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1. INTRODUCTION

1.1. Black Women and Breast Cancer

1.1.1. Breast Cancer Incidence and Mortality

Breast cancer is the most common cancer observed in women with an estimated one million new cases diagnosed throughout the world each year (Cancer Research UK, 2011a). In the UK the incidence of breast cancer has increased by 50% over the past two decades (Cancer Research UK, 2011b). The latest figures show that 48,034 new cases were diagnosed in 2008 with women residing in the UK having a 1 in 8 life time risk of developing breast cancer. (Cancer Research UK, 2011b).

Whilst the incidence and prevalence of breast cancer continues to increase survival rates have improved (Cancer Research UK, 2011a). However, there is increasing evidence that this improvement in survival has not benefited all communities. This is the case for black British women who have a higher mortality rate than white women despite their lower incidence (Bowen et al., 2008; Thomson, Forman, and Shelton J, 2009). One study which compared black and white women in Hackney demonstrated that black women were more than twice as likely to die from breast cancer than white women (Bowen et al., 2008). Another study analysing the South East England population found that black West African women had a worse overall survival rate than other ethnic groups (Wild et al., 2006). Yet another analysis identified that for the age group 15-64 the relative survival rate was significantly lower for black British women (Thomson, Forman and Shelton, 2009). Care must be taken when drawing conclusions from these studies as there were some limitations. One limitation was the small sample sizes which make generalisation and statistical accuracy a challenge. Large sample sizes are hard to achieve when looking at ethnic minority populations as cases that fit the inclusion criteria occur less frequently. In the Thomson, Forman and Shelton (2009) study data from 58,463 white patients were available to researchers whilst data from only 419 black patients were available. Another limitation of this study which was highlighted by the researchers was the lack of ethnicity data for 25%

of the cancer patients that were analysed which meant that a crude method of assigning these patients to an ethnic group had to be utilised. This introduced a high level of uncertainty about the findings of the study. The Bowen et al (2008) study was smaller still with data from only 102 black women being available and this study was based in Hackney making it hard to generalise to the wider population. The final study cited which was conducted by Wild et al. (2006) looked in total at 33,291 breast cancer deaths in the UK to determine standard mortality rates based on country of birth. Of the 33,291 deaths only 83 were West African, which is a relatively small number to make general conclusions about the mortality of black African women. In addition, this study was based on country of birth so it didn't fully capture ethnicity as there could have been black women who were born in the UK who could have been included in the England group. Another limitation of these studies was the lack of analysis of the different black populations. Potentially there may be a difference in breast cancer survival between women of black Caribbean, black African or black “other” backgrounds making it hard to conclude that black women in general have a higher mortality rate as the higher mortality could be due to just one of the three black sub groups.

The studies to date have been useful in identifying the increased mortality in the black community but the above mentioned limitations have made accurate interpretation of the existing data a challenge.

1.1.2. Stage at Diagnosis

The stage of a cancer gives an indication of the extent to which the cancer has grown and spread. Breast cancers diagnosed at a late stage have a worse prognosis than those diagnosed at an early stage. This is because late stage tumours are larger in size, tend to have lymph node involvement or have metastasised making them harder to treat. It has been shown that black women are more likely to be diagnosed with breast cancer at a later stage when prognosis is poor. For example a study conducted by Lannin et al. (1998) comparing white American women with black American women showed that 12% of white women were diagnosed with late stage disease while 29% of black women were diagnosed with late stage disease. In addition the odds ratio for black women for late stage diagnosis of breast cancer was 3.0 (1.9-4.7) which means that black women in this study were three times as likely to be diagnosed with late stage disease than white women. Another US study showed similar results in that 24% of black women in their study were diagnosed with late stage disease compared to 14% of white women (Eley et al., 1994). In the UK one study showed that 7% of white women were diagnosed with metastatic disease whilst 11% of black Caribbean and 15% of black African women were diagnosed with metastatic disease (Jack, Davies and Moller, 2009). The limitation of this study was that approximately 30% of women did not have the stage of their disease recorded therefore a true picture may not have been obtained. In addition, the number of black women in the study was relatively low, 652 black Caribbean women and 344 black African women compared to 31,109 white women (Jack, Davies and Moller, 2009). In another UK study it was found that for black women the risk of being diagnosed with late stage disease was 28% higher than white women (Cuthbertson, Goyder and Poole, 2009). These studies suggest that the increased mortality observed in black women could be a result of a higher percentage of black women being diagnosed with late stage disease.

1.1.3. The Impact of Genetics on Cancer Mortality

Another factor that is increasing in importance in explaining the increased mortality in black women is the genetics of breast cancer. Evidence has now shown that a significant number of black women throughout the world are developing a different type of breast cancer to white women (Bowen et al., 2008; Stead et al., 2009; Lund et al, 2009; Kwan et al, 2009; Huo et al., 2009). This form of cancer is called triple negative breast cancer. It has been found that black women in the UK have a higher frequency of triple negative breast cancers than white women and genetically triple negative breast cancer is thought to be linked to African ancestry (Bowen et al., 2009). Furthermore triple negative breast cancer has been found to be more aggressive and to develop at a much younger age than the hormone sensitive cancers that tend to affect white women (Bowen et al., 2009; Kwan et al., 2009; Huo et al., 2009). This would explain the late stage diagnosis seen in black women.

1.1.4. Addressing the Increased Mortality in Black Women

To reduce the mortality of black women affected by breast cancer more work is needed to determine both the sociological and biological factors that have contributed to late stage presentation. This dissertation endeavours to identify factors that may be contributing to the delayed diagnosis of black women by utilising sociological theory. Sociology applied to health care can provide a mechanism to understand the individual and societal behaviours that affect health outcomes. Two sociological concepts will be explored in this dissertation, black women's lay beliefs about breast cancer and their anticipated help seeking behaviour. It is important to study these two concepts together because the beliefs that people hold regarding health and illness determine if and when they seek help from a health professional. The analysis of these concepts will be conducted utilizing the Health Belief Model (HBM) as the analytical framework.

1.2. Aims and Objectives of this Study

The aim of this dissertation is to explore the lay beliefs of black women with regards to breast cancer and to understand their help seeking behaviour to determine if there are any factors that may be contributing to delayed diagnosis. In order to achieve this aim my dissertation has the following objectives:

1. To gain an understanding of black women's lay beliefs of breast cancer including such areas as causation and the nature of breast cancer;

2. To identify any barriers to help seeking;

3. To evaluate black women's level of awareness of the signs and symptoms of breast cancer; and

4. To understand the anticipated help seeking behaviour of black women.

2. LITERATURE REVIEW

2.1. Literature Review Strategy

A literature review was conducted to help shape the direction of the study, to understand the current thinking on this topic and to identify any gaps in the literature which this dissertation could explore. The literature search was conducted by firstly identifying papers concerning black women and their lay beliefs about breast cancer, then searching for studies concerning the help seeking behaviour of black women with respect to breast cancer and finally exploring the literature for the background and definitions of lay beliefs and help seeking behaviour. Literature searches were conducted using PubMed, MedLine, Google Scholar and Google. For the PubMed and MedLine searches, searches of all publication types were conducted and the year of publication was left open to capture all studies in this area. In addition, the searches were limited to articles published in English. The actual key word searches are listed in appendix 4.

The sections that follow will firstly describe the literature concerning black women's lay beliefs about breast cancer; this will then be followed by their help seeking behaviour. Finally, this section will end with a review of the definitions, explanations and background to lay beliefs and help seeking behaviour.

2.2. Black Women's Lay Beliefs About Breast Cancer

In the UK the number of studies conducted to understand the lay beliefs of breast cancer across ethnic groups is minimal. In the US more extensive studies have been conducted that are useful in predicting what may be the beliefs amongst black British women. It is anticipated that though their cultural experiences are not identical their general experience as an ethnic minority from the same "race" may result in some similar experiences and beliefs. The US literature is reviewed in the following sections but whilst exploring the situation in the US it is important to remember that the health care systems in the UK and US differ. The UK has a national health system with universal access to health care while the US has a private health system where the public has to purchase health insurance. This difference may influence the help seeking behaviour and beliefs of black women in each country. For instance the fact that the US systems requires the purchase of health insurance may mean income and affordability may play a significant role in the ability of women so seek help whilst this may not be the case in the UK.

US studies have shown that black women construct beliefs about breast cancer that fall into three broad categories – causation, the nature of breast cancer and the effectiveness of treatments. These will be discussed in the following sections.

2.2.1. Lay Beliefs: Breast Cancer Causation

A study conducted by Greg and Curry (1994) examined the lay beliefs of low income black American women. They found that black women attributed a number of causes to breast cancer. These causes included chemicals in food; lifestyle factors such as smoking and drinking; and physical injury to the breast. These beliefs were similar to white women's beliefs but what differed was the underlying religious context. In this study it was shown that black women believed that co-existing with these factors was the will of God and that ultimately it is God that determines if an individual will develop breast cancer and thus individuals are unable to alter their destiny in any way.

In a case-control study conducted by Lannin et al. (1998) it was found that a significant proportion of black Americans had the following beliefs:

- Air causes breast cancer to grow;
- High blood pressure causes breast cancer;
- Thin blood causes breast cancer; and
- Spiritual elements cause breast cancer.

Another study compared two groups of low income black American women. One group felt that breast cancer was a punishment from God and the second group felt that lifestyle factors such as smoking, consuming alcohol and a lack of exercise contributed to breast cancer development (Bailey, Erwin and Belin, 2000). In addition, this second group also felt that there was a spiritual aspect to developing breast cancer stating it was a test of faith from God (Bailey, Erwin and Belin, 2000).

Salant et al. (2006) examined the lay beliefs of high risk women. Their level of risk was determined by using a model that calculated risk based on exposure to known risk factors. 75% of these women were black American and the majority felt that genetics was the major cause of breast cancer. Other causes were thought to be:

- Stress, anger or worry;
- Lifestyle habits such as smoking and diet;
- Spiritual - as part of God's plan; and
- Some did not know.

