MUSLIM WOMEN'S COUNCIL

Muslim Women's Understanding of Cancer

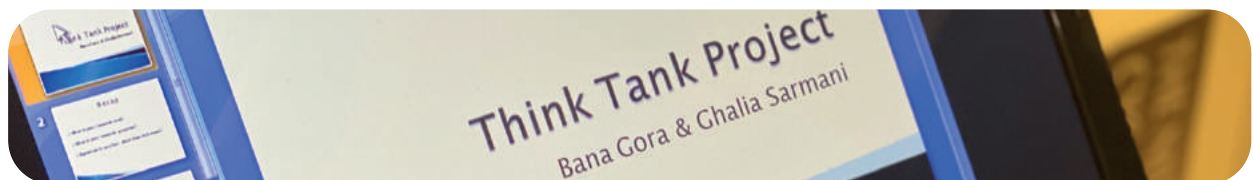
September 2021 | MWC Think + Do Tank Report

Background

The way we do research to inform policy isn't working. Today, most community based/'led' research is done through collaborations between large science or specialist research institutes partnering with local organisations beyond their institutions. Whilst this is an attempt to enrich the quality of research and to bring wider social benefits, it still lacks the true representation of the communities they are trying to help. Where such partnerships are formed the experiences are not always productive or conducive to drawing on the knowledge and expertise of all participants, as they remain the subject, not the co-authors of the research.

There is a need for a process that places these individuals and communities as the authors of research that considers the issues they face; and develops practical responses and recommendations from the ground up. There is a need for a radical shift and movement in how authentic data and insights are collected from women of Black and Minority Ethnic backgrounds.

In response MWC have developed an approach that focuses on the delivery of authentic and appropriate research to create better policy and practice, driving practical solutions that address women's health and wellbeing.



Think +Do Tank

With the support of Wellcome Trust, Smallwood Trust & Friends Provident Foundation, we hope to reverse the current trend of Muslim males and non-Muslims researching and advocating on behalf of Muslim women, especially regarding issues of health, wellbeing and bioscience.

Our approach will straddle the 'Think+Do Tank' between both policy and beneficiaries (Muslim women) and will offer authentic insight and appropriate solutions, as it will be led by the beneficiaries. We focus on the relevance, credibility, legitimacy and utility of the research we do, ensuring that we position our research for use.

We focus on Muslim women from Bradford and surrounding areas. Within this group there is a climate of misogyny and patriarchy fuelled by public stereotyping and male-dominated interpretations of women's roles and positions. In short, society is denying these women their ability to think and act independently or contribute to the creation of health, wellbeing and bio-science policies and practices that affect them and their community.

For example, Muslim women have not been engaged as contributors to research and policy reflective of them. It seems that most research is a male bastion, which undermines their effectiveness and puts them at a disadvantage and impacts on how they research and present the needs of women. This project will be women led and women governed, therefore putting these women at the heart of the research.

What This Study Covers

Breast and cervical cancers are the most common cause of cancer death among women in the world. These cancers are detectable early, however only a few women participate in cancer screening. Family, culture and religion can influence why women take part in screening.

