



**Paul's Cancer
Support Centre**

**African Caribbean Cancer Awareness and
Outreach Community Based Assessment**

Abi Ajose-Adeogun

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Table of Contents

| | |
|---|---------|
| 1. Introduction..... | Page 3 |
| 2. Purpose and Remit of the Assessment..... | Page 9 |
| 3. Methods Employed..... | Page 9 |
| 4. Findings..... | Page 12 |
| 5. Recommendations..... | Page 19 |
| 6. Conclusion..... | Page 21 |
| 7. References..... | Page 21 |

1. Introduction

Cancer is now one of the biggest health challenges in the UK with one in three people expected to develop some form of cancer in their lifetime. Approximately 308,000 new cases of cancer are diagnosed each year in the UK with the most common cancers being breast, lung, colorectal and prostate cancers (Cancer Research UK, 2012). Mortality from cancer is high with just over 156,000 deaths in the UK resulting from cancer in 2009 (Cancer Research UK, 2012). The incidence of cancer has remained stable for the past ten years and mortality rates have decreased illustrating the improvements in outcome as we have gained a better understanding of the biological mechanisms of the development of the different types of cancers.

Although the general picture of cancer indicates an improvement in terms of incidence, mortality and survival, inequalities exist with a number of social groups having worse outcomes than the general population. Studies have shown that inequalities are experienced by those from a low socio-economic group; the elderly; ethnic minorities; the disabled; those residing in rural areas; and the lesbian, gay and transgender community. This current work aims to address ethnic inequalities focusing on the African Caribbean community in Wandsworth. To understand what inequalities exist in this community cancer-related key statistics were reviewed and this is summarised in the following sections.

1.2. Summary of the Key Statistics

The Demographics of the African Caribbean Population in Wandsworth

The African Caribbean community make up 9% of Wandsworth's population. This is a much higher proportion than the national figure where the African Caribbean population make up just 2% of the UK's population. In terms of age, the majority of black Caribbeans in Wandsworth fall into the 40-59 year old age group whilst the Black African population is slightly younger with most falling into the age groups 20-39 and 40-59. The Black Other population is younger still with most falling into the age group 5-19 year old age group (ONS, 2011). Additionally, there is a slightly higher proportion of females to males in Wandsworth's black community (ONS, 2011). In terms of socio-economic status data from the 2001 census shows that the black Africans in the UK predominantly fall into social class group B and C1 as do Black Caribbeans (Gill et al., 2004). Thus we can make the conclusion that the majority of the black community in Wandsworth would fall into social class group B and C1.

Cancer Incidence in Wandsworth and in the African Caribbean Community

It was identified for black and white males residing in Wandsworth there is no significant difference between their incidence rates for all cancers combined while the incidence of all cancers combined in black females in Wandsworth is significantly lower than that of their white counterparts (NCIN, 2010). It was also found that the incidence of breast cancer is significantly lower in black women than white women and there is a significantly lower incidence of lung and

colorectal cancer in both black males and females compared to their white counterparts (NCIN, 2010). It was found that the type of cancer that is of particular concern for the black community in Wandsworth is prostate cancer with black men have a significantly higher incidence rate of prostate cancer and at its worst the rate is almost three times that of white men (NCIN, 2010).

National data sets also suggest that there may be particular concerns regarding other cancers with respect to the black community. It has been identified that on a national level both black females and males over the age of 65 have a higher incidence of stomach and liver cancers as well as myelomas than their white counterparts (NCIN, 2009). In addition, black women over the age of 65 have a higher incidence of cervical cancer (NCIN, 2009).

Cancer Mortality Rates in Wandsworth and in the African Caribbean Community

Due to the lack of ethnicity data this review is unable to make a comparison between the mortality rates of the black and white population in Wandsworth but reference can be made to national data sets. This data reveals that there is a higher breast cancer mortality rate in black women compared to white women under 65 (NCIN, 2009; Wild et al., 2006). Data also suggests that there is a higher mortality in black men with prostate cancer compared to white men (Wild et al., 2006). For lung and colorectal cancer there was no significant difference between mortality rates in the black population compared to the white population (NCIN 2009). Therefore any intervention that encourages the early detection of breast and prostate cancer would be particularly beneficial to the black community in Wandsworth.

Cancer Screening in Wandsworth

In the UK there are three cancer screening programmes these are the breast, bowel and cervical screening programmes.

