang out and so I went to A&E.”

3.3 African Caribbean Specific Focus Group

A focus group consisting of 6 African Caribbean cancer patients and carers took place in Leeds on the 14th September. Six people participated, 4 females and 2 males. All participants were patients and a number had also cared for family members when they had received a diagnosis of cancer.

3.3.1 Experiences in Primary Care

The majority of participants shared a similar experience of primary care even though the time of first diagnosis ranged from 2 years to over 14 years. The majority of participants reported that they had presented a number of times to their GP only to be told there was nothing wrong and no action taken, in some instances participants were given antibiotics.

“I Attended the GP 6 times over an 18 month period, each time telling the doctor something didn’t feel right, and requesting a PSA test and being told I was too young and didn’t need one. The 7th appointment was with a locum, he did a DRE and referred me to the hospital….I was diagnosed with Prostate cancer”

“I went to my GP while I was breast feeding as I was feeling lots of pain in one breast, but was told it was just a blocked duck, and sent away. The pain continued so I went back after 3 or 4 weeks and then got referred but it took 4 weeks before I got to see anyone else.

“I went to GP after passing out and was given iron tables, but they didn’t help and the symptoms didn’t go away, so I went back to the GPs again and on the second visit I was referred for further tests and investigations”.

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3.3.2 Experiences of Test & Investigations

Participants had a range of experiences regarding having tests which included ranged from a positive experience one a participant worked in the hospital carrying out the tests, to participants receiving very little information of what to expect.

One participant described how when she went for the mammogram the nurse asked if she was in the right place as she was so young!

Participants recall, not being told how to break the news to their families, or having access to counselling or support when first diagnosed.

3.3.3 Experience of Treatment

Most participants reported a positive experience of treatment. However those that had chemotherapy recalled of being offered inappropriate wigs, other than one participant who was offered both a tone specific prosthesis and an appropriate wig. She puts this down to the excellent clinical Nurse Specialist (CNS) who was African Caribbean. Other participant’s experience of treatment was generally positive.

3.3.4 Experiences of Discharge and Support

All the participants described a sense of being “dropped off the edge of a cliff” once they were discharged from hospital, they described a sense of isolation, with no support offered by the hospital or even needs assessed before discharge. This specially affected a young mum who had 5 children at home under the age of 11 with no support after her surgery, her diagnosis was some time ago. However, another participant who had been diagnosed within the last 12 months, recalled of a similar experience, in that no assessment was undertaken of her needs.

One participant described how when she did find support “It felt like everything was geared to white people, like the support groups where for white middle class older women...... I felt isolated. I was viewed as angry, loud and a trouble maker, all because I asked lots of questions, It was an awful experience.”
4. **Focus Group Identified Themes**

The focus groups revealed some clear shared experiences of care which was compounded by language, and culture.

4.1 **Primary Care – GP Referral**

Primary care was problematic for the majority of focus group participants, issues included the number of times they presented before referral, or needing to make a case to be referred on. The Irish and African Caribbean participants’ response was one of acceptance of what the doctor told them, even though they knew something wasn’t right. The Chinese experience was to insist that the GP refer them on to a specialist, in most cases they were sent on non-urgent referrals.

4.2 **Tests and Investigations**

This was more mixed overall, common themes were around lack on information regarding the referral process and what to expect, or information overload, with little options for information provided in different languages.

4.3 **Treatment**

All participants felt they generally had a positive experience of their actual treatment (operation) however, where chemotherapy or radiotherapy was required, experiences varied from “ok” to “poor”, with participants feeling ill informed and with little access to culturally sensitive services such as access to translators, appropriate coloured prosthetics and appropriate wigs.

4.4 **Aftercare Support & Hospital Discharge**

Support required and not offered after treatment had concluded, and patients being sent home without a needs assessment, was a consistent theme identified across all 3 focus groups. Participants described it as “a sense of isolation”. Participants described a lack of support offered after their procedure was completed. They were unaware of services to support them and their families. They described a lack of culturally sensitive support groups and services where they would be able to feel at ease and supported with people who had similar shared experiences as themselves. Participants either tried to manage alone or turned to faith, and or community/ charity culturally specific charities for support.

“The Chinese Cancer Care Organisation has provided so much support to all of us”
“I come to the Irish centre to get out, it’s the first time I’ve spoken about this to anyone, we should have more opportunities to talk about this, it’s been really good”

“BHI have really saved my life…without their support I don’t know what I would have done”

“It is important to have this group as I have been trying to use the dictionary to make sense of the letters the hospital gave me”

4.5 General Issues

A number of participants across the 3 focus groups felt it was difficult to make informed choices regarding treatment, due to a lack of information and understanding.

