

Understanding the Barriers to uptake of Cervical, Breast and Bowel Cancer for women speaking Farsi and Kurdish Sorani

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Introduction

This research was conducted in our community in Brighton-Hove, particular cancer screening for females. The aim was to get a grip of the community understanding cancer screening and explore their issues in this area.

Research

This research was progressed by making efforts to contact over twenty ladies in Brighton and Hove areas. That was including participants' background, systemic barriers that prevent of accessing to National Health Services i.e.GP, lifestyle barriers, culture barriers and improvement or suggestions.

Problems and issues:

Truly, it was difficult to find volunteers and participants for this research due to

1. Lockdown due to COVID-19, there was so difficult to meet people and interview face to face
2. Problem with virtual and telephone survey
3. Culture, tradition and ethnicity, majority were not comfortable with answering questions to a male researcher
4. Difficulty with establishing trust with the Participants and convince them to share their personal data with me a male Researcher
5. Some Participants didn't like to talk about cancer at all
6. Some had no knowledge and experience about research in general

I struggled to contact my community and had problem with finding volunteer to have an interview about cancer. Over 20 people were contacted, initially five Participants accepted having interview, however two of them didn't like to go further and complete the interview. Finally, three ladies from our community accepted to participate and be interviewed.

Research

For establishing the research properly, a questionnaire in five parts, including background, systemic barriers, lifestyle barriers, culture barriers and improvement/conclusion was created, and three interviews were conducted with three participants ladies in Farsi and Kurdish (Sorani) languages and then they were translated into English. To reflect the outcomes of each individual interview, a brief of the interviews would be quoted here as follow:

Interviews

Part one - background

All the three participants were living in Brighton and Hove. They were Immigrants from two different countries Iran and Iraq. They were registered with GP and able to access to the NHS. Multiculturalism, variety, common senses and high tolerance were main reasons for them to feel welcome and happy in the area. Furthermore, they felt connected to own community and culture as well.

The research showed that cancer screening including cervical smearing test, bowel test, mammography for breast cancer, and their symptoms were known well in the community. They had a good knowledge about cancer screening. They believe it would be a professional way to find out about the type of cancer and the best cure out for the disease as early as possible. Most of Participants knew how to access GP and specialist for further investigation.

One participant had experience of bowel cancer and initially had difficulty with their GP. Quote "I had difficulty in the beginning with my GP until got a referral to specialist. I was diagnosed by my Doctor in Iran initially. When I returned to the UK, I showed my medical certificates and diagnosing documents to my GP, then finally I was referred to Digestive Diseases Centre at Royal Sussex County Hospital in Brighton for further investigation. I experienced language barriers as well. I really appreciate my Interpreter from Sussex Interpreting Services, who assisted me during my appointments."

Another participant had a bad experience of her Mum's cancer: Quote "I have a really bad experience about my mom's cancer she had liver cancer and it was a terrible disease ever and just before she sadly passed away, she lost a lot of weight the most depressed thing she had to go through was chemotherapy which made her lose all her hair and it made her down and she cried."

Part two - systemic barriers

In responding of whether they had ever attended a cancer screening, 2 out of 3 participants stated they had cancer screenings with one said "Yes, I never had any difficulty to access a cervical smear or mammography so far. In the beginning of the year 2019 I felt a lot of pain in my right breast for some days and called my GP and within 2 weeks the mammography screening was done with a good result."

The other participant said "Yes, it was for the bowel cancer. Initially I had difficult to persuade my GP to refer me the hospital."

In terms of barriers and difficulties to access NHS and medical teams 2 out of 3 who took part in the research described language barriers as the main issue. Quote: "Language is a hard barrier to cross especially when everyone around you does not speak your language." And "Language barriers and the most important a reliable Interpreter and female clinicians and doctors, who are keeping confidentiality in our small community in Brighton and Hove. Culture, family, honour, decency and faith and another barrier."

All 3 participants believed that COVID-19 had significant impact on accessing cancer screening.