The breast screening programme aims to screen all women between the ages of 50 and 70 (being extended to 47-73) for the early signs of breast cancer. The most recent breast screening data suggests that Wandsworth has the lowest breast screening coverage in South West London. Its coverage is 63.5%, compared to 72% for Croydon, 73% for Kingston, 70% for Richmond and 72% for Sutton (NHS Wandsworth, 2010a). In addition, breast screening coverage is significantly lower than the England average of 76.5% (NHS Information Centre, 2011).

The cervical cancer screening programme screens all women between the ages of 25 and 64. Wandsworth's screening coverage is 68.4% which is slightly lower than the England average of 73.7% (Trent Cancer Registry, 2010)

Finally the bowel cancer screening programme invites everyone between the ages of 60 and 69 for screening. Wandsworth's screening coverage is significantly lower than the England average. It is 38.6% compared to the England average of 52.1% (NHS Wandsworth 2010b)

National surveys and datasets identified that screening uptake for cervical, bowel and breast cancer was lower for ethnic minorities and we can assume that this will be the case in Wandsworth

This data shows that there is room for improvement in terms of screening uptake and thus it would be beneficial to raise awareness about cancer screening amongst the residents of Wandsworth be they black or white.

Cancer Awareness in the African Caribbean Community in Wandsworth

In 2010 the South West London Cancer Network conducted a survey with residents of Wandsworth to determine their level of awareness on a range of cancer-related issues (Social Research Institute, 2010). It was found that BME groups had a lower level of awareness of the signs and symptoms, the causes of cancer and cancer screening than the white population. This lack of awareness was linked to more BME communities having less personal experience with cancer.

The results of this survey demonstrated that health promotion messages regarding cancer are not reaching the African Caribbean population in Wandsworth. This appears to be having a negative effect as suggested by the increased mortality seen in certain types of cancers in the African Caribbean community compared to the white population.

1.2. Implications of the Key Statistics

This data summarised in the previous sections shows that Wandsworth is experiencing the same challenges highlighted by the Department of Health's (DoH) Improving Outcomes Report such as the disproportionately poor outcomes in disadvantaged communities, delayed diagnosis, poor screening uptake and lack of public awareness. Furthermore the specific inequalities experienced by the African Caribbean community in Wandsworth are:

1. An increased prostate cancer incidence compared to the general population.
2. The possible increased incidence of stomach and liver cancers as well as myelomas as suggested by national datasets.
3. The possible increased incidence of cervical cancer in black women over the age of 65 as suggested by national datasets.
4. The possible increased breast and prostate cancer mortality.
5. The lower cancer screening uptake.
6. The lower level of awareness of signs and symptoms, cancer screening services and causes of cancer.

The above mentioned inequalities have been known for some time and are true for African Caribbean populations throughout the UK. The challenge has been to develop sustainable interventions that address these inequalities. To address these issues the DoH recommends a big society approach where organisations work together each taking on the area where their

expertise lies. The Improving Outcomes report stresses that public interventions should focus on two areas, prevention and early detection. It states that prevention can be achieved through encouraging behaviour change whilst earlier detection can be achieved through increased awareness of cancer symptoms and encouraging uptake of cancer screening services. It also suggests that charities like Paul's Cancer Support Centre carry out the following:

- Raise awareness of cancer;
- Raise money to fund research and services;
- Deliver services such as information resources and campaigns for change.

1.3. Current Strategies for Tackling Ethnic Inequalities

Over the past few years a number of mainstream organisations have introduced approaches that aim to target the BME community. Their approaches have included producing publications in a range of languages, incorporating more BME imagery in their health promotion material, contributing to Ethnic Minority Cancer Awareness Week and general BME community engagement. These approaches have had minimal success with surveys still showing a low level of awareness in BME groups compared to the white population. This could be due to the fact that there is still a lack of understanding of the target population leading to such interventions being seen as tokenistic and not truly culturally appropriate. Grass roots organisations, i.e. black cancer charities, have been fairly successful at engaging with their local African Caribbean community because they have an in-depth knowledge of the target group but the lack of funding has limited their effectiveness. For the success of Paul's Cancer Support Centre's BME project there needs to be an effective combination of the mainstream and grass roots approaches. This is the reason for the community based assessment which will enable the BME community to frame the way in which health promotion is delivered by Paul's Cancer Support Centre to ensure that it is culturally appropriate, effective and not tokenistic.