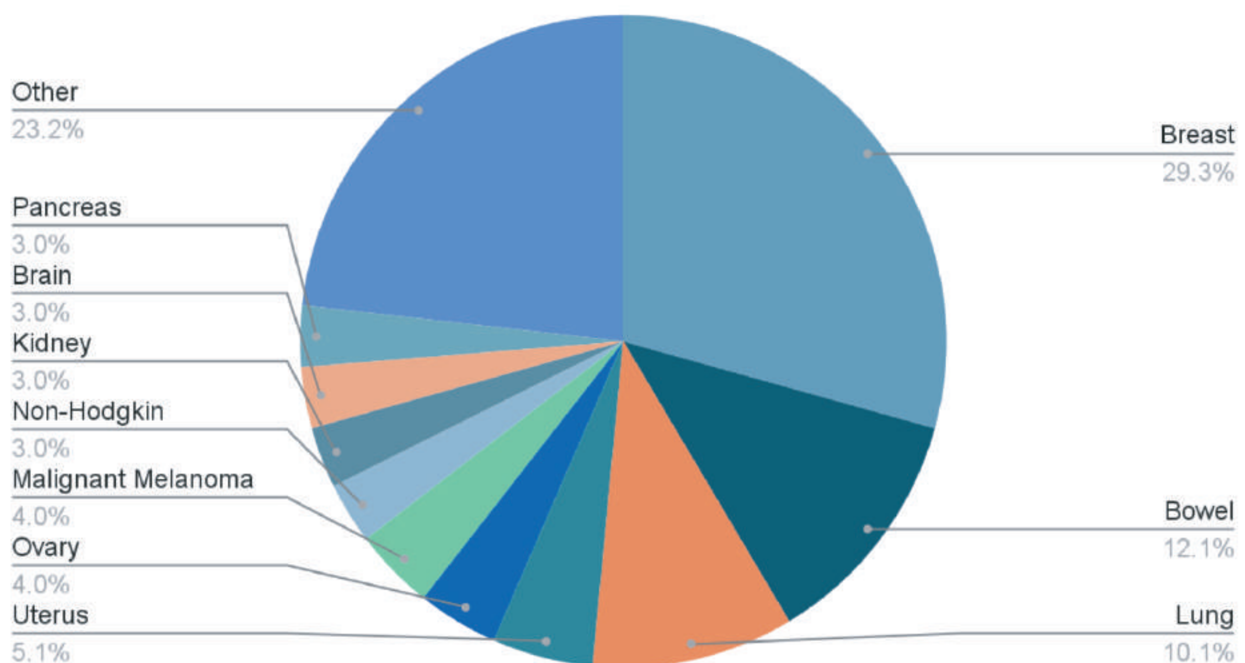
This study aims to evaluate and understand what Muslim women's thoughts on cancer are. British Asian Muslim women face some unique challenges when it comes to cancer. This report will try to elaborate on these challenges.

We will also try to understand why they have these ideas about cancer, whether these ideas are relevant or if they are misconceptions due to lack of knowledge or tradition. We will then try to make recommendations on how to improve on this.

There are more than 200 types of cancer, and each comes with its own risks, symptoms and forms of treatment. The most common cancers in women are breast, lung, bowel and cervical cancer.

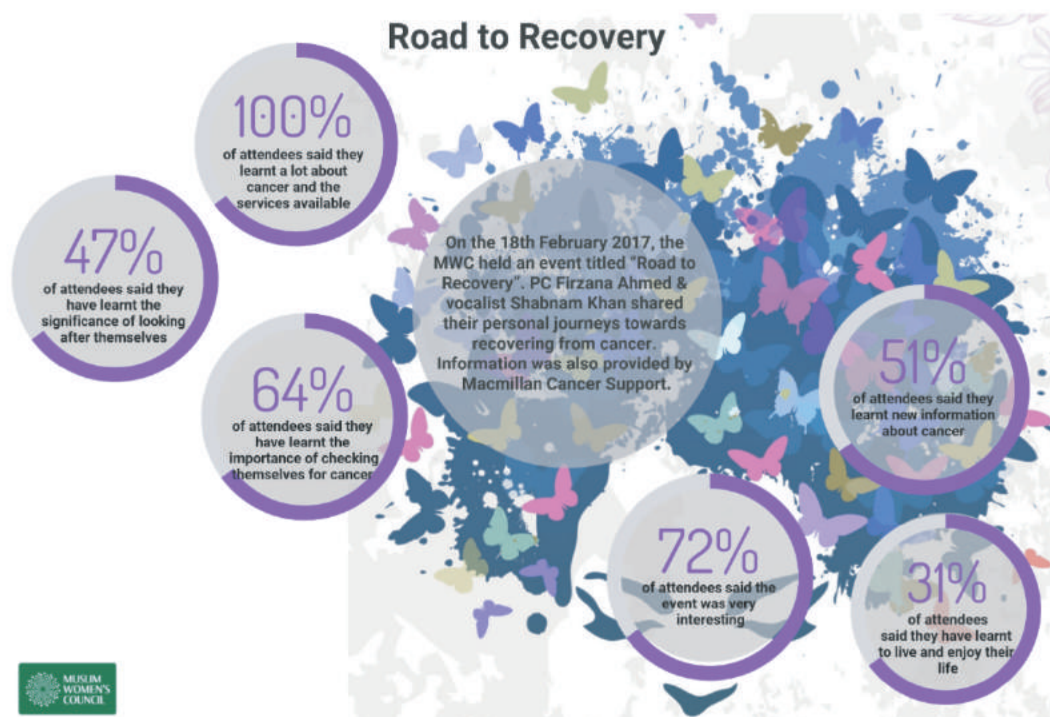
According to Cancer Research UK, cancer has increased by more than a third over the last 20 years. It is estimated that 1 in 7 women in the UK born after 1960 will be diagnosed with some form of cancer and by 2035, 243,690 new cases will be diagnosed each year in women. [1]