Quote-1: "Yes, because all public transport has been shortened due to the pandemic and it's hard for people who have small children as they don't stop moving and it's been hard to move around especially for people who don't have a car that can easily be driven to access screenings."

Quote-2: "I think many breast, cervical and bowel cancer screening programmes were disrupted due to the covid pandemic as NHS was overwhelmed by covid patients. Many appointments were either cancelled or postponed."

Quote-3: "Yes, my appointments have been cancelled or postponed during pasted two years. In addition, there was serious concerns that hospital was unsafe, and I could contract COVID there. However, after receiving COVID jab, eventually the situation went a little bit to normal."

Part three - lifestyle barriers

In regarding their lifestyle barriers, for instance working/childcare commitments etc, how would affect their ability to access cancer screenings or GP appointments, all three responded that it would not affect them, however they believed that the time of appointments could have impact on them.

Furthermore, they all believed that access to transport would affect their ability to access cancer screenings or GP appointments. For example, getting to their appointment by using family vehicle or public transport was not affordable and that could have impact on the community in general as well.

Quote-1: "Transport is very expensive in Brighton due to the high economy and people living under pressure with a low income. They need cancer screening; however, they will be stuck and won't get the proper support they need. It is very hard for most people to get around even if they are not in need of going to a cancer screening."

Quote-2: "The big problem in Brighton is finding a parking lot. The Public transport is another issue. Buses are not running properly. Sometimes you need wait for a bus for a long time then two or three buses come at the same time. Sometimes you see there is chaos and traffic jam in buss road, particular in Churchill Square in Brighton. I believe it can affect families with small children at school and nursery."

Quote-3: "I believe the travel cost in Brighton-Hove and around areas is not affordable for people on benefit and low income. And families with small children at school and nursery have problem with arranging time for their appointment."

In responding to whether they had any solution for the issues, they suggested covering travel costs and childcare at clinics and hospital and improving bus system in the town. The alternative would be moving hospitals and GPs out of urban areas.

Part four - cultural barriers

All participants stated that the ethnicity of the GP or Nurse undertaking the screening wouldn't matter to them, however 2 out of 3 preferred of having a female practitioner.

One of Participant said: "I prefer a reliable female GP or Nurse, who can offer me a confidential service and treatment. However, ethnicity is not important."

Whilst the other stated: "To me it does not matter what gender helps me the only important thing is that they give me the treatment I need to get better."

With regarding how it would be important to be getting the screening done by someone who can speak their first language, they stated it would be great, comfortable, and could prevent any serious mistake. They believed accessing clinician, who would speak their language could have a positive impact on their community, however one of them said: "It is great; however, the person should be reliable and keeping confidentiality."

2 out of 3 participants said they wouldn't talk about cancer in their community. They believed it would be hard and uncomfortable.

Quote-1: "I am not comfortable to talk about my condition to anyone. It is my personality. Nothing would encourage me to tell them, it is a sort of natural reaction."

Quote-2: "I am not comfortable and don't like people have false feelings about my condition."

However, all participants stated they would share their experiences and symptoms with own family and friends straight away. They could comfort them and give mental support and sympathy.

Quote-1: "Yes, just to my closed one. I feel responsible to inform them about what is happening in the future. It is not fair to keep them in dark. I tell them from the beginning."

Quote-2: "Yes, I told my husband not friends. My husband always has been concerned about my health and given me a good support. I felt I needed share it with my husband. It was fair he knew it and ready for any circumstances."

Part five - improvements

The Participants would feel more comfortable to talk about cancer symptoms/screenings as they wanted to help with improving treatment or finding a new treatment.

Quote: "Access to reliable treatment, rehabilitating and mental health teams, I believe it could have a significant impact on your mental health."

In regrading what could be done to improve the access to cancer screenings or to overcome the barriers that were covered earlier, they suggested improving communication between GP, clinician, and patients, having a constancy language support, updating and giving information by sending leaflet to the community, receiving a regular reminder about cancer screening in their language, and supporting to access a cheaper public transport in Brighton and Hove would be vital.