“The oncologist did not explain properly the radiotherapy, the chance of redeveloping the disease”

“No psychological support, all support is supplied by the Chinese Cancer Care Association which receives no funding at all”

“The language barrier is a big issue. There is no after treatment support because of communication. There should be resources allocated to help with this, more effective management to support ethnic groups. It is overwhelming for patients, whilst waiting for letters. They rely on patients to take notes whilst in a consultation, that is not possible when you don’t understand. A support worker or something of that sort would be good”

“No referral to social care, or counselling offered after surgery. I did go to the Robert Ogden Macmillan Centre but I didn’t feel welcome, there was nothing once I was discharged”

“ All the pictures of women who had reconstruction were white, so I did not get to see what my surgery might look before I made my choice, as there were no pictures of Black women”
5 Deliberative Event

A deliberative event took place on the 5th October at the Park Plaza in Leeds; the aim of the event was to explore further the findings identified from the focus groups and interviews which took place.

5.1 Methodology

The event used facilitated round table discussions with live prioritisation consensus voting on consolidated action points.

Key themes from round table discussions across the cancer pathway

- There should be culturally sensitive family support after people die.
- Psychological support should be available in various languages and culturally sensitive.
- There should be access to support groups for carers.
- Training, funding and capacity building required to support people develop culturally sensitive support groups.
- Access to culturally sensitive support from the start to the end of the cancer journey.
- More time should be given for people to make informed decisions regarding treatment options and choosing care providers.
- There should be a liaison person who works with the consultant and patient, providing time and space for discussion of options.
- There is too much variation in cancer care and support across the country, it needs to be standardised for individuals and carers alike.
- There should be a recovery pathway specifying where/how to get services which should be available to all with appropriate types of support available for all cultures.
- Staff should be more sensitive to the needs of cancer patients and their carers.
- Staff should not assume that certain cultures have extended support though family networks once discharged.
5.2 Prioritisation

Participants at the event were asked to prioritise the themes they had discussed previously. The discussions were categorised into 7 topic themes:

- Language
- Communication
- Information
- Patients being empowered to make decisions & challenge appropriately
- Aftercare & support
- See the person not the illness first
- Accessibility

Each theme in turn was briefly discussed and participants were asked to vote for the one they believed was most important to them. The results are in the table below:

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<td>Accessibility</td>
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6. **Findings**

Both the focus groups and the deliberative events identified the lack of appropriate aftercare and support as the key issue that had the most dramatic effect of their cancer patient experience.

6.1 **Aftercare & Support**

For both focus group members and participants at the deliberative event, the lack of support after their cancer treatment caused serious problems for both patients and carers, with many feeling let down, isolated and alone, with no one to turn to who understood what was happening to them. They felt let down by the NHS after their treatment. Carers also spoke of the lack of support available to them to help both themselves and those they cared for. There was a strong emphasis throughout the event on the need for access to psychological support, and better signposting to support available in the community. Participants spoke of the need for care and support to be appropriate, both culturally and age related, with people that both looked like themselves and had similar shared lived in experiences of life.

6.2 **Communication**

All aspects of communication were identified as important by focus groups participants and those attending the deliberative event. Communication fell into two main areas, how healthcare professional’s verbally communicated with patients and carers, and how healthcare professionals communicated with each other about the patients needs (coordination of care).

Participants spoke of a general feeling of not being listened to, especially in primary care before they received their diagnosis, many had to attend a number of times or be extremely insistent with the GP in order to gain a referral for tests and investigations. In many cases patients were not insistent and ended up attending 2 or 3 times over several months and in some cases over 12 months, at which time many required more invasive treatment due to the diseases progression.

Carers and patients spoke of their frustration of having to repeat themselves on a number of occasions within the same hospital and between primary and secondary care. They described this as feeling they had to be in control of their information as the health care professionals seems as though they did not speak to each other, and this filled them with fear and uncertainly on a number of occasions.

An example within the focus group was given where a Chinese patient had had an operation and the doctors came round while the daughter was present and asked for him to be taken down for his operation. She had to quickly explain he had already undergone the procedure.
6.3 Accessible Information

Accessibility and accessible information where seen as key issues by participants, this can be broken into 3 main areas:

- lack of access to written information that was appropriate & on time
- lack of verbal information to make choices and informed consent
- lack of access to culturally sensitive information / information in different formats/languages

7. Conclusions

The findings from the culturally specific focus groups and the wider diverse deliberative event provide insight into the experiences of cancer patients and carers from different BME groups across England. The qualitative information gathered during the event highlight a number of factors that are contributing to the poor experiences of BME cancer patients and carers.

Poor experiences of aftercare and support where the lost prominent factor which contributed to the poor experiences of care, this lack of emotional, psychological and social support for both patients and families was described by all throughout the process as the worse part of their cancer journey.

Issues around poor communication and accessible information also impacted greatly on those who took part in both the focus groups and the deliberative event.

The findings demonstrate that improvements in communication, accessible information and robust and culturally sensitive aftercare and support would greatly improve the experiences of both patients and carers affected by cancer from BME groups across England.

The focus groups and deliberative event provide a snapshot of the experiences of people from a number of long established BME communities. It is limited in that it did not look at the experiences of some of the more recent BME communities’ experience, notably those from Eastern Europe and the newer East African communities.

A larger more in-depth piece of work is required to look at the experiences of young people from BME communities as well as looking at the experiences of new BME communities and the aging population from these communities.
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