With inequalities still prevailing in the African Caribbean community a number of organisations are still working towards ensuring better community engagement. It is worth Pauls Cancer Support Centre aligning with these organisations to avoid duplication of effort, to share best practices and to ensure that some of the general challenges can be tackled in a collaborative manner. These organisations include the National Cancer Action Team (NCAT), Jo's Cervical Cancer Trust, The Prostate Cancer Charity, Cancer Black Care, Betterdays Cancer Care and the African Caribbean Leukaemia Trust.

NCAT: NCAT is responsible for implementing the Department of Health's vision of delivering world class cancer services. NCAT aims to support the UK's cancer networks in developing early diagnosis initiatives, improving services, developing cancer prevention strategies, developing better information for cancer patients and improving cancer treatments. A significant aspect of NCAT's work is to ensure that any inequalities in the cancer space are addressed and NCAT currently has a number of initiatives that focus on ethnic inequalities. These include:

- *The BME Cancer Voice (formally known as the BME Patient Panel)* – This initiative is aimed at raising awareness of cancer, its symptoms and cancer screening. It also focuses on cancer patients and carers giving them a voice so that services and the BME patient experience are improved. (<http://www.bmecancerveice.co.uk/>)
- *Community Ambassadors Project* – This project aims to raise cancer awareness in specific communities in collaboration with Spectrum Radio. An initial pilot is being conducted with the Ghanaian and Bangladeshi communities which will involve community ambassadors hosting an interactive radio show featuring health professionals, representatives from a variety of cancer charities, cancer patients and community figures. (<http://www.cancerinfo.nhs.uk/patient/current-projects/community-ambassadors-project>)
- *Libraries Project* - NCAT also aims to raise awareness in the BME community through a series of events in libraries across South London. These events will involve NCAT hosting information stalls with awareness materials that are aimed at the BME community. (<http://www.cancerinfo.nhs.uk/patient/current-projects/libraries-project>)
- *The Cancer Awareness Supplement* – In July 2012 NCAT published a Cancer Awareness Supplement in The Voice newspaper. This supplement specifically raised awareness of cancer amongst the African Caribbean community and currently NCAT are developing a similar supplement aimed at the Asian community. (http://ncat.nhs.uk/sites/default/files/Voice%20Supplement%20July%202011_0.pdf)
- *Cancer Ethnicity Resource Portal* – This portal provides a collection of resources that explore the experience of BME cancer patients with the overall aim of identifying gaps in services so that these can be addressed and to ensure best practices can be shared. (<http://www.cancerinfo.nhs.uk/healthcare-professional/bme-patient-experience/cancer-and-ethnicity-portal-cerp>)
- *BME Baseline Audit* – NCAT conducted a BME baseline audit in 2009 across all Trusts and cancer networks in the England to evaluate the policies and services each organisation has that relates to BME communities. (http://www.cancerinfo.nhs.uk/images/stories/ncip_bmeaudit_june_10.pdf)
- *The Cancer Does Not Discriminate Campaign* - In Dec 2011 the Cancer Does Not Discriminate Campaign was launched. This campaign was launched to focus attention on the BME community and aims to raise awareness of various aspects of cancer within the BME community. All the previously mentioned NCAT projects are now all a part of this campaign.

Jo's Cervical Cancer Trust: Jo's Cervical Cancer Trust conducted a survey in 2011 which showed that awareness of cervical cancer and uptake of screening was lower in BME communities compared to the general population. As part of Cervical Cancer Awareness Week in early 2012 Jo's Cervical Cancer Trust held a conference entitled 'Raising Awareness and Overcoming Barriers'. The purpose of this event was to discuss ways of improving awareness of cervical cancer and the benefits of cervical cancer screening and it is part of Jo's Cervical Cancer Trust's drive to increase awareness in women from BME groups. (<http://www.jostrust.org.uk/>)

The Prostate Cancer Charity: The Prostate Cancer Charity through its on-going African Caribbean Communities Project carries out a range of activities to increase awareness of prostate cancer amongst African Caribbean men. Their work involves raising awareness through their awareness volunteers, educating health care professionals in regions with a large African Caribbean population and working with people with prostate cancer to share their experience through their Prostate Cancer Voices Network. (<http://www.prostate-cancer.org.uk/get-involved/african-caribbean-communities>)