Finally, the lay beliefs of black Americans were explored with black health care professionals They explained that views such as breast cancer was caused by physical trauma, punishment from God, emotional stress, anger and chronic negativity were common amongst black Americans (Ashing-Giwa and Ganz, 1997). This study also included black women who had a personal experience with breast cancer. They attributed the cause of their disease to genetic, environmental and stress factors (Ashing-Giwa and Ganz, 1997). They had a strong conviction that stress was the most significant factor. This highlights the difference between the views of the general black public and those with first-hand experience of breast cancer.

2.2.2. Lay Beliefs: How Black American Women View Breast Cancer

Black American women have a very negative impression of breast cancer. From the US literature there is a feeling that breast cancer is incurable, always diagnosed at a late stage, a devourer of the body, a creator of poverty/worsens poverty and causes severe mental distress (Gregg and Curry, 1994; Peek, Sayad and Markwardt, 1997;

Bailey, Erwin and Belin, 2000; Frisby, 2002). Many associate breast cancer with death, loss of hair and the loss of breasts (Ashing-Giwa and Ganz, 1997; Peek, Sayad and Markwardt, 1997; Bailey, Erwin and Belin, 2000; Moore, 2001; Frisby, 2002). The negativity surrounding breast cancer has stigmatised this disease within the black community (Ashing-Giwa and Ganz, 1997; Bailey, Erwin and Belin, 2000; Dein, 2004). The stigma seems to have resulted due to a deep sense of fear but also due to a feeling that being labelled a breast cancer patient makes one weak physically and mentally, a characteristic that is frowned upon in the black community.

Finally, there is also the idea that breast cancer is a disease that only affects white women (Bailey, Erwin and Belin, 2000; Moore, 2001). This belief appears to be a direct result of media and health promotion campaigns that have predominately targeted white women (Moore, 2001). This has resulted in the underestimation of risk by some black women (Bailey, Erwin and Belin, 2000; Lannin et al., 2002; Salant et al., 2006; Moore, 2001; Gerend and Pai, 2008).

2.2.3. Lay Beliefs: Breast Cancer Treatment

The final area of exploration in the US literature is that of the beliefs regarding the effectiveness of breast cancer treatments. With respect to the main cancer treatments – chemotherapy, radiotherapy and surgery – one group of low income black American women did not feel that any of these were effective at treating breast cancer or restoring health (Greg and Curry, 1994). They mostly believed that the treatments caused comparable damage to the body as breast cancer itself. They were particularly negative about surgery stating that the exposure of the tumour to air stimulated its growth but there were a group of these participants (30%) who did feel that surgery was a viable option.

In a study that looked at both black and white American women from a range of socio-economic backgrounds a higher percentage of black women supported taking the standard treatments (chemotherapy, radiotherapy or surgery) for treating breast cancer (Lannin, 1998). A similar percentage of black and white women believed in surgery as a viable method for treating breast cancer. More black women believed in alternative therapies with 28% of black women supporting taking herbs remedies compared to 9% of white women and 25% of black women believing in chiropractic therapy for breast cancer treatment compared to 6% of white women. This difference in the support for alternative therapies was because the African American women in the study held the belief that standard treatments, especially surgery, exacerbate breast cancer.

In another study black American women were found to have less confidence in standard treatments with significantly more black women than white women stating that they would not follow their doctor’s advice to proceed with surgery, chemotherapy or radiotherapy (Lannin et al., 2002).

2.2.4. Summary of the Findings from US Studies on Lay Beliefs

The studies reviewed suggest that black women have a very negative, fatalistic view of breast cancer which has led to stigmatisation of this disease within the black community. There is also the feeling that breast cancer is a disease that only affects white women and that black women are not at risk of developing breast cancer. Black women attribute a number of causes to breast cancer most of which are similar to the causes white women attribute to breast cancer. The major difference is the religious aspect with more black women believing that their health is in God’s control and they have little influence over whether they develop or survive breast cancer. Because black women believe their risk to be low of developing breast cancer this may mean that they will see breast cancer as less of a health concern and this may result in delayed help seeking. The fatalistic view of breast cancer may lead to an attitude that nothing can be done except appealing to religious beliefs thereby further contributing to delayed help seeking. On the other hand the seriousness of the disease and the negativity associated with it may provide some motivation to seek help.

It is important to note that most of these studies looked at low income black American women and it could be that the negative views could be related to socio-economic status rather than race and culture. Lannin et al. (1998) suggests that late stage presentation of black women with breast cancer compared with white women is a result of the combination of cultural beliefs and attitudes with socio-economic factors. This means that any delayed help seeking would be worse in black women from low income communities as their low income compounds their negative cultural beliefs about breast cancer. In the UK this may not be true as there is universal access to health care and therefore it might be that low income black women in the UK are better able to access services than low income women in the US where health insurance is required.

2.3. Black Women’s Help Seeking Behaviour and Breast Cancer

2.3.1. Black British Women and Help Seeking Behaviour

There has only been one study that has analysed the help seeking behaviour of ethnic minorities in the UK with respect to cancer (Waller et al., 2009). This study evaluated cancer in general as opposed to any specific cancer and it focused on the awareness of cancer symptoms, the length of time taken to visit a GP following identification of a symptom and barriers to help seeking. These areas were explored in individuals of Indian, Pakistani, Bangladeshi, Caribbean, African and Chinese descent. Black Caribbeans demonstrated the best recall of cancer symptoms whilst black Africans had the worst recall of symptoms. In a recognition exercise the black Caribbean population recognised the most symptoms (an average of 5.45 symptoms) and the black African population recognised the least number of symptoms (an average of 4.29 symptoms). The differences seen between ethnic groups were significant for all symptoms except one. When the participants were probed regarding the length of time it would take them to visit the GP following identification of a symptom the African and Caribbean populations reported the least delay.

Finally, Waller et al. (2009) evaluated the barriers to help seeking. Barriers were divided into three categories, emotional, practical and health services. Black African women were shown to have the least barriers whilst black Caribbean women experienced a number of emotional barriers with the most significant being anxiety regarding what the doctor might find following a consultation. The other significant barrier identified for black Caribbean women was in the health services category with black Caribbean women expressing difficulty in making appointments.

This study indicates that in the UK there may be no major delay in help seeking in black women and any delay may be a result of the lack of symptom awareness in black African women. Further work is needed to obtain a definitive view as this study conducted by Waller et al. (2009) was the only one to date that has looked at the anticipated help seeking behaviour of ethnic minorities in the UK with respect to cancer. Furthermore it evaluated cancer in general and not breast cancer. A study focusing specifically on black British women and their help seeking behaviour with respect to breast cancer is needed and hence the reason for exploring this area in this dissertation.

Although the Waller et al. (2009) study is the only published study a survey conducted by the charity Breast Cancer Care provides some useful data (Breast Cancer Care, 2005). This survey explored the level of awareness that black and ethnic minority (BME) groups in the UK have of breast cancer. The BME groups included in this study were Indian, Pakistani, Bangladeshi, Black African, Black Caribbean, Chinese and Irish. In reporting the results all these ethnicities were grouped together and identified as BME. Therefore from this study it is hard to determine specifically the level of awareness of the black African and black Caribbean participants but the results may give some indication of their level of awareness. Two of the conclusions from this survey were:

- 56% of BME women were not aware of the signs and symptoms of breast cancer; and
- 32% of BME women stated that they did not know much about breast cancer.

This would suggest that the level of awareness of the signs and symptoms of breast cancer in black British women could be low and this could be a cause of delayed diagnosis.

2.3.2. Black American Women and Help Seeking Behaviour

In the US studies exploring the help seeking behaviour of black women with respect to breast cancer have been conducted. It would thus be useful to review these studies to gain some understanding of the issues that may impact the help seeking behaviour of black British women.

In a significant number of the US studies looking at race, help seeking behaviour and breast cancer one criticism by Lauver (1994) was that the populations being compared were from a mixed background therefore a number of confounding variables existed. This led Lauver (1994) to conclude that the difference in help seeking behaviour could not accurately be attributed to race because of differences in the samples and the setting of the studies. When the help seeking behaviour of black and white populations with a similar socio-economic status were compared race had no bearing on help seeking behaviour (Coates et al., 1992; Lauver, 1994,). Both black and white women in these studies exhibited the same behaviour with respect to when and why help was sought. This supports the UK study in the previous section conducted by Waller et al. (2009) which suggested there may be no significant delay in help seeking in black British women.

Coates et al. (1992) found that the time between first experiencing a perceived breast cancer symptom and seeking help was 14 days in white American and 16 days in black American women; this difference was not statistically or clinically significant. Reifenstein (2007) found that black women delayed on average 63 days after first noticing a symptom before consulting their doctor. Lauver and Ho (1993) found the average time of delay was 85 days for all women (black and white). In a study that focused on a low income population in Harlem which was 94% black, 44% of the population sought help within three months of experiencing symptoms, 27% between three and six months and 29% waited longer than six months after first experiencing symptoms (Freeman and Wasfie, 1989). There is quite a difference in length of delay in seeking help in the Coates et al (1992) study compared to the other studies. This difference could be due to one of the limitations cited by Coates et al. (1992) which was that data concerning the length of time between symptom recognition and first consulting the health service could not be collected from all participants particularly older women and those with late stage disease. It could be that if this was included the average delay would be more similar to the other studies. These studies suggest that women delay help seeking, at least in the US, for approximately two to three months.

Lauver (1994) found the same factors were important in black and white women seeking help. These factors were:

- Perceptions of the benefits of help seeking;
- A women’s normal pattern of help seeking;
- Feelings about help seeking; and
- Ability to seek help.

In addition to the above factors Lauver (1994) identified additional variables which affected help seeking behaviour. One such variable was indirect experience with breast cancer, for example women who had a friend with breast cancer tended not to delay help seeking. Another variable was optimism with women having a more positive outlook on life tending not to delay help seeking.