Female Cases by 2035



Key Findings

Since 2017 we have been engaging with local women to gain an insight into their thoughts towards cancer. We have spoken to 35 women, including holding a focus group discussion at our event, 'Road To Recovery', in partnership with Macmillan Cancer Support, which had over 100 women in attendance. All attendees found the topic and discussion very useful. The Muslim women who attended this event left feeling inspired and much more informed about cancer. 100% of attendees felt that they had learnt about cancer and the services available whilst 51% felt that they had learnt something new about cancer. These statistics clearly show that there is a lack of awareness and knowledge about cancer in the Muslim female community in the UK.[2]



Unfortunately, cancer awareness is low in the Muslim community, as is knowledge about national cancer screening programmes. As a result, bowel, breast and cervical cancer screening uptakes are much lower.

In addition, this means that cancer is detected and diagnosed at a much later stage in Muslim women and as a result, they have a much higher mortality rate than their non-Muslim counterparts.

Also, husbands in Muslim families have a significant role in the family's health including their wife's reproductive health. However, information about Muslim husbands' roles in their wife's health especially cancer is limited. This behaviour could be a hindrance to Muslim women's participation in prevention and the early detection of cancer.

Some of the beliefs and attitudes that Muslim women hold about cancer are:

- ‘Cancer is a taboo and has a stigma attached to it’. - Muslim women do not like to talk about cancer in public and do not want people to know that they have cancer. This is due to fear of burdening others, of judgment, of losing work and many others. Women with gynaecological cancers experience even more problems. Muslim women who consider sexuality to be a taboo topic and feel shame about asking sexuality-related questions are not likely to seek the relevant information from health professionals. The notion of going to get yourself checked out by strangers, sometimes men, and even being embarrassed in the presence of women, puts the women off.

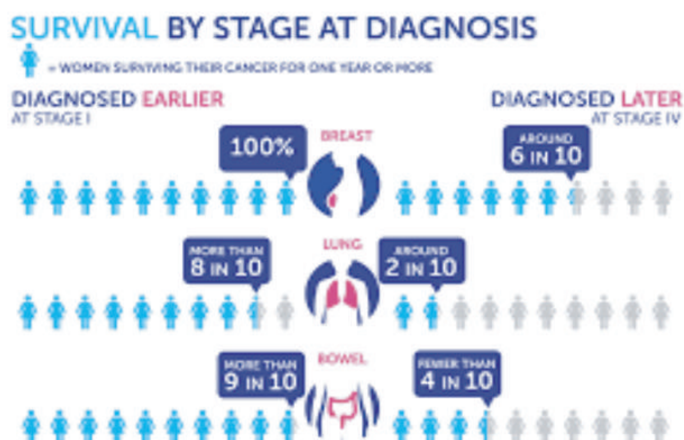
- ‘Most information is in English, which I do not understand.’ ‘We hear about cancer, but we do not have any specific knowledge about it.’ - They all expressed a clear need to have language specific information on risks, symptoms, prevention and treatment. As most information is in English, it prevents women whose first language is not English to completely understand the information they have been provided with.

- ‘We do not know how to examine ourselves and if we find something, we are Muslims. We believe illnesses are from Allah. We should make Dua (prayer) to Allah.’ – A step on from this is that not only is prayer seen as a cure, but also alternative untested medicines and interventions are used, which have led to many fatalities.

- ‘GP’s are not empathetic to your needs’, ‘We are only told about diabetes, not cancer.’ - When speaking to their doctors, the women feel there is almost an air of arrogance and superiority coming from them. It restricts the amount they tell them but also makes them feel like their problems are insignificant, otherwise the doctor would have taken more time out to explain the seriousness of what is happening.

- ‘Cancer affects white people’- However this is not the case as cancer can affect anyone.

- ‘If you have Cancer you will die’ - the risk of dying with cancer has decreased since the 1970’s and many cancer patients now go on to have a full recovery. However, this is only possible through early screening and fast treatment. The image below from the British Medical Association (BMA) clearly shows the benefits of early screening.[3]



- ’It’s from Allah, we should have patience and be grateful’ - Whilst trials and tribulations are viewed as a test from Allah, He has created cures for all illnesses and as Muslims we are required to seek treatment.