Cancer Black Care: Cancer Black Care was established to serve the BME community, to raise awareness of cancer and to influence the information, care and treatment of cancer to ensure it is appropriate and sensitive to ethnic and cultural diversity. They raise awareness through their community health awareness events and a range of other activities aimed at the BME community. (<http://www.cancerblackcare.org.uk/>)

Betterdays Cancer Care: Betterdays Cancer Care is a community led organisations that aims to raise awareness of breast cancer amongst the African Caribbean community. Betterdays Cancer Care hosts regular community events that raise awareness of breast cancer and how it affects the black community. They have also produced a range of awareness materials using black imagery and have recently piloted a project called the Patient Navigation Programme in partnership with NHS Southwark and NHS Lewisham which aimed at proactively raising awareness and encouraging women from the African Caribbean community to participant in the NHS Breast Screening Programme. (<http://www.betterdays.uk.com/>)

ACLT: The Afro Caribbean Leukaemia Trust is a community led organisation whose main aim is to increase the number of Black, Mixed Race and Ethnic Minority people on the UK Bone Marrow Register. They have been very successful at engaging with the African Caribbean Community due to their in-depth knowledge of the African Caribbean community.

2. Purpose and Remit of the Assessment

Through this Community Based Assessment Paul's Cancer Support Centre aims to gain an understanding of how best to deliver a cancer outreach and awareness programme that targets the African Caribbean community in Wandsworth. The key statistics that were collated provided some insight into Wandsworth's African Caribbean community with respect to their

demographics, the epidemiology of cancer in this group and their level of awareness of cancer. This information informed the direction of the assessment to ensure that the recommendations for the development of any cancer outreach and awareness programme are relevant to the needs of the African Caribbean community.

The literature review showed that Wandsworth has a large African Caribbean population who have particular challenges with respect to cancer. In general the picture is good in the sense that incidence rates are mostly lower than the white population but there is concern over the higher incidence of prostate cancer and the higher breast and prostate cancer mortality. In addition to this there is a lower level of awareness of a range of cancer-related issues such as the signs and symptoms, screening and causes of cancer in this group compared to the white population. A targeted health promotion campaign is thus needed to address these issues.

Paul's Cancer Support Centre is well placed to deliver a health promotion campaign that targets these issues and the first step in this process is to conduct a community based assessment of how best to deliver an outreach and awareness programme. Using this assessment to engage directly with the African Caribbean community will enable a culturally relevant approach to be developed with the needs of the community at the heart of it. Additionally, it has been recognised that for the success and sustainability of this programme the Centre will need to form close working relationships with black community groups and organisations that work with the black community. With this in mind the aims of the community based assessment were:

- To identify African Caribbean community organisations based in Wandsworth that Paul's Cancer Support Centre can work in collaboration with to deliver a cancer outreach and awareness programme;
- To identify how feasible it would be to form a working relationship with the identified groups; and
- To engage directly with the African Caribbean community in Wandsworth to identify how they view cancer and what the best community engagement approach may be.

3. Methods Employed

To achieve the aims of the Community Based Assessment the following method was employed:

- One-to-one discussions with individuals from the African Caribbean community to determine their view on cancer and what might be the best approach to implementing an outreach and awareness programme.
- A scoping exercise to determine the possibility of working with African Caribbean community organisations to implement a cancer outreach and awareness programme.

3.2. One-to-one community engagement

Residents of Wandsworth who were from an African Caribbean background were randomly selected and interviewed. The interviews were semi-structured to enable participants to offer ideas and points of view that the interviewer might not have considered. Seven questions were included that covered three main themes:

- Individual and community perceptions of cancer
- Cancer awareness
- Recommendations for better engagement with the African Caribbean community

Participants' responses were noted and following each interview the responses were typed up and reviewed. After all the interviews were typed up data analysis commenced. The data analysis method that was used was a variation of the Analytical Hierarchy approach (Ritchie et al, 2003). This involved familiarisation of the data by categorising the data into the three main themes that were mentioned previously (perceptions of cancer, cancer awareness and recommendation). The data was then further categorising into sub themes. Once data familiarisation was complete the data was summarised and then explained with reference to the aims of the assessment.