Reifenstein (2007) found that denial in black women was associated with an increased delay in help seeking whilst confrontive coping, social support and problem solving strategies had no relationship to delayed hep seeking. She suggests that in black women religious beliefs play a major role in help seeking although this was not explored.

These studies by Lauver (1994) and Reifenstein (2007) are very useful in that they provide some key areas that require exploration in this dissertation such as the impact of religion.

2.3.3. Summary of the Findings from the Literature on Help Seeking Behaviour

The literature suggests that there is no significant difference in the length of time it takes for black women to seek help after they recognise a possible symptom of breast cancer compared to white women. Therefore if there is any delay it may occur in the recognition of the symptoms of breast cancer. If there is a low level of awareness of the signs and symptoms of breast cancer in black women then this would lead to delayed help seeking. The triggers for help seeking are, in general, similar for both black and white women. The literature suggests that the only difference in triggers is that of feelings about breast cancer with black women displaying more anxiety about breast cancer which could cause a delay in help seeking. In addition, another difference that exists is in religious beliefs. It has been suggested that black women's religious beliefs possibly play a significant role in the pattern of their help seeking behaviour, this needs further exploration.

In summary, if there is a delay in help seeking in black women the literature suggests this could be a result of the following areas:

- A low level of awareness of the signs and symptoms of breast cancer;
- A high level of anxiety about breast cancer; and
- Strong religious beliefs.

Overall the implication of the literature is that there may be no significant delay in help seeking in black women especially with black women of Caribbean descent, but this does need to be clarified with a study that specifically focuses on black British women. If there isn't a major delay in help seeking behaviour then other factors must be contributing to the late stage diagnosis in black women. As mentioned previously one factor that is increasing in importance is the genetics of breast cancer in black women with a significant number of black women developing more aggressive forms of breast cancer than white women (Bowen, 2008; Stead et al., 2009; Lund et al., 2009; Kwan et a.l, 2009; Huo et al., 2009) .

2.4. Background to Lay Beliefs and Help Seeking Behaviour

In studying lay beliefs and help seeking behaviour it is important to have a clear understanding of what these concepts mean. The following sections summarise published work that describe both lay beliefs and help seeking behaviour and introduce the HBM as an analytical framework for this dissertation.

2.4.1. Background to Lay Beliefs

Lay beliefs have been defined by Blaxter (2004, p.46) as:

> *"...common-sense understandings and personal experience, imbued with professional rationalizations."*

A person's lay beliefs about an illness are primarily defined by their social environment and culture. It is through their cultural experience that they develop a perception about a disease and how to respond to it. A person's cultural experience is determined by such factors as their ethnicity, age, gender, socio-economic background, family background and educational attainment. In short, a person's lay beliefs about an illness are rooted in their culture and shaped through the summation of their life experiences with that disease whether directly or indirectly.

Black women in the UK are either of African or Caribbean descent and many have very strong links to Africa and the Caribbean such as close family members residing in these countries, practicing African and Caribbean customs and having some of the same beliefs as native Africans and West Indians. This means that the beliefs of black and white women in the UK will differ but also the beliefs of the black African and black Caribbean population. We can therefore hypothesise that there may be differences in lay beliefs about breast cancer and this may result in different attitudes towards the disease that may act as barriers or facilitators to help seeking.

To help our understanding of these beliefs and to see how they impact help seeking the HBM can be utilised. This model will be explained briefly in the following section to show its usefulness in providing an analytic framework for this dissertation.

2.4.2. The HBM and Lay Beliefs

To enable a better understanding of how lay beliefs about a disease affect help seeking psychologists have developed the HBM. The HBM was first conceptualised in the 1960s by Rosenstock (1966). This early framework by Rosenstock (1966) was developed into its current form which consists of five individual lay beliefs as shown in figure 1 (Glanz et al, 2008). It is thought that these key beliefs have an impact on a person's help seeking behaviour in that these beliefs may either act as facilitators or barriers to help seeking.

The HBM also recognises that a person's lay beliefs are dependent on such factors as age, gender, ethnicity, personality, socio-economic status and educational background (lay belief modifying factors). These factors together with lay beliefs will impact a person's help seeking behaviour.

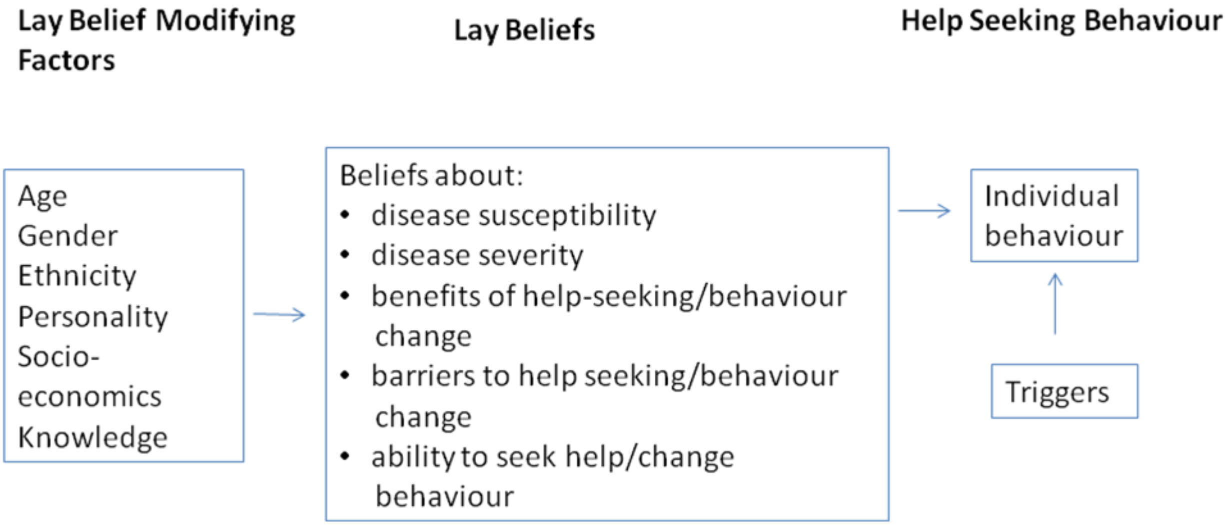

Figure 1: Components of the HBM (Taken and adapted from Glanz et al, 2008 p.49)

2.4.3. Background to Help Seeking Behaviour

Help seeking behaviour is the process by which an individual recognises that they possess symptoms that constitute an illness and are motivated to seek help in order to correct their state of illness. Help seeking can be seen as a social process based on the fact that individuals define their symptoms based on their own definition of sick and tend to be prompted to seek help based on social factors (Zola, 1973). These triggers include, as defined by Zola (1973 p. 683):

> *"the occurrence of an interpersonal crisis; the perceived interference with social or personal relations; sanctioning; the perceived interference with vocational or physical activity; and a kind of temporalizing of symptomatology."*

Zola (1973) also found that help seeking behaviour is dependent on ethnicity and culture with Italians, the Irish and Anglo-Saxons being influenced by different help seeking triggers. For example Italians more frequently responded to an interpersonal crisis and perceived interference with social or personal relations whilst the Irish responded to sanctioning. Therefore any delay or facilitator in help seeking can best be identified by determining the lay beliefs of a particular population but it is also important to have an appreciation of personal circumstances which may influence help seeking.

Lay beliefs can assist in evaluating help seeking behaviour by explaining why people exhibit particular behaviours and choose to seek help but other practical, personal factors need to be considered to get the full picture; the HBM can be applied here.

2.4.4. The HBM and Help Seeking

The HBM model allows researchers to understand help seeking behaviour in that the five personal beliefs described previously impact if and when help is sought. In addition, the HBM puts forward, like Zola (1967), the idea that as well as lay beliefs, triggers are required for help seeking to take place. These triggers can include biological, environmental or social events such as experiencing symptoms, severe discomfort, exposure to known risk factors or increased public focus on a disease area. The HBM suggests that an individual's beliefs are a result of their personal circumstances and these beliefs together with specific triggers will impact help seeking. The HBM thus links demographics, lay beliefs, help seeking behaviour and triggers as depicted in figure 1.

The HBM gives a clear structure on which to explore black women's lay beliefs and help seeking behaviour. By understanding the totality of the HBM in the context of black women and breast cancer we can develop a clear sociological appreciation of what within this continuum could act as barriers or facilitators to black women seeking help so that we can begin to address the late stage diagnosis observed in this population.

3. METHODOLOGY

3.1. Overview

This dissertation aimed to explore black British women's lay beliefs about breast cancer and their help seeking behaviour. To explore these sociological concepts a qualitative study was conducted which consisted of in-depth, part semi-structured, part structured interviews. The semi-structured segments of the interviews explored black women's lay beliefs and their help seeking behaviour whilst the structured segment explored their level of awareness of the signs and symptoms of breast cancer. An initial small pilot was conducted on one participant to ensure the effectiveness of the format of the interview. This participant were subsequently included in the final data analysis as the data collected from her pilot interview was found to be of sufficient quality to be included in the final analysis. Interviews only commenced after ethics approval was granted from the King's College Biomedical & Health Sciences, Dentistry, Medicine and Natural & Mathematical Research Ethics Committee (REC Reference Number BDM 1011 76, see appendix 3).

3.2. Research Design

3.2.1. Qualitative Research Methods

Qualitative research aims to understand why and how a particular phenomenon occurs. It enables rich, in-depth information about a particular topic to be collected with context included to enable a real-life subjective interpretation of data. This kind of approach was utilised for this dissertation as a clear understanding of the beliefs of black women and their help seeking behaviour was required. These beliefs and behaviours require cultural and individual context to be applied to them and this can only be achieved through a qualitative approach.