- ‘I know I can cure it with prayer and alternative medicines and practices’ -Alternative and complementary therapy can pose dangers - some concerns include delaying surgery, radiation, chemotherapy, or other traditional treatment by using an alternative therapy can allow the cancer to grow and spread to other parts of the body. Some complementary and alternative therapies have been reported to cause serious problems and even deaths. Certain vitamins and minerals can increase the risk of cancer or other illnesses, especially if too much is taken. Other approaches are unlikely to cause harm and won’t interfere with cancer treatment. Here are some examples:

    Acupuncture may help with mild pain and some types of nausea.
    Art or music therapy may promote healing and enhance quality of life.
    Massage therapy can decrease stress, anxiety, depression and pain, and increase alertness, according to some studies.
    Prayer and spirituality help many people with the emotional side effects from cancer.
    We will cover alternative and complementary therapy in another report.

- ‘Multiple screening causes cancer’ - Healthcare professionals would advise of any risks with regards to multiple screenings.

As can be seen from the discussions, a lot of the women do not have a clear picture about cancer. What to do, where to go, who to talk to and who can help them.

Health professionals should provide information to women diagnosed with cancers about changes that they are likely to experience in their bodies and possible difficulties in sexuality.

According to the religion of Islam, Muslims are strongly encouraged to seek treatment and care. Still some Muslims use cultural and dietary supplements to help treat their cancer or relieve their symptoms. Black seed and special herbs are such examples. Many Muslims believe black seeds will cure many diseases.

Some of these special herbs may interfere with their cancer treatment. However, if they speak to the care providers, they could be advised to not take them while undergoing cancer treatments.

Also, many Muslims do not consume products that contain gelatine- derived from pork- for religious reasons, but some medications contain this substance. It is important for the health care experts to know this so that they can prescribe another treatment that does not have this ingredient, or at least discuss this with the patient. Muslims are excused from certain religious practices or obligations when there is no other alternative.

The physicians' lack of understanding of these practices among the Muslim women could lead to adverse health outcomes.

Due to these preconceptions, many Muslim women will choose not to have chemotherapy or the different treatments available even if it meant the prevention and relief of suffering.

Many Muslim women think that it is their role in life to be a homemaker and that means being at home for the husband and children even if you seriously need help, such as palliative care, which could be there for them to optimize quality of life for the patient as well as the families that are facing the problems. The thought of palliative sedation causes a lot of discomfort for women.

They also have many outdated notions that they cannot stay elsewhere unless their husband is with them, that can put the Muslim women at a great disadvantage as they may need to be hospitalised or cared for by others with more experience.

Key Recommendations

Based on the above findings, we suggest the following recommendations that would provide meaningful and effective changes that would improve the knowledge and understanding of cancer in Muslim women. This will hopefully allow them to identify problems faster and therefore, increase the probability of curing the cancer before it is too late.

- Government funded initiatives are needed to help tackle the stigma of talking about sexuality in the Muslim community but also to be used as a means of getting more information out to Muslim women to increase their knowledge about cancers.

- Female-only clinics so women are not feeling as self-conscious when talking to their doctors, so they feel more comfortable about speaking about their problems.

- Language and culturally specific information on risks, symptoms, prevention and treatment. This will allow women to gain a better understanding of cancers as they will be able to read the information for themselves, rather than it being explained to them.

- An initiative to improve knowledge and create a larger emphasis on cancers and to give it as much importance as diabetes. Muslim women need to understand that whilst cancer treatment is painful, it is potentially life-saving and their chance of survival is greatly increased when using the accepted medical treatments.