The final sample consisted of eleven African Caribbean participants, seven African and four Caribbean, between the ages of 17 and over 50. The majority of participants were female with eight female participants and three male participants. Table 1 summarises the participants.

| Participant | Age | Profession | Gender | Self-Identification |
|-------------|-------|----------------------|--------|----------------------------|
| 1 | 45-50 | Business Owner | Female | Black Caribbean |
| 2 | 45-50 | Civil Servant | Female | Black African (Ghanaian) |
| 3 | 30-35 | Biomedical Scientist | Female | Black African (Zimbabwean) |
| 4 | 50-55 | Patient | Female | Black African (Nigerian) |
| 5 | 30-35 | Engineer | Male | Black African (Nigerian) |
| 6 | 30-35 | Barber | Male | Black African (Nigerian) |
| 7 | 15-20 | Student | Female | Black Caribbean |
| 8 | 20-25 | Student | Female | Black British |
| 9 | 45-50 | Hair dresser | Female | Black African |
| 10 | >50 | Retired | Female | Black Caribbean |
| 11 | 35-40 | Business Owner | Male | Black African |

Table 1: A Summary of the Participants

3.1. Project Partnership Scoping

African Caribbean community groups and organisations that work with the African Caribbean community were identified and contacted to determine their interest in working with the Centre to raise awareness amongst their users and within their local community. Organisations that were willing to work in partnership with the Centre were noted to ensure further contact during the implementation stage of the project.

4. Findings

The results from the community based assessment can be divided into three main areas. These are:

- Participants' views about cancer;
- General awareness of the disease;
- Participants' thoughts on effective ways of reaching the black community with the key messages about cancer.

Each of these areas will be discussed in the following sections.

4.1. Participants' Views About Cancer

Individual Beliefs and Views on Cancer

Participants had a negative and fatalistic view of cancer associating cancer with death, pain and chemotherapy. Participants explained that:

"You think it is the end" – Participant 1

"It is something that never goes away" – Participant 1

"I feel cancer does nothing other than kill" – Participant 3

"[Cancer is a]...terminal disease" – Participant 6

"Cancer ostracizes" – Participant 11

Furthermore strong emotions such as fear and sadness were associated with the disease. For example:

"Scary, very scary" – Participant 1

"Sad" – Participant 1

"....scared me" – Participant 3

Community's Beliefs and Views of Cancer

When asked how the African Caribbean community views cancer participants felt that there was a negative attitude towards cancer with there still being a stigma associated with the disease.

"We are not as positive about it as white people" – Participant 1

"The black community think it is the end" – Participant 1

"There is still a sense of embarrassment....." – Participant 2

“The perception is death is inevitable” – Participant 2

“...most uneducated think it is a result of witchcraft, this may be mainly [because] there is no cure for it hence the association with dark forces as there is no control over it.” - Participant 3.

“Prostate cancer is viewed negatively and men associate it with loss of manhood, similarly cancer of the womb in women.” – Participant 3

“Perhaps there is a stigma attached to such diseases.” – Participant 6

“They see it as a death sentence” – Participant 7

“The black community is quite afraid of cancer” – Participant 9

It was also felt that there is a great sense of fear about cancer and it is something that the community does not want to talk about. For example:

“...viewed with great apprehension” – Participant 6

“ The black community is quite afraid of cancer” – Participant 9

“There is still a sense of embarrassment to discuss these topics in detail” – Participant 2

“Like with many diseases Nigerians tend not to speak too much about the detail. You don’t tend to hear about the details unless you are a very close family member. “ Participant 6

It was also suggested that the community considers cancer to be a “white disease” and that views varied *“depending on the level of education.”*

The Consequences of Cancer

When discussing the consequences of cancer physical and emotional consequences were put forward. These included:

1. Effects on the body - *“The body might be cut to remove the cancer, like your breasts”*
2. Effects on relationships - *“A lot of marriages break down”*
3. Ethnic differences - *“...we do a lot worse than white people when we get it; it takes us quicker”.*
4. Uncertainty: *“...they seemed to have gotten over it but then it came back and they died”*
5. Recurring effect: *“ It always comes back”*
6. Scale: *“It affects a lot of people’s lives – mothers, young people”.*

The Origin of Individual Beliefs about Cancer

Participants' views of cancer tended to be based on their personal experience with cancer. For instance below one participant describes why he feels the way he does about cancer:

"[When I think of cancer] I think of my dad first and foremost, he died of prostate cancer. I think of pain, chemo and death. I think of these things because of my father's experience."
Participant 7

Participant 6 stated that when she thinks of cancer she feels "cancer does nothing other than kill" She went on to explain that "my sister in law died of liver cancer in 2007". It appeared that this experience formed her belief that cancer does nothing but kill.