In this dissertation the overarching qualitative research methodology of Phenomenology was utilised and for data collection and preliminary analysis Grounded Theory was applied. Phenomenology tries to understand how people view particular issues. It aims to identify a person's understanding of an issue, its importance and what it means to them (Ritchie, Spencer and O'Connor 2003; Trochim, 2006). This method is appropriate because we are aiming to explore how black women view and understand the breast cancer experience. Phenomenology involves the use of various techniques such as interviews, focus groups and observations to collect detailed information with the view to understanding a target group's views, perceptions and beliefs on a particular topic. For this study one-to-one interviews were selected as it was felt that focus groups or group interviews would not have allowed the privacy which some participants may have required as this topic can be quite sensitive. In addition, it was felt that focus groups would not have allowed for in-depth exploration of the issues that each participant may raise and there was the need for each participant to be allocated a significant period of time with the researcher so that topics could be comfortably and extensively explored. For data collection and preliminary analysis Grounded Theory was applied. Grounded Theory aims to develop emerging theory from the data and does so in an iterative process as interviews are conducted (Ritchie Spence, and O'Connor, 2003; Trochim, 2006). This is appropriate for this dissertation because the lay beliefs and help seeking behaviour of black British women have not been fully explored and hence the need to conduct the interviews and preliminary analysis in such a way as to allow for new ideas to emerge.

3.3. Participants, Research Setting and Context

3.3.1. Sampling Method

The sampling method used was purposive sampling where individuals are selected based on particular criteria (Ritchie, Spencer and O'Connor, 2006). The criteria used in this dissertation was women who were UK residents based in London who self-identified their cultural background as either black African, black British or black Caribbean and were over the age of 25. This age group was selected based on the age of diagnosis of breast cancer in black British women, which has been determined to be an average of 46 years old (Bowen et al, 2008). The sampling aim was to obtain a fairly homogenous sample in that the study endeavoured to focus on a subculture, black British women. The required sample was described as fairly homogenous because it aimed to recruit black women from a range of backgrounds and ages to obtain a true reflection of the views that exist in this subculture.

Women who fit the criteria were recruited by recommendations through professional and personal contacts the researcher had within the black community in London. These contacts had access to women who fit the criteria either through their professional or social networks.

Participants were given an information sheet that explained the purpose of the study and confirmed their rights with reference to the conventions of King's College's research ethics committee. Before the interview commenced participants read the information sheet and signed the consent form.

3.3.2. The Research Sample

The final sample consisted of seven Black women over the age of 25 who resided in London. It was estimated that ten women were required to achieve saturation of viewpoints but at participant seven it was felt that this was achieved. The make-up of the final sample is summarised in table 1. The majority of participants were from a black African background which led to the limitation that the views of the African community were more heavily represented than those of the black Caribbean and black British community.

3.3.3. Location of the interviews

Participants were interviewed at a location of their choice to ensure that they were as comfortable as possible. Most interviews were conducted in participants' home but two participants for reasons of convenience opted to be interviewed at their work place and in a quiet park in central London. These different locations did not appear to affect the interviews.

Table 1: Research Sample Demographics

Participant	Age	Qualification	Profession	Self-Identification
1	34	MSc	IT Consultant	Black African
2	38	MSc	Nurse	Black African
3	50	BSc	Social Worker	Black Caribbean
4	46	Diploma	Social Worker	Black British
5	29	BSc	House wife	Black African
6	43	BSc	Business Owner	Black African
7	40	BSc	Policy Officer	Black African

3.4. Data Collection

The interviews were divided into three main sections that aimed to explore participants':

- Lay Beliefs about breast cancer;
- Level of awareness of the signs and symptoms of breast cancer; and
- Anticipated help seeking behaviour.

The sections exploring lay beliefs and help seeking behaviour were semi-structured using a topic guide which was developed with the HBM framework in mind as well as areas the literature revealed needed exploration. There was also room for other unforeseen topics to be identified and discussed.

To explore the accurate identification of the signs and symptoms of breast cancer the Cancer Awareness Measures (CAMs) were utilised. The CAMs are a validated collection of questions designed by Cancer Research UK, King's College and the University of Oxford to assess the level of awareness of cancer of a given population (Cancer Research UK, 2008; Stubbings et al, 2009). There is a specific breast cancer CAM and this was downloaded and domain 1 implemented during the interview.

The interviews were recorded with consent from participants and then fully transcribed by the researcher following the interview. Transcripts were reviewed as soon as possible after each interview to assist with the next interview and to get a feel for emerging themes. Themes were assigned codes and this process of developing codes started after the first two interviews and continued thereafter as new themes emerged. Coding of interviews started as soon as codes began to be developed. Further coding and in-depth analysis was conducted once all interviews were complete. This iterative process is Grounded Theory which accommodates the emergences of new theories.

3.5. Data Analysis

The final data was analysed using the Analytical Hierarchy approach which is a step-wise approach to the analysis of qualitative data and is summarized in Table 2 (Ritchie, Spencer and O'Connor et al, 2003). The first step of this approach, data management, involved the familiarisation of data, the identification of themes, the development of codes based on these themes, the utilisation of these codes to tag data and the sorting of data by themes. The second step involved summarising the data and applying the summarised data to the HBM framework. Finally, the explanatory step involved the identification of associations between different themes, the interrogation of data to develop explanations for the beliefs and behaviours of participants and the application of these explanations to the wider phenomena of the delayed diagnosis and increased mortality seen in black women affected by breast cancer.

Table 2: Analytical Hierarchy (Adapted from Richie, Spencer and O'Connor, 2003 p. 212)

Step	Procedure
Data Management	• Data Familiarisation • Theme Identification • Code Development • Coding/Tagging of Data • Data Sorting and Framework Development
Data Description	• Data Summary • Application of Data to Framework
Data Explanation	• Detection of Associations Between Themes • Data Interrogation to Develop Explanations • Application of Explanations to wider theory

4. RESULTS

The main findings from this study were analysed based on the HBM framework (see figure 1 on page 17) and are presented in this chapter. The HBM states that there are certain beliefs an individual holds about a particular disease that will affect when and if they seek help. Furthermore these beliefs will be affected by certain demographic factors called lay belief modifying factors which together with certain triggers will further impact an individual's help seeking behaviour. This chapter will describe the main findings starting with the lay belief modifying factors; this will be followed by a summary of participants' beliefs about breast cancer and then their individual help seeking behaviour.

4.1. Lay Belief Modifying Factors

To understand why people may hold certain beliefs about breast cancer the HBM is useful in that it includes the concept of lay belief modifying factors. These factors contribute to shaping an individual's belief and thus can affect whether they will seek help promptly or not. In this study a number of lay belief modifying factors were identified. These were age, culture and ethnicity, past experience with breast cancer, religious beliefs, socio-economic status and knowledge about the disease.

4.1.1. Lay Belief Modifying Factor: Culture and Ethnicity

As predicted by the HBM culture and ethnicity acted as a strong modifying factor. The first way in which it did so was in relation to access to culturally appropriate information. From the data participants tended to express that if you belonged to an ethnic minority there is a lack of culturally appropriate information. This appears to have created a sense that breast cancer does not affect the black community, leads to a lack of awareness and fosters an environment of doubt, ignorance and misconceptions about the disease. This lack of appropriate information creates a low level of awareness that can contribute to delayed help seeking. For example:

> *"The problem that we have is that the pamphlets are not specific to us so we don't take them on board….we just think ah ok white women suffer from breast cancer, ok but I am not a white woman!"* (Interview 1, page 4)

Another way in which culture and ethnicity seems to act as a modifying factor was the perception that the health service was culturally insensitive. This view created a feeling that the health service does not meet the needs of black women and thus black women are less likely to engage with the health service. This was explained by one participant as follows:

> *"I think black people generally feel they have more difficulty in accessing services so they are more likely to not have a good experience with their GP, to not trust their GP, to not feel that the system represents them, to trust their Auntie Julie to tell them information rather than the doctor, urm, and to feel that they are being fobbed off."* (Interview 7, page 4)

The data also unearthed that the life experience of black women is very different to white women; this affects the way health is prioritised and may delay help seeking. For example:

> *"I think we see life differently, sometimes our struggles are different. I think it affects the priority we might place on ourselves."* (Interview 4, page 7)

Yet another example from the data that demonstrated the impact of culture and ethnicity was the difference in beliefs between the African and Caribbean community about breast cancer. For example the shame and taboo associated with breast cancer seemed to be stronger in the African community. This was hard to fully explore as there was only one woman from a Caribbean background; she did not feel there was stigma associated with breast cancer. The data did seem to demonstrate that there was still a lot of shame associated with breast cancer within the black African community which can lead to women feeling like an outcast should they be diagnosed with breast cancer. This can potentially affect help seeking in that African women may endeavour to avoid being stigmatised. The stigma was highlighted clearly by one participant as follows:

> "*You are an outcast; people still don't show a lot of sympathy for cancer. I mean, you hear horrible, horrible, ok, if I have one breast and somebody wanted to marry me, I am not sure about the Caribbean community, in the African community, they would be like you've got a woman and she's only got one breast, they would be like how is she going to bear children, you know, that really unkind…she doesn't deserve to be married, she doesn't deserve to take care of us.*" (Interview 6, page 9)

4.1.2. Lay Belief Modifying Factor: Past Experience with Breast Cancer

Another modifying factor that was identified was an individual's past experience with breast cancer. From the data, individuals' views and beliefs about breast cancer were strongly influenced by whether participants had a family or friend with breast cancer. For those with a friend of family with breast cancer their belief mirrored the experience of their loved one. These individuals were more aware of the disease and it appeared that they would be more likely to seek help promptly.

4.1.3. Lay Belief Modifying Factor: Religion

The data also revealed that a person's religious beliefs have a significant impact on the way individuals view breast cancer, health and help seeking and this can facilitate or inhibit the help seeking process.