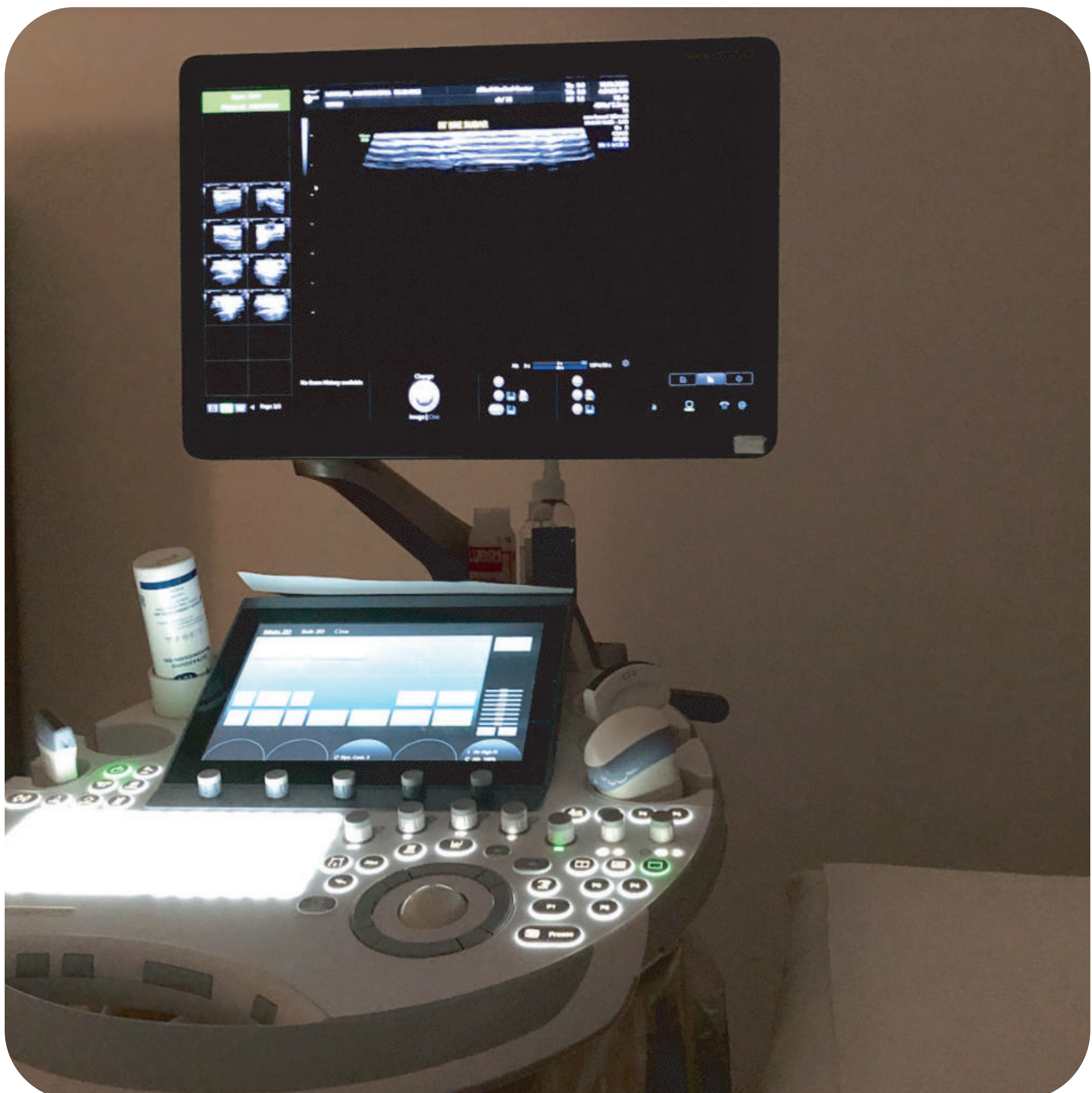
- Make screening mandatory for women over the age of 50 rather than something that is voluntary. Perhaps start screening even earlier than that, such as at 45 and above. This would also be a perfect opportunity to provide relevant information to women to improve their knowledge of cancer and stress the importance of screening and early diagnosis.

- There is a need to improve Muslim men's awareness in women's cancer, so they can support and help their spouses, mothers and sisters tackle the problem head on. The men's increased knowledge and awareness will help reduce the burden and stress women feel, as they will feel supported in their decision to get treatments and their responsibilities at home will be managed by others.

- Physicians need to have a better understanding of the Muslim women they treat and the alternative remedies they may be using. Perhaps it should be compulsory for doctors to ask what alternative remedies they are trying so they can analyse whether these remedies are okay to be used in conjunction with traditional therapy or are detrimental to use.

- Muslims need to understand that whilst their ailments may be seen as a test from Allah, He has provided cures for all ailments and treatment should be sought after. These tests are a test of faith, for you to continue to turn to Allah for help, but it does not mean that you should not receive medical treatment. When the Prophet Muhammad (pbuh) was ill, he sought treatment from trained healers as well as making a prayer to Allah.

- Involve Islamic faith leaders (Mufti's and Sheikhs) in the process so they can help promote the idea of early screening and the use of treatments such as chemotherapy and radiotherapy. Faith leaders are a very important aspect of a Muslim's life as the opinions they share have a huge influence on a Muslim's decision. It has been demonstrated that collaborations between healthcare providers and faith institutions to address public health concerns can lead to better health outcomes, as demonstrated in countries with pandemic HIV and AIDS. [4,5]



Case Study 1

Farida was diagnosed with Stage 3 Breast Cancer in 2017 at the age of 47. The cancer was oestrogen receptive. She is a homemaker and a mother of 4 with her youngest child being 6 at the time. She was born in Bradford, England.