When participants didn't have a personal experience they based their opinion on their immediate environment such as the media, for example:

"I haven't had a direct experience of a close friend or relative who has had cancer so I am probably not as informed about it as I should be. So I view it based on what I have seen in the media or what I have heard from others." – Participant 6

Another participant describes why she views cancer in such a negative way; she too had not had a personal experience with cancer:

"When I hear the word 'cancer', the first thing that comes to mind is death. Though a negative thought as not everyone diagnosed dies, the perception is death is inevitable. The survivors of cancer are not publicized as much as those who pass away." – Participant 2

4.2. Cancer Awareness

General Awareness of Cancer

The majority of participants were aware of the existence of various different types of cancer. Eight participants specifically mentioned that they were aware of breast, prostate, lung, bowel, pancreatic, ovarian, throat, bladder, leukaemia, liver, womb, cervical and skin cancer. The cancer that most participants identified was breast cancer followed by prostate, then bowel and lung cancers.

It was clear that messages about breast cancer were successfully reaching this community but messages about other cancers were not as evidenced by the following statements:

"I am only aware of the signs and symptoms of breast cancer, the rest I don't know." – Participant 1

"I really don't know much about cancer at all. I think breast cancer takes over, I hear about that all the time." – Participant 5

“I am aware of breast and lung cancer, I am not aware of any other type of cancer.”
Participant 8

Awareness of Signs and Symptoms

In terms of the signs and symptoms of cancer six participants named symptoms of cancer. Of the six, five participants recalled a breast lump as a sign of breast cancer and one of the five was also able to identify a mole as a sign of skin cancer. The final of the six participants who were able to name a symptom of cancer named bladder problems as a symptom of prostate cancer.

Awareness of Risk Factors

There was a general lack of awareness of risk factors for cancer with participants stating:

“Not sure what the risk factors for cancer are or what causes cancer” - Participant 9

“Not sure of what the risk factors for cancer are. I know healthy people that have gotten cancer.” – Participant 10

Two participants made some suggestions:

“Stress plays a big part. I think this country is very stressful.” – Participant 1

“The risk factors are things like smoking.” – Participant 6

Awareness of Cancer Screening

Five participants mentioned that they were aware of cancer screening with two specifically mentioning breast cancer screening and one mentioning prostate cancer screening (PSA test).

Awareness of Cancer Campaigns

Four participants stated that they were aware of on-going cancer awareness campaigns. The specific campaigns that participants mentioned were Cancer Research UK and Macmillan’s TV advertisements and The Race for Life. Two people stated they had seen TV adverts raising awareness of cancer but were unable to provide specific information on the advertisements that they had seen.

Community Awareness

Some participants had thoughts on the African Caribbean community’s level of awareness and why awareness levels were quite low. One issue that arose with some participants was the lack of willingness to discuss cancer. One participant summarises this very well:

“You don't tend to hear about details unless you are a very close family member. I think this means that one isn't always aware of how many others go through the same thing so it's difficult to create awareness or for people to seek support from others who have been through the same experience.” – Participant 6

It was identified that this lack of communication meant that the African Caribbean community is isolated and therefore lacking in support.

“We are dealing with issues alone and even if we don't live alone we don't feel like we can discuss these issues.” - Participant 11

One participant stated it wasn't until she started attending a black community group that she heard discussions about cancer and realised how many black people were affected by the disease.

“It wasn't until I started going to church that I realised how common it is and that is when I started to hear a lot about cancer.” Participant 10

This suggests that black people need to have more opportunities to come together as a community to address some of the issues that they encounter. At the moment this is a challenge because as one participant stated

“...the black community is dispersed, for example in Tooting there are isolated pockets of black people which makes us hard to reach.” - Participant 11

In addition, similar cultures would rather discuss these issues within their community rather than with someone from a different culture as stated by participant 4:

“They are more likely to want to talk to other African women rather than white or Caribbean women.”

Furthermore it was felt that Africans are less likely to want to discuss health issues than the Caribbean community as suggested by participant 4 who stated:

“Africans are less likely to talk about any issues that they have. Caribbeans are more likely to talk about cancer and want to have long discussions.” – Participant 4

Finally one participant noted that:

“We generally are not very health conscious, our health is not our first priority, we don't take it seriously. It is not until we break a leg or something like that that we actually go to the doctor; we don't go for regular check-ups. Right now it's only if black people are personally affected, they will sit up and take notice.” – Participant 7

4.3. Thoughts on How to Effectively Engage with the African Caribbean Community

A number of participants felt that cancer awareness approaches needed to be more proactive with health professionals having more of a presence in the community.