Example of religion as a barrier:

> *"I know that the people in the particular faith that I follow, people believe that God will heal them so they won't go for treatment and help so they can wait*

> *until the latter stages and that could have a negative effect. It obviously does."* (Interview 7, page 2)

Example of religion as a facilitator:

> *"…with religion that gives you a reason to get better, a keenness, a hope to get better. In that way it plays on us positively to want to get better, to aspire to get better and probably pick yourself up and do what we need to do instead of giving up totally."* (Interview 2, page 4)

4.1.4. Lay Belief Modifying Factor: Socio-economic Status

It was identified that socio-economic status was a lay belief modifying factor in the black community with a low socio-economic status affecting beliefs and leading to delayed help seeking. This is explained below.

> *"Poverty puts things in a different perspective*." (Interview 2, page 5)

> *"The immigrant population will be poorer...and have less access….they are marginalised and may not even realise what they can benefit from."* (Interview 2, page 6)

4.1.5. Lay Belief Modifying Factor: Age

It emerged that the older generation had certain beliefs or behaviours that would tend to delay help seeking. For example:

> *"My mum's generation just, you know, they use their….always have something they can make up or something that their mum told them, you know what I mean, rather than go to the doctor."* (Interview 3, page 2)

4.1.6. Lay Belief Modifying Factor: Knowledge

Finally, the HBM suggests that knowledge about a disease can act as a modifying factor and this was true too in this study. It was identified that lack of knowledge on a range of issues such as signs, symptoms and risk can affect participants' view of breast cancer which can delay help seeking whilst a high level of awareness can act as a facilitator to help seeking.

4.1.7. Summary of Lay Belief Modifying Factors

In summary, age, culture and ethnicity, past experience with breast cancer, religious beliefs, knowledge and socio-economic status acted as lay belief modifying factors. This next section will describe the lay beliefs of participants and make reference to how lay belief modifying factors may impact these beliefs.

4.2. Lay Beliefs about Breast Cancer

The HBM suggests that the beliefs that impact whether an individual will seek help are beliefs regarding:

- Disease severity;
- Disease susceptibility;
- Benefits of help seeking;
- Ability to seek help; and
- Barriers to help seeking.

These themes were clearly identified from the data. In addition, it was found that beliefs about treatment severity could impact help seeking.

4.2.1. Disease Severity

Participants had beliefs on a wide range of areas and expressed many emotions about breast cancer. The summation of all these beliefs and emotions shaped how participants assessed the severity of the disease. Disease severity was analysed by dividing participants' beliefs into four subthemes. These included: a) emotions evoked by breast cancer; b) individual and community perceptions of the disease; c) survival, cure and recurrence; and d) the consequences of breast cancer. This section will describe briefly the main findings of these subthemes and will culminate with how these subthemes impact how participants view the severity of breast cancer and how this may impact help seeing. It will also identify any lay belief modifying factors that may have an impact on beliefs about disease severity.

Emotions Evoked By Breast Cancer

Participants recounted very strong emotions when reflecting on breast cancer. These emotions were sadness, fear, shame, horror and boredom. One participant felt a sense of hope in that when she thinks of breast cancer she has images of those that have survived.

> "*...they fought it and got well, [so] I think of survival most of the time"* (Interview 5, page 1)

Individual Perceptions of Breast Cancer

Participants described breast cancer as a terminal disease, life and death threatening, a deadly disease, an aggressive cancer, quite tragic, rapidly depreciating, something you detect late and a challenge. One participant had a very fatalistic view stating:

> *"....because the final is death isn't it? I think death is inevitable."* (Interview 3, page 1)

The Black Community's Perception of Breast Cancer

Participants also provided their view on how the black community as a whole feels about breast cancer. They felt there was still fear and shame in the black community. Participant 4 had an opposing view; she felt that the shame associated with breast cancer no longer existed stating *"...before it was a taboo"* she went on to explain that it was no longer a taboo because "*…since we have had black people…being diagnosed…seeing it I think we are a little bit more aware*."

In addition it was felt that in some groups there was apathy with respect to breast cancer.

> *"I think most black people from an African background just take it so lightly, we are not very serious about it".* (Interview 5, page 1)

Cure, Survival and Recurrence

Several participants felt that breast cancer could be cured if caught early but the majority felt that breast cancer couldn't be cured but life could be extended and the disease managed.

Many participants had a view regarding breast cancer survival. A few participants felt that the survival rate for breast cancer was low but participant 5 had a more positive outlook with respect to breast cancer survival.

> *"I've heard of people who have survived, you know, who had breast cancer at one time and they fought it and got well, [so] I think of survival most of the time.*" (Interview 5, page 1)

A related topic to cure and survival emerged with two participants, this was recurrence. Participant 3 in particular had strong views on recurrence.

> *"It doesn't matter how much you go into remission…it will come back in a few years and it does kill you, that's how I feel, end of."* (Interview 3, page 5)

Participant 7 had the following thoughts on recurrence.

> *"I think people go into remission but I think they are always at risk of the cancer coming back."* (Interview 7, page 3)

Consequences of breast cancer

Finally participants felt that breast cancer had a number of serious consequences on the individual with the disease, her family and the wider community. Analysis of the data showed that participants felt that there were a number of physical, health-related and emotional consequences of the breast cancer experience. The most obvious consequences were related to state of health and the physical appearance of the affected woman for example a sense of great illness and pain, death, loss of breasts, hair loss and lethargy. Participants also felt that there were a number of emotional consequences of the breast cancer experience. These included a feeling of isolation, fear and anxiety about not only the disease but a range of other issues. For example:

> *"It is the thought of having to leave your children or family behind, that's more scary. It's the thought of leaving your loved ones behind, you might be out of the pain but I think you worry more about the pain they would be left with.*" (Interview 3, page 2)

> *"…will I survive, what stage is the cancer, what is going to happen, like fear of the unknown*. (Interview 5, page 3)

There were other emotional consequences that were identified by participants such as loss of femininity and losing one's self esteem. One participant felt that a lot of pressure was placed on women with breast cancer as she explained below.

> *"It puts a lot of pressure on you because it's part of the way we look, it's our body, it's almost like having to apologise to your husband or something that you have one breast now or something, very funny kind of illness, I think it has that impact on the person, on the sufferer whereby she always has to apologise….because it has that physical effect."* (Interview 6, page 2)

There was the feeling that breast cancer had far reaching consequences extending from the women affected to her family through to the wider community. The effect on family was thought to be the anxiety of their increased risk of developing breast cancer and the negative affect on the woman's role as a wife and mother, as explained below.

> *"…and then the fact that now it's in your family so does that make you more likely to get it."* (Interview 4, page 5)

> *"For example if the woman loses her breast what is going to happen to her child. If she has a small child how is she going to breast feed, is she going to be able to get pregnant, what are the implications. The man also has to deal with a wife without breasts; all these thoughts*." (Interview 1, page 6)

The possible consequence of breast cancer on the wider community was explained as follows:

> *"…because if a lot of women start suffering from breast cancer, women are the heart of the community, they are 50% of the income within a community, if that percentage is dying the community will suffer."* (Interview 1, page 5)

Summary and Assessment of Disease Severity

Participants held a negative impression of breast cancer as shown by the emotions it evoked such as fear and horror. Furthermore there was some fatalism about breast cancer. This combined with the fact that participants mostly felt that breast cancer was incurable, survival rates were low, recurrence was inevitable and that there were serious consequences on the women affected, her family and the community meant that participants viewed breast cancer as a very severe disease. The HBM suggests that individuals that view a disease as severe are more likely to seek help should they recognise a symptom. Thus we expect black women's beliefs on the severity of the disease to act as a facilitator to help seeking. We can note here that certain lay belief modifying factors that were described previously may have an impact in that even though the disease is seen as severe such factors as an older age, strict religious beliefs, cultural beliefs and socio-economics may delay help seeking in some individuals. Conversely, past experience with breast cancer, a younger age and liberal religious beliefs may act as facilitators to help seeking.

4.2.2. Disease Susceptibility

The second belief that the HBM suggests impacts help seeking is an individual's belief about their susceptibility to a disease. In this dissertation the theme of disease susceptibility arose in different guises. This included individual risk perception, the black community's perception of risk and those who participants felt were more at risk of developing breast cancer. With respect to individual risk, three participants did not feel they had a significant risk of developing breast cancer.

> *"I think it can happen but I think because nobody in my family or no one from my extended family that I know, nobody has had cancer."* (Interview 3, page 2)
>
> *"It can't happen to me. No one in my family has had it. I haven't done any breast implants. I haven't messed around with my breasts in anyway, so I am ok."* (Interview 6, page 1)
>
> "*I don't feel a personal fear*" because "I *see it as something that tends to run in families.*" (Interview 7, page 1)

One participant did show some concern about her risk of developing breast cancer.

> *"My cousin shares genes with me so that means there must be some breast cancer in my family so for me it hit me that actually should I be investigating more about who of our relatives have had this and how... what are my chances of getting it and what I can do for myself in order to try and prevent myself from…you know, getting that."* (Interview 2, page 2)

The next theme that emerged around risk was how the black community as a whole viewed their collective risk of developing breast cancer. The following statements describe these views.

> *"I have heard someone say it is very much a white disease*." (Interview 2, page 2)

> *"Black people from an African background just take it so lightly, we are not very serious about it, we just think it's not going to happen to me."* (Interview 5, page 1).

> "*…we just don't realise it can happen to us."* (Interview 7, page 9)

Many participants had a view on who was the most at risk of developing breast cancer. The majority of participants felt that breast cancer tended to be an inherited disease with some families being genetically predisposed to developing breast cancer. There was also a feeling that lifestyle factors increased one's risk of developing breast cancer so that smokers, drinkers and those with an unhealthy lifestyle were thought to have an increased risk of developing breast cancer.