They all agreed that reliable information about treatments, accessing to talking therapy services, meeting, and hearing other people's stories, who had condition and how cancer

screening changed their lives, would give their community motivation and encouragement to take cancer screening seriously.

Results and Conclusion

This cancer screening research was done with a small, targeted group in the community, therefore there was not any space for generalising the results. However, as a result of the research, it is crystal clear that the majority in the community had some serious problems with accessing the GP, cancer screening and National Health Services (NHS) including:

1. Lack of information and knowledge about cancer screening and NHS system
2. Language barriers
3. Struggling with making an appointment with GP and sometimes convincing their GP to make a referral for further investigation and getting diagnose as early as possible
4. Access to reliable treatment being a challenging to them
5. Rehabilitating services were not established properly
6. Emotional support, mental health teams were not available
7. Cultural issues for instance most women were not happy to be examined or interviewed by male medical professional
8. Travel issues expensive, not affordable and lack of parking space in Brighton-Hove areas, when they want to access GP and hospital.

Remark

The research was an incredible experience for me. I got a great feeling and sympathy when I was listening to my Participants particular, when they shared their own experiences with me and what they went through in their lives. It was amazing when a Participant shared her own experience with me about her own cancer and the other expressed her feeling how she lost her own mother in battle of cancer. I needed to be patient to let them express their feelings fully even when they had emotional time and cried.

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Appendix

Interview questionnaire

Part one - background

Q1 - Tell me about your community and what do you like about living in your community.

Q2 – As you know that we are carrying out this research about cancer screenings, can you tell me what you know about cancer screenings and what they are?

Q3 - Are you aware of the symptoms of cervical/breast/bowel cancer? Can you name the symptoms? Where would you go to find this information?

Q3 - if you know anyone that has experienced cancer, what was their experience like? Did they experience any barriers?

(follow up questions)

Part two - systemic barriers

Q1 - Have you ever attended a cancer screening?

Prompt: for example, a cervical smear or a mammography screening?

Yes – what was your experience like? Did you struggle to access it? How did you overcome any struggles that you were faced with?

Q2 - Do you think there are any barriers to accessing cancer screening? If so, can you give us any examples?

Important: whichever barriers people mention we should explore them - do not need to just focus on language for example if they suggest something else.

If it works – ask what change is needed to improve these barriers.

Q3 – Do you think COVID has had an impact on accessing screenings? How?

Part three - lifestyle barriers

Q1 - Are you registered with a GP surgery? If not, why not?

Q2 - How does the time of appointments affect your ability to access cancer screenings or GP appointments, for example after work/childcare commitments etc.? If not you, do you think the time of appointments can have any impact on your community?

Q3 - How does access to transport affect your ability to access cancer screenings or GP appointments, for example are family members able to take you or are you able to get public transport and is it affordable for you/is there a bus stop nearby to where you live? If not you, do you think it can have any impact on your community?

How do you think this can be resolved?

Part four - cultural barriers

Q1 -How does the gender or ethnicity of the GP or nurse undertaking the screening matter to you? How important is it to be getting the screening done by someone who can speak your first language? OR how important do you think these things are for your community?

If another barrier is mentioned then explore it.

Q2 - How comfortable are you talking about cancer in your community? Why/why not?

Q3 - If you have had cancer, did you tell your friends/family? Why, why not? How far through was it when you told them?

What encouraged you to tell your friends and family?

OR Would you tell your friends or family if you experience any symptoms?

If there any particular reasons why not? If you do not feel comfortable sharing that is ok.

Part five - improvements/conclusion

Q1 - What would make you feel more comfortable to talk about cancer symptoms/screenings?

Q2 - Is there anything that can be done to improve the access to cancer screenings or to overcome the barriers that we spoke about earlier? Do you have any further improvements that are?

Q3 - Is there anything that would help you or friends/family/your community to go for cancer screenings?

Prompt: for example, hearing stories of people who have recovered, being reassured you can choose the practitioner etc.

Follow up – would the gender or the ethnicity in a video matter?

Q4 - Thank you so much for your time today. The information you've shared is really valuable in informing changes in health and care systems.