“I think what you are doing now, one-to-one with people.” – Participant 1

“Like you are doing now, physically get out in the community and talk to people” – Participant 7

“...need less paperwork but on-the-ground hands-on approach. Not a paper intervention, a practical health intervention.” – Participant 11

“.....go out to the community, instead of the community having to go to it, need to be more practical.” – Participant 11

It was also felt that there needed to be a better understanding of the social interactions of the African Caribbean community as stated below:

“To reach black people you have to understand where they go, what they do, where people meet, like churches, groups where people meet - book clubs, home groups, clubs, dances, functions, black organisations, high commissions – these places have a captive audience.” – Participants 11

In addition, it was felt that the differences between the African and Caribbean populations needed to be considered when implementing a cancer outreach and awareness programme.

“The African and Caribbean population need to be separated. Each has different needs and are culturally very different. The African population is more practical and would like a more action orientated approach” – Participant 4

When considering the formats to utilise to deliver awareness messages one participant did warn that although seminars were effective at raising awareness they would tend to only reach people who *“...have a personal connection with cancer, the average black person would not attend”*. Therefore as several participants suggested a variety of methods and outlets should be explored to raise awareness in the African Caribbean community. The following were suggested:

“I think the one way might be to use media, drama, movies for example to try to get it more discussed in the open. To do it in ways, in which people can connect or identify with. I only mentioned movies because I don't think campaigns are really that effective, even here in the UK. However, in Naija (Nigerian) movies, we see so much about attitudes, witchcraft etc. I think movies or shows that provide an insight (if done in a sensitive way) into what it means to have cancer might be effective.” – Participant 6

“I believe the Church could be a good place to bring awareness to the masses. I believe the church would be a good platform because our society spends a lot of time there. Another platform could be the radio stations and television.” – Participant 2

“....having talks, printing flyers, just reaching out to people. I think a cancer seminar would be great, I think everywhere they should talk about it, in church in schools too.” – Participant 1

“....ads on the TV and target black people specifically.” – Participant 7

It was also felt that more black imagery was needed and health professionals from the African Caribbean community should be used so that the target group connects with the messages being delivered.

“It would be great if public Nigerian figures who have the disease could help others by sharing their experiences especially survivors so people know that it's something that can be fought.” – Participant 6

“Use more black people to get the message across,” – Participant 7

“More black people in the adverts and when they show Race for Life show more black people. Lots of black people participate in Race for Life but you would never know, it gives the impression that we are not there, and we are because our family members are affected, that would raise awareness that black people are affected by cancer.” – Participant 9

4.4. Summary of Findings from the Community Based Assessment

The findings suggest that the African Caribbean community in Wandsworth have a very negative fatalistic view of cancer which has led to the stigmatisation of the disease within this community. The fatalistic view of cancer may have led to the attitude that nothing humanly can be done if afflicted by this disease leading to a lack of motivation to learn about symptoms, risk factors and the cancer services that are available. The negative beliefs about cancer seemed to have stemmed from the personal experience that participants tended to have with cancer. These experiences involved a person known do the individual dying from cancer. Where participants didn't have a personal experience their views of cancer were shaped by media images of cancer patients and the cancer experience; these tended to be negative.

Participants had a fair amount of awareness of breast cancer and that a breast lump is a sign of breast cancer but there seemed to be a lack of awareness of other signs of breast cancer. In addition, there was some awareness of the existence of the most common cancers such as prostate, lung and bowel cancer but a low level of awareness of the existence of other cancers. There was also a low level of awareness of the signs and symptoms of these cancers (prostate cancer, lung cancer, bowel cancer and other cancers). Furthermore the findings identified a low level of awareness of the risk factors for all cancers.

It was felt that the African Caribbean community had a low level of awareness for a number of reasons. Such as:

- The unwillingness to discuss the disease outside of their family circle, social network and cultural group;
- The lack of opportunity to meet with others from the same cultural group which would provide a perceived safe environment to discuss serious health issues;
- The feeling that cancer :

- is a terminal disease so nothing can be done if one has the disease;
- doesn't commonly affect the African Caribbean community;
- has a stigma associated with it
- The inability of mainstream cancer awareness campaigns to effectively reach the African Caribbean community
- The inability of the African Caribbean community to culturally relate to the approaches used to raise awareness of cancer

Finally participants recommended that a variety of approaches are explored when implementing a cancer outreach and awareness strategy and approaches should be based on a sound understanding of the culture of the African Caribbean community.