From this it would appear that, in general, participants in this study and the black community perceived that they are not risk of developing breast cancer. One reason for this was that many felt that breast cancer was an inherited disease and most participants did not have a family history of breast cancer. Another reason for this view on risk can be explained by the HBM modifying factor culture and ethnicity. The underestimation of risk could have occurred because ethnic minorities in the UK lack access to culturally relevant information, as stated by many participants, regarding their risk of developing breast cancer. This lack of information is being interpreted by the black community as they are not at risk of developing breast cancer. The HBM would suggest that this would delay help seeking. There was one participant in this study that showed some concern about her risk and this was due to the modifying factor of past experience with breast cancer. The participant who was concerned about her risk had a close family member with breast cancer and hence this impacted her view on her disease susceptibility which acted as a facilitator to help seeking.

4.2.3. The Benefits of Help Seeking

The HBM recognises that if individuals can see clear benefits of help seeking then they are more likely to seek help promptly. Participants did feel that there were benefits to seeking help and it appeared these benefits would act as significant motivating factors to seeking help. The benefits identified by participants were:

a. Enables early detection thus improving outcome. For example:
   "I think it's a type of cancer that can be cured if it is detected in time." (Interview 5, page 1)

b. It prolongs life. For example:
   "...I could live a bit longer, so I would go to the doctor, I wouldn't be scared" (Interview 3, page 7)

   "If you don't you might die so it's a choice, treatment or die." (Interview 7, page 2)

4.2.4. Barriers to help seeking

The HBM suggests that the beliefs that an individual has regarding what barriers exist with respect to help seeking will determine if and when they seek help. The data revealed that participants either felt there were no barriers to help seeking in the UK, there were individual personal barriers or there were barriers created by the health service.

Individual Barriers to Help Seeking

It emerged that religion could in certain circumstances act as a barrier to help seeking as explained below.

> *"She didn't go for treatment. She decided she was going to pray and though she was an educated woman her faith was much more important to her and it was something she said at the time her pastor told her to do."* (Interview 1, page 5)

Participants also identified other priorities in life as barriers to help seeking. These priorities included family commitments such as caring for sick family members, other health concerns and other life issues such as financial problems. The challenges of being an immigrant and age-related beliefs and behaviours (as discussed previously) were also identified as personal barriers to help seeking.

Health Service Related Barriers

Participants also felt that the health service itself created barriers to help seeking. These barriers included the lengthy referral process, difficulties in getting appointments and general inaction and delays as described below.

> *"I knew something was wrong and they basically made me feel like I was going mad."* (Interview 2, page 8)

> *"…but maybe they fob you off too because you are younger because they have fobbed off a lot of people. It turned out to be that they did have cancer and it did affect them in a big time, had they catch it earlier they probably wouldn't have had such drastic results."* (Interview 3, page 4)

> *"…my doctor wouldn't listen to me. I had it for a year until I ended up in hospital."* (Interview 7, page 6)

4.2.5. Ability to Seek Help

The HBM states a person must feel like they have the ability to seek help in order for them to seek help promptly. In this dissertation participants felt able to seek help and didn't see accessing services as a major issue from their own point of view in terms of the physical process. At any one time there may be some of the personal barriers mentioned above but there were some participants who were more concerned about the NHS's effectiveness once they initiated help seeking (see the health related barriers mentioned previously). Some participants felt that they had to assert themselves to be heard and to receive the health care they felt that they deserved, as explained below.

> *"...one has to know a lot about their own health to extract what they need from the NHS. Otherwise if you sit back and say you will get whatever you are supposed to get you are joking. I don't know how many times I have gone to PALs to actually make sure I have gotten the service I am supposed to get from the NHS and even then I still get a second opinion when I go back to Africa."* (Interview 2, page 8)

> *"If something is bothering you and you know what is happening to you and the doctors are not taking you seriously you just have to keep going and keep going, isn't it, and it can be quite frustrating. You have to be kind of clever about this and go to drastic measures."* (Interview 3, page 4)

> *"I am not confident that they would meet my needs. I am confident in myself that I would make sure I get my voice heard."* (Interview 7, page 6)

It was also felt that the health service did not practice the cultural sensitivity that was needed to effectively engage with the black community. When the HBM is applied here the lay belief modifying factor of culture can impact an individual's belief in the effectiveness of their attempt at help seeking and this may deter them from seeking help.

4.1.6. Treatment Severity

Another belief that emerged which was not included in the HBM that might impact help seeking was beliefs about treatment severity. Participants had a very negative view about breast cancer treatment (chemotherapy and radiotherapy). There was a feeling that it is the harshest treatment administered to a patient, it was considered by some to be a poison and it was felt to have a horrific effect on the body. There was a feeling that the severity of the treatment could be a deterrent to help seeking as stated below.

> "*I would have to be pushed, if I could try one of my mother's remedies or something I would, I wouldn't be going to the doctor in a hurry".* (Interview 3, page 6)

Hence an individual's beliefs about the severity of treatment could delay help seeking

4.3. Help Seeking Behaviour and Triggers to Help Seeking

Having looked at lay beliefs and lay belief modifying factors in the previous sections this section will explore the main findings around individual help seeking behaviour and the triggers that lead to help seeking. There will be references to the previous concepts of beliefs and modifying factors where relevant.

An important part of help seeking is the recognition of symptoms. All participants when asked to name as many of the signs of breast cancer as they could were able to recall a breast lump. There was a lack of awareness of the other signs of breast cancer with only one participant being able to name four other signs, three participants were able to name two other signs, one participant was able to name one other sign and the final two were not able to name any other signs of breast cancer.

Participants were probed on what they thought their reaction would be if they noticed a breast lump. Participants stated what would trigger help seeking would be the size of the lump, the persistence of the lump beyond a week and if the lump was accompanied by pain. In general, participants would seek help within a week of detecting a breast lump. The HBM modifying factor of knowledge can be applied here. The high level of awareness that a breast lump could be a sign of breast cancer acts as a facilitator to help seeking.

When probed on their responses to other signs of breast cancer because there was a low level of awareness of these symptoms participants stated that they would either self-medicate or wait to see if the sign persisted. If the symptom persisted after self-medicating or observation they would seek help. It might take them anywhere from a week to several weeks before they sought help. When the HBM is applied here we see that the modifying factor of knowledge has impacted help seeking with the lack of knowledge on the full range of the signs and symptoms of breast cancer delaying help seeking.

Participants who had a close friend or family member with breast cancer or who had their own personal scare with breast cancer stated that they would seek help immediately. As mentioned previously past experience with breast cancer fits in to the HBM framework as a health belief modifying factor that facilitates help seeking.

5. DISCUSSION

The results from this study helped provide an understanding of black British women’s lay beliefs about breast cancer and their help seeking behaviour. This is useful because the lay beliefs and help seeking behaviour of black women residing in the UK have not been studied in great detail in the area of breast cancer. The results may provide some explanation as to whether the increased mortality due to late stage diagnosis observed in black British women could be due to delayed help seeking. In addition it can help to understand the reasons for any delay in help seeking and thus enable them to be addressed.

Due to the lack of data on lay beliefs and help seeking behaviour of black British women reference will be made to black American women in this discussion because a number of studies have been conducted on this group of women. In addition, the HBM will be utilised as the framework for this discussion. This discussion will begin with the main findings regarding the lay belief modifying factors comparing them to what was found in the literature, it will then focus on the main lay beliefs participants held about breast cancer and finally their help seeking behaviour. Following this the implications of the results will be discussed and the limitations of this dissertation.

5.1. Lay Belief Modifying Factors

This dissertation identified a number of modifying factors that impacted black British women's help seeking behaviour, these were age, religion, knowledge about breast cancer, culture and ethnicity, past experience with breast cancer and socio-economic status. These factors could act as facilitators or barriers to help seeking. In the literature exactly the same lay belief modifying factors impacted the help seeking behaviour of black American women although the impact of age did not seem to be explored extensively in the US literature (; Greg and Curry, 1994; Ashing and Ganz, 1997; Lannin et al., 1998; Bailey et al., 2000; Lannin et al., 2002; Salant et al., 2006). What is interesting is the different ways and extent to which some of these factors impact black British women compared to black American women. For example, looking at religion it would appear that black British women tended to place less of an emphasis on religion than black American women. A religious undertone seemed to exist in the black American studies whilst when black British women discussed breast cancer religion was not at the forefront of their mind. A good example of this was in relation to perceptions about the causes of breast cancer. Whereas black British women made no mention of God when discussing the causes of breast cancer, in all the American studies there was a strong religious undertone in their beliefs about the causes of breast cancer. Black American women tended to think that breast cancer was either a punishment from God, part of God's plan or a test of one's faith in God

(Lannin et al., 1994; Greg and Curry, 1994; Ashing and Ganz, 1997; Bailey et al., 2000; Lannin et al., 2002; Salant et al., 2006). Because of the belief that breast cancer is part of God's plan and that their health is in God's control black American women tended to feel that they had little influence over whether they develop or survive breast cancer. Black British women in this dissertation tended not to hold this view with respect to causes and in general felt that one's actions could impact their risk of developing breast cancer and one's survival. Applying the HBM, religion is a modifying factor for beliefs about the causes of breast cancer. In the case of black American women their strong religious beliefs about causes may contribute to delayed help seeking whilst the more liberal religious beliefs of black British women may act as a facilitator to help seeking.

Another lay belief modifying factor where there was a clear difference was socio-economic issues. Many of the American studies looked at the beliefs of black women from a low socio-economic background while this dissertation included black professional women. In addition the US system of health insurance means that health care is at a cost to the patient whilst this is not the case in the UK. This means that affordability is a major consideration for US patients. The fact that the US studies looked at women from low socio-economic background and health care is dependent on ability to pay meant that economics tended to be of great importance in the US studies. For example black American women described breast cancer as a creator of poverty or as a disease that worsens poverty. This sentiment was not expressed by black British women. Whilst there was recognition from Black British women that poverty and finances were important issues these issues weren't a significant part of the discussion. Because women in the US studies may have had limited funds to access services this would mean that they would be more likely to delay help seeking than the black British women in this dissertation.