She was lucky to be diagnosed, as women generally do not get called for a routine mammogram until after the age of 50. She was informed that if they had diagnosed it later, her cancer would have been terminal. She had a male doctor and female nurses.

Farida underwent surgery to remove the tumour and her lymph nodes in her right arm. She also attended 8 sessions of chemotherapy and a daily session of radiotherapy for 30 days.

Farida believes overall that she was well informed and looked after well by the medical staff who oversaw her treatment. However, she did feel that sometimes the Doctor was quite emotionless/arrogant and would not answer her questions clearly enough. She would resort to speaking with the nurses to gain a better understanding.

In addition, she felt that the doctor disregarded and belittled any natural and herbal remedies which were out there which could have been used in conjunction with the normal medical treatment.

Farida went through a wide range of emotions. Namely: fear, anger, shock, sadness and guilt. This was mainly due to the fact that she was quite young and had children who would have been left without their mother.

She is happy to be alive for her family and thankful to the medical staff who were very helpful through this trying period. She is also grateful to Macmillan Cancer Support for the help they provided. She believes early screening is essential in saving more lives, more information should be readily available to make women aware of the risks of cancer and the risks of not catching it early enough. She also believes that a female doctor would have made her treatment easier as they would have empathised with her more.

Finally, she feels that whilst her experience was "pretty good," other Muslim women would have found it much more difficult if English was not their first language and if they were reluctant to see a male doctor. She also feels that Macmillan Cancer Support is essential in helping people with cancer and that patients should be informed about them. She only found out about them as her daughter was a volunteer with them.

Farida has been in remission for the last 2 years and will continue to be monitored regularly for another 3 years by having a yearly mammogram and hospital check-ups. She is required to take medication for 10 years in order to block the oestrogen levels in her body.

Case Study 2

Jabine was diagnosed with stage 2 Ovarian Cancer in late 2017 after undergoing many tests including blood tests, MRI and PET scans. She was 45 years old at the time of diagnosis. She is a single mother of 2, with both her children still under the age of 16. She was born in Pakistan.

She was diagnosed after meeting with her doctor and complaining about stomach pain, trouble with eating and urinary symptoms. She had a male doctor and female nurses, however any internal examinations were carried out by a female doctor upon her request.

Jabine underwent surgery to remove her uterus, both fallopian tubes and both ovaries. She also attended 6 sessions of chemotherapy and 25 cycles of radiotherapy.

She felt she was looked after well by the medical staff who oversaw her treatment. However, as English is not her first language, she felt she did not understand a lot of the information that was given to her. She had to take a family member with her to appointments so they could translate and explain things for her. This was very hard for Jabine as she didn't want anyone to know about the cancer as she was afraid that she would be judged and looked down upon due to the fact that it was ovarian cancer and the shame she felt speaking about it.

She initially refused the treatment as she thought that this was a test from God and that prayer and patience would cure her. However, as her symptoms worsened, she confided in her family member who convinced her to take the treatment.

Jabine went through a wide range of emotions such as shame, fear, shock, sadness and guilt. This was because she was afraid of leaving her young children alone and the fact that she had no one to confide in.

She is very thankful for the support and help she had received from her doctors and nurses, but also stressed the fact that without the support from her family member, she would probably not be alive today. She feels that all women should have some sort of support structure in these situations and that medical staff should actively try to find out what each individual requires, as each case would present a different situation. Whilst she was happy with the treatment she received, she felt that if a female doctor was her primary physician, it would have made her a lot more relaxed.

Whilst Jabine is very grateful, she feels like her situation would be very common for Muslim women whose first language is not English and who are not comfortable around men. She hopes this can be looked at so other women do not feel the same way she did. She also hopes that all information that is given in the future is language specific to each patient, so they can make their own informed decisions.

Jabine has been in remission for the last 3 years and will continue to be monitored regularly for another 3 years by having yearly hospital check-ups. She is required to take medication for the foreseeable future.

References

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4. Austin KL, Power E, Solarin I, Atkin WS, Wardle J, Robb KA. Perceived barriers to flexible sigmoidoscopy screening for colorectal cancer among UK ethnic minority groups: a qualitative study. J Med Screen. 2009;16:174-179.

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