

Summary Report – The Lake Foundation’s Cancer Support Group

Introduction

The Lake Foundation ran a cancer support group for two years from 2014 to 2016 and this report aims to give a concise overview of this project and the lessons learnt.

Why We Set Up The Support Group

The African and African-Caribbean Cancer Support Group was set up after conducting a literature review on the support available for black cancer patients.

In 2004, the UK’s National Audit Office carried out a study on the Patient Experience of Cancer Care. Patients in this study stated that there was no customized support service or information for black and minority ethnic (BME) patients.

In 2005, the National Audit's Office carried out another study which found that BME patients felt that the NHS takes a Eurocentric approach to cancer care which is not relevant to their needs, there are no customised support services for BME patients and the key issues around religion and culture were trivialized during patient assessments.

In 2009, the Department of Health published their report on the experience of BME cancer patients and they found that BME patients are less likely to report a positive experience with regards to the care they receive. Also in 2009, a report entitled ' Better Access, Better Service' concluded that "Information and support needs were not always met, particularly those specific to Asian and African Caribbean women." They found that African Caribbean women experienced poor signposting to culturally appropriate services, particularly those related to their practical support needs. They also found that patients would prefer locally-based services and that peer support was strongly desired.

In 2010, the National Cancer Action Team published the "Analysis of the National Black and Minority Ethnic Baseline Audit". It was found that Mayday Hospital (Croydon University Hospital) does not provide access to culturally specific advocacy and support services.

In 2012 a community based assessment was carried out, this involved interviews with the African and Caribbean community in Wandsworth and one participant stated "They [African women] are more likely to talk to other African women" and one of the conclusions of the assessment was that "There is a need to create a safe, non-threatening, non-judgmental environment to discuss serious health issues so that cancer can be discussed openly."

These studies provided the evidence for the need for our work especially as we were not aware of any such support group in Croydon, there was an Asian Cancer Support Group; the closest African Caribbean Cancer Support group is in Clapham Junction.

Croydon has a large BME population (41%) and the incidence of cancer is above the London average so a culturally appropriate cancer support group would be of benefit.

Overview of the Support Group

Outcomes: Recruitment

Our cancer support group sessions started on Wed 4th June 2014 and continued monthly on the first Wednesday of the month. It took some time to get significant numbers to attend and we worked tirelessly to promote and recruit members. We engaged with many organisations and either met with them in person, sent them a leaflet and/or emailed them the leaflet and we appeared on Croydon radio twice to promote the support group.

We also ran a digital campaign with The Voice newspaper, the leading African Caribbean newspaper in the UK. We had an online ad live for 7 days and developed an advertorial which remains live until today. On the day the advertorial was published it was the 3rd most viewed health article of the day out of 10 articles. Additionally we worked with Mi Soul radio to create a web banner which was live on their site for one month.

As a result of our promotional activities we were able to recruit six members and we had several enquires about our support group from patients who were keen to attend but then were either too unwell or couldn't make the date and time of our sessions. In addition several organisations contacted us about research opportunities, media work and to promote their own support services.

Outcomes: Supporting our members

The members of our support group had various needs and below are the main areas that members wanted the support group sessions to address:

- How to move forward after cancer
- How best to support my partner
- The need for practical support and advice on managing a cancer diagnosis
- Tackling the isolation and distress caused by a cancer diagnosis
- How best to manage a cancer diagnosis along with other life challenges

During each session our facilitator had the opportunity to have in-depth discussions with members of the group and was also able to provide tools to ease distress, for example one session focused on relaxation and mindfulness.

Members of the support group found sessions to be useful giving the following feedback:

“I found the session to be very useful and I am so glad that I came. I was feeling very down and really wasn’t going to attend but I am glad that Abi called me and picked me up. Hazel was very insightful and had a lot of meaningful things to say. She gave me a lot to think about.”

“The relaxation and mindfulness session was really useful.”

“I wish to thank Hazel for her kind words and encouragement.”

Challenges

The main challenge was attendance. We were pleased to have six members in the group but had hoped we could reach a larger number of black patients. Despite all our efforts to promote the group we weren’t able to increase the numbers. We did receive feedback from one patient who stated that the African Caribbean community would definitely benefit from attending these sessions but support groups don’t appeal to many black people as the perception is that support group sessions involve “a lot of talk” and many black people are more practical.

Lessons Learnt and Conclusion

The support group did provide much-needed support to our members who benefited from having discussions with patients and a facilitator from the same cultural background. It is worth testing a different format of support for black cancer patients. We believe a structured health and wellbeing course, with time for discussion and social activities may attract more black patients and is something we are currently exploring.