The modifying factor of age was not explored in detail in the US literature but this dissertation was able to ascertain that older black women held certain beliefs that could delay help seeking. These were a general lack of trust and a suspicion of the health care system and more of a belief in the effectiveness of alternative therapies than the younger generation.

The other modifying factors seemed to impact black American and black British women in the same way. For example in both populations past experience with breast cancer indirectly through a family member or friend tended to change or shape the beliefs that women had about breast cancer that facilitated help seeking. Furthermore with regards to the modifying factor of culture and ethnicity there where particular beliefs that were shaped by culture that could then impact help seeking. An example of this is that both black American and black British women from an African background expressed that there was a stigma associated with breast cancer. This belief could lead to delayed help seeking as women try to avoid being stigmatised.

5.2. Lay Beliefs

The HBM framework suggests that beliefs about disease severity, disease susceptible, benefits of help seeking, ability to seek help and barriers to help seeking will impact an individual's help seeking behaviour. When considering disease severity both black British women and Black American women have a very negative impression of breast cancer but it would appear that black American women had a more negative impression of breast cancer. Both black British and black American women felt that breast cancer was incurable, always diagnosed at a late-stage and caused severe mental distress. Black American women went on to describe breast cancer as a devourer of the body, a creator of poverty and something that worsens poverty (Gregg and Curry, 1994; Peek, Sayad and Markwardt, 1997; Bailey, Erwin and Belin, 2000; Frisby, 2002). In addition both black American and black British women associated breast cancer with death, loss of hair and the loss of breasts (Ashing-Giwa and Ganz, 1997; Peek, Sayad and Markwardt, 1997; Bailey, Erwin and Belin, 2000; Moore, 2001; Frisby, 2002). The HBM identifies beliefs about disease severity as one of the major beliefs that will impact help seeking. It is believed that if individuals believe a disease is severe they are more likely to seek help if they experience symptoms of that disease. Therefore in theory black women should seek help promptly but as discussed previously certain lay belief modifying factors will have an impact and could delay help seeking.

Moving on to the next HBM belief, disease susceptibility, black Americans tended to feel that they were not at risk of developing breast cancer and that breast cancer only affects white women (Bailey, Erwin and Belin, 2000; Moore, 2001). This belief appears to be a direct result of media and health promotion campaigns that have predominately targeted white women (Moore, 2001). This has resulted in the underestimation of risk by some black American women. (Bailey, Erwin and Belin, 2000; Moore, 2001; Lannin et al., 2002; Salant et al., 2006; Gerend and Pai, 2008). This dissertation suggests the same is true for black British women with participants stating that the perception in the black British community is that breast cancer is a white disease. It was identified that leaflets and health promotion campaigns in the UK cultivated this belief. In addition, some women in this dissertation felt that their individual risk was low because they did not have a family history of breast cancer and they lived a generally healthy lifestyle.

The third HBM belief that emerged from this study was the benefits of help seeking. Black British women recognised that there were significant benefits to help seeking in that it enabled breast cancer to be caught early and prolonged life. It wasn’t clear from the US studies whether black women felt there were any real benefits to help seeking as their perceptions of the breast cancer experience was so negative and there were significant financial implications of seeking help. One study in the UK conducted by Waller et al. (2009) which looked at the help seeking behaviour of ethnic minorities supported the finding in this dissertation that black British women see the benefits of help seeking. The Waller et al. (2009) study explored the help seeking behaviour of ethnic minorities with respect to cancer in general and showed that black Caribbean and black African populations stated they would seek help promptly. This would imply that the participants in their study saw the benefits of help seeking.

The final HBM beliefs that were explored were participants’ beliefs on the barriers to help seeking and their ability to seek help. The barriers to help seeking in this dissertation tended to fall into two categories personal and health services. Personal barriers included work and family commitments. The health service barriers included difficulty making appointments and GP delays. These were similar to those in the Waller et al. (2009) study except the participants in the Waller et al. (2009) study also expressed emotional barriers such as fear. In this dissertation although there was fear associated with breast cancer it didn’t appear to be a barrier to help seeking; women in the study believed that they would seek help despite the fear. This appeared to be the case because they appreciated the benefits of help seeking and also because (in some participants) of the strong impact of the experience of a family member or friend who had had breast cancer. Finally when their ability to seek help was explored participants felt able to seek help and didn’t see accessing services as a major issue from their own point of view based on their own personal ability. Although some of the above mentioned personal barriers may exist at any one time many of these were felt to be temporary and not permanent barriers. When looking at the literature the affordability of health care affected the ability of black American women to seek help profoundly because they were from a disadvantaged background. The concern from participants in this dissertation was the effectiveness of the NHS once help was sought. It was felt that quite a significant delay could result due to GP delays, the lengthy referral process and lack of cultural sensitivity. Some participants did express a very positive impression of their GP stating that they did act promptly. In summary, participants’ belief in their ability to seek help would facilitate recovery and whilst there may be some personal barriers to help seeking these would act only as temporary delays while the health service delays may be create more of a persistent delay to help seeking.

A belief that emerged which was not included in the HBM that might impact help seeking was beliefs about treatment severity. Participants had a very negative view about breast cancer treatment. The belief that treatment is very severe could be a deterrent to help seeking. This was similar to what was seen in the literature with studies showing that black American women had a very negative impression of breast cancer treatments (Greg and Curry, 1994). Studies showed that some black America women would not proceed with the recommended standards treatments (Lannin, 1998; Lannin et el., 2002). This demonstrates the delay that could occur due to negative views about treatment

5.3. Help Seeking Behaviour

Having explored lay belief modifying factors and lay beliefs and determining how these may impact help seeking the next step in the HBM framework is to explore the anticipated help seeking behaviour of participants. An important aspect of help seeking is first recognising a symptom and then deciding whether or not to seek help. This study aimed to analyse black women's help seeking behaviour by first assessing their awareness of the signs and symptoms of breast cancer and exploring their response to these symptoms. The awareness of the signs and symptoms were tested through a recall method where participants were asked to recall as many of the signs and symptoms of breast cancer as they could remember. Through this method participants were able to recall an average of 2.6 symptoms. In a study conducted by Waller et al. (2009) analysing the level of awareness of the symptoms of cancer generally the black Caribbean participants in this study recalled an average of 1.5 symptoms while the African population recalled an average of one symptom. The participants in this dissertation were able to recognise more breast cancer symptoms than when participants in the Waller et al. (2009) study were asked about general cancer symptoms. This is probably due to that fact that asking for general cancer symptoms might be perceived as quite vague and thus might be harder to recall.

When participants in this dissertation were asked to name as many of the signs of breast cancer as they could all were able to recall a breast lump but there was a lack of awareness of the other signs of breast cancer.

Participants were probed on what they thought their reaction would be if they noticed a breast lump. Participants stated what would trigger help seeking would be the size of the lump, the persistence of the lump for a week and if the lump was accompanied by pain. In general, participants anticipated that they would seek help within a week of detecting a breast lump. When probed on their responses to other signs of breast cancer because there was a low level of awareness of these symptoms participants might take anywhere from a week to several weeks before they sought help. In the study conducted by Waller et al. (2009) it was determined that the black African and black Caribbean populations would be more prompt at seeking help than other ethnic groups; for most symptoms they would consult their GP less than two weeks after recognition of a symptom. This is similar to women in this dissertation showing that it is not anticipated that the black population would delay help seeking significantly once a symptom was recognised.

Participants who had a close friend or family member with breast cancer or who had their own personal scare with breast cancer stated that they would seek help immediately. This is similar to what was seen for black American women. (Lauver, 1994).

5.4. Implications and Importance of the Main Findings

This dissertation provided a first exploration of the lay beliefs and help seeking behaviour of black British women helping to fill a gap in the literature regarding these concepts in this ethnic group. The importance of exploring these areas was to gain an understanding of the causes of the delayed diagnosis seen in black British women affected by breast cancer. It was felt that by exploring these areas any beliefs and behaviours that may be contributing to delayed diagnosis could be identified and understood. This would then enable specific strategies to be developed to overcome any barriers to early diagnosis and thus improve the breast cancer mortality rate of black women.

Overall from this dissertation it would appear that there would be no major delay in help seeking once black women recognised a symptom of breast cancer. The women in this study were quite proactive in their help seeking and all had a high level of awareness that a breast lump was a symptom of breast cancer. Therefore there would be no delay to help seeking in the context of a breast lump. It was recognised that where a delay could occur would be in recognising other symptoms of breast cancer as there was a low level of awareness of these symptoms. Other areas where a delay may occur would be in older black women who have a lack of trust in the health system, in black African women due to the stigma that still surrounds breast cancer in the African community, in particular religious denominations where the inclination is to depend on their religious belief rather than medical interventions and the existence of personal, family and life challenges. Furthermore there was a lack of culturally appropriate information which has created the feeling that breast cancer is a white disease; this belief could cause a delay in help seeking as breast cancer might not be in the forefront of the community's mind. Finally, there was a feeling that the health service lacked cultural competence and this would affect the successful engagement of the black community.

To address some of these issues health promotion campaigns need to provide more culturally relevant information that targets the African Caribbean population, the non-conventional symptoms of breast cancer should be highlighted in the same way as the breast lump and church leaders should be engaged to ensure messages about breast cancer are provided to their congregations. Some focus could be paid to the African community and older black women. In the case of African women effort should be made in trying to de-stigmatise breast cancer and in ensuring that women feel supported and able to discuss breast cancer openly. For older black women the health service needs to endeavour to encourage their engagement with the health service through better communication. Finally the health service would benefit from a strategy to improve their culturally sensitivity.