5. Recommendations

5.1. Addressing the Negative Perception of Cancer

- 5.1.1. The face of cancer in the black community needs to change so that cancer is not seen as a death sentence. Survival rates for some cancers are quite good but that message is not reaching the African Caribbean community. It is recommended that more stories of survivors are shared with the community, survival rates communicated and survivors of cancer who are from the African Caribbean community be given a platform to share their story.
- 5.1.2. The message that early diagnosis is important in ensuring a good outcome from cancer should be promoted within the black community and survivors who share their stories should stress that early diagnosis was key to their survival. Using this line might put a more positive, proactive light on cancer that is less fatalistic and clearly shows that personal behaviour (prompt help seeking) can impact prognosis.
- 5.1.3. The stigma associated with cancer needs to be addressed. This can be addressed by dispelling the myths about cancer and ensuring that the African Caribbean community is properly education on the science behind cancer so there is a clear understanding of what cancer is, how it develops, risk factors and the possible causes of cancer.
- 5.1.4. There is a need to create a safe, non-threatening, non-judgemental environment to discuss serious health issues so that cancer can be discussed openly. This will help to destigmatise the disease and begin to enable a more positive community response to cancer. To achieve this requires a clear understanding of what a safe environment is for the African Caribbean community. The community based assessment identified that a safe environment was not within the confines of the health system i.e. not in a clinic, office or professional environment but in a relaxed location with the most appropriate people facilitating that discussion; preferably facilitators from the same cultural background. This could involve creating opportunities to discuss serious matters on a

one-to-one basis, within a group or possibly utilising communication aids (phone, email, Skype, instant messenger and/or social media).

- 5.1.5. Prominent African Caribbean figures could be used to communicate messages about cancer which could encourage discussion and create a more positive perception of cancer.

5.2. Raising Awareness

- 5.2.1. There is a need to think creatively about how to implement an outreach and awareness programme targeting the African Caribbean community. It is recommended that Paul's Cancer Support Centre develop a programme that is all encompassing and includes:

- Seminars
- The creative arts (poetry, drama, writing, film etc)
- Health and wellbeing events (cancer prevention events that focus on a healthy lifestyle as a way of reducing risk)
- Media campaigns targeting black media outlets e.g:
 - Black radio e.g. Colourful Radio, Choice FM, Premier Radio etc
 - Black print media e.g The Voice, Pride Magazine, New African Woman
 - Black TV stations e.g. BET, BEN TV, Vox TV etc
- Community outreach – the community based assessment identified that health workers getting out in the community engaging one-to-one with individuals would be beneficial. Information stands in key locations would be one way of achieving this.

- 5.2.2. It is recommended that as far as possible that the programme is sustainable so a continuous presence is felt in the African Caribbean community. Adequate funding would thus be needed to achieve this.

- 5.2.3. It is recommended that Paul's Cancer Support Centre works in partnership with a range of organisations such as:

- Black community groups (churches, elderly groups, black hairdressers, barbershops, elderly groups, women's groups, men's groups, black charities etc)
- Cancer charities and organisations (local and national)
- Charities that focus on other chronic diseases as these diseases tend to have similar risk factors

- 5.2.4. It is recommended that any events (health and wellbeing events and seminars) are culturally appropriate and proactive providing practical advice on how a healthy lifestyle can be achieved bearing in mind the diet, culture and religious beliefs of the African Caribbean community.

6. Conclusion

The African Caribbean community in Wandsworth have a negative fatalistic view of cancer and have a low level of awareness of the signs and symptoms of cancer, screening and services available. This can mean that the African Caribbean community is disadvantaged and should they become affected by cancer the low level of awareness of the signs and symptoms could result in delayed help seeking and thus delayed diagnosis. To address these issues to ensure that early diagnosis is achieved Paul Cancer Support Centre aims to develop a cancer outreach and engagement programme. For the success of this programme there is a need to understand the culture of the African Caribbean community, include BME health professionals in the development and implementation of the programme, form working relationships with BME community groups and ensure a sustainable funding model so that there is consistency in the programme. This will enable a culturally appropriate approach to be taken that meets the needs of the community.

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