5.5. Limitations and Future Work

This dissertation explored the lay beliefs and help seeking behaviour of seven UK residents from the black community. The reason that seven women were interviewed was because saturation of views appeared to have occurred after the seventh interview. Although the seven participants provided a rich data source and some insight into the beliefs and behaviours of black women with respect to breast cancer these beliefs cannot be generalised to the wider black community. The main reason for this is that the seven women included in the study did not fully represent the diversity found in the black community. The final sample included mostly women from a black African background. Only one woman self-identified as being from a black Caribbean background and one self-identified as black British. In addition to this all the women in this study were educated to degree level and could be considered as coming from the same socio-economic background. Therefore further work needs to be done to explore the beliefs of a wider range of black British women especially those from a

Caribbean background and those from different socio-economic backgrounds. It might also be useful to explore and compare the beliefs and behaviours of first, second and third generation black immigrants (a first generation immigrant being the first generation of the family born in the UK).

Another limitation of the dissertation was the possibility that participants may have wanted to project themselves in a certain light and may not have given a true account of their beliefs and behaviours. The researcher made every effort to make participants feel as comfortable as possible and to encourage participants to put forward any ideas as there were no wrong or right views. Although participants appeared to be very comfortable and straightforward about their views there is always the possibility that they may have altered them slightly to project a certain image.

A further issue to discuss is the reliability of the data. The reliability of research is related to whether data is repeatable and this can be divided into external and internal reliability. External reliability refers to the repeatability of the entire study and its findings whilst internal reliability refers to repeatability of the steps within a piece of work (Ritchie, Spencer and O'Connor et al., 2003). In assessing the external reliability of this dissertation the similarities of the main findings with published literature would suggest that this study is externally reliable. In addition, the topic guide and direction of the study was framed by making reference to previous work which built in a degree of reliability due to the need to explore similar areas as previous studies. Internal reliability can be assessed by requesting that another researcher reviews and codes one of the interview transcripts. If this researcher and the researcher for this dissertation code the transcripts in the same way then we can conclude the data is internally reliable. Due to time constraints this was not completed but the researcher is keen to establish internal reliability and will ensure this is established.

6. CONCLUSIONS

The objectives of this dissertation were to:

- To gain an understanding of black women's lay beliefs of breast cancer;
- To identify any barriers to help seeking;
- To evaluate black women's level of awareness of the signs and symptoms of breast cancer; and
- To understand the anticipated help seeking behaviour of black women

With reference to this first aim of exploring the lay beliefs of black British women this dissertation identified that black British women have a very negative impression of breast cancer as shown by the emotions it evokes such as fear and horror. Furthermore there was some fatalism about breast cancer and the feeling that it was a stigmatised disease in the black African community. This combined with the fact that participants mostly felt that breast cancer was incurable, survival rates were low, recurrence was inevitable and that there were serious consequences on the women affected, her family and community meant that participants viewed breast cancer as a very severe disease. There were a minority of participants that were more positive about breast cancer with respect to one's ability to survive the disease.

The second aim of the dissertation was to identify any barriers to help seeking in the black community. This dissertation identified two categories of barriers to help seeking; there were personal barriers and health service related barriers. Personal barriers included:

- Other priorities in life (e.g.: family commitments, other health concerns and financial difficulties);
- Immigrant issues (language barriers and lack of access to information and services);
- Beliefs and behaviours of the older generation and black Africans;
- Lack of culturally relevant information;
- Lack of breast cancer knowledge; and
- A low socio-economic status.

The health service related barriers included the lengthy referral process, difficulties in getting appointments, cultural insensitivity and inaction by GPs

The third aim of assessing the level of awareness of the signs and symptoms of breast cancer led to the conclusion that there was high level of awareness that a breast lump was a sign of breast cancer but there was a lack of awareness of the other signs of breast cancer.

Finally exploring the help seeking of black women led to the conclusion that overall it would appear that there would be no major delay in help seeking once black women recognised a symptom of breast cancer. As there was a high level of awareness that a breast lump was a sign of breast cancer there would be no delay in this context. A delay would occur in the recognition of the other signs of breast cancer. It was also identified that the size of a lump, pain and persistence of symptoms would trigger help seeking. In addition to the barriers mentioned previously it was identified there were lay belief modifying factors which could either delay or facilitate help seeking depending on the context. These factors included knowledge about breast cancer, religion, culture and ethnicity, previous experience with breast cancer, age and socio-economic status.

This dissertation has helped identify how black British women view breast cancer and how these beliefs may impact their help seeking. It has also identified possible barriers to help seeking which can be addressed to ensure the earlier diagnosis of breast cancer in black women. In general it does appear that there would be no significant delay in help seeking in black women and thus other factors must be contributing to the delayed diagnosis observed in this group of women. Further work is needed to explore the beliefs of a wider range of black women and to clarify the extent to which genetic predisposition to more aggressive forms of breast cancer contributes to late stage diagnosis.

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8. APPENDIX

8.1. Appendix 1: Information Sheet and Consent form (Pilot Study)

REC Reference Number: BDM 1011 76

YOU WILL BE GIVEN A COPY OF THIS INFORMATION SHEET

Title of Project: Exploring Black Women's Lay Beliefs of Breast Cancer and their Help Seeking Behaviour with a View to Determining any Factors that May Contribute to Delays in Seeking Help

I would like to invite you to participate in the pilot study for this postgraduate research project. You should only participate if you want to; choosing not to take part will not disadvantage you in any way. Before you decide whether you want to take part, it is important for you to understand why the research is being done and what your participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask me if there is anything that is not clear or if you would like more information.

Aim and benefits of the research

The aim of this research project is to understand your perception of various aspects of breast cancer. The reason for trying to understand these issues is because although black women are less likely to develop breast cancer they are more likely to have a worse outcome than white women. This is because black women tend to be diagnosed with breast cancer at a later stage when it is harder to treat. By understanding your views we can better understand factors that may contribute to delayed diagnosis.

You will be asked questions about what you think causes breast cancer, how you feel about breast cancer, who you think is at risk of developing breast cancer, your views on breast cancer prevention, what the signs and symptoms of breast cancer are and what you would do if you noticed any of the symptoms of breast cancer. The benefit of exploring these areas would be to gain a better understanding of the beliefs that black women collectively have about breast cancer and their help seeking behaviour.

I am carrying out this pilot study in preparation for the research project with the above title. The aim of the pilot is to ensure that the approach taken in the project is effective at covering all the main issues.

Who we are recruiting?

I will be recruiting black women residing in London who are over the age of 25

What will I have to do if I take part?

If you agree to take part, I will ask you to take part in an interview in a place and time of your choosing. The discussion should take about an hour at the longest. The questions will relate to your perceptions of breast cancer, your awareness of the signs and symptoms and what you think you would do if you experienced any of the symptoms of breast cancer.

If I agree to take part what happens to what I say?

All the information you give me **will be confidential** and used for the purposes of this study only. The data will be collected and stored in accordance with the Data Protection Act 1998 and will be disposed of in a secure manner. The information will be used in a way that will not allow you to be identified individually. Interviews will be recorded, subject to your permission. Recordings of the interview will be deleted once I have produced a typewritten copy of the interview; this copy will be anonymised and you will not be identifiable.

Do I have to take part and if I agree now can I change my mind later

Taking part is voluntary. If you decide to take part you are still free to withdraw at any time and without giving a reason. The information you provide might be used in the final analysis and included in the final report. You can withdraw any information you have provided up until it is analysed and about to be written into the report. The deadline for notifying me should you want to withdraw your information is 1st Sept 2011. If the information you provide is used in the final analysis it will be published as part of the report and you will be sent a copy. Please **note that confidentiality and anonymity will be maintained** and it will not be possible to identify you from any publications**.**

What do I do next?

Think about the information on this sheet, and ask me if you are not sure about anything. If you agree to take part, I will contact you to make the arrangements, and before the interview commences, I will discuss the study information sheet with you and ask if you have any questions, before I ask you to sign a consent form to participate in the study. The consent form will not be used to identify you. It will be filed separately from all other information. If you do decide to take part you will be given this information sheet to keep. If you want any more information about the study please contact Abi Ajose-Adeogun abisoye.ajose-adeogun@kcl.ac.uk.

If this study has harmed you in any way please contact the study supervisor, Kirstie Coxon, or Chris McKevitt, the post graduate project coordinator; both of their contact details are provided below.

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CONSENT FORM FOR PARTICIPANTS IN RESEARCH STUDIES

Please complete this form after you have read the Information Sheet and/or listened to an explanation about the research.

Title of Study: ____

King's College Research Ethics Committee Ref:________________

Thank you for considering taking part in this research. The person organising the research must explain the project to you before you agree to take part. If you have any questions arising from the Information Sheet or explanation already given to you, please ask the researcher before you decide whether to join in. You will be given a copy of this Consent Form to keep and refer to at any time.

Please tick or initial

- I understand that if I decide at any time during the research that I no longer wish to participate in this project, I can notify the researchers involved and withdraw from it immediately without giving any reason. Furthermore, I understand that I will be able to withdraw my data up to the point of publication. ☐

- I consent to the processing of my personal information for the purposes explained to me. I understand that such information will be handled in accordance with the terms of the Data Protection Act 1998. ☐

- I consent to my interview being recorded. ☐

Participant's Statement:

I ____

agree that the research project named above has been explained to me to my satisfaction and I agree to take part in the study. I have read both the notes written above and the Information Sheet about the project, and understand what the research study involves.

Signed Date

Investigator's Statement:

I ____

Confirm that I have carefully explained the nature, demands and any foreseeable risks (where applicable) of the proposed research to the participant.

Signed Date

8.2. Appendix 2 : Information Sheet and Consent Form (Non-pilot)

REC Reference Number: BDM 1011 76

YOU WILL BE GIVEN A COPY OF THIS INFORMATION SHEET

Title of Project: Exploring Black Women's Lay Beliefs of Breast Cancer and their Help Seeking Behaviour with a View to Determining any Factors that May Contribute to Delays in Seeking Help

I would like to invite you to participate in this postgraduate research project. You should only participate if you want to; choosing not to take part will not disadvantage you in any way. Before you decide whether you want to take part, it is important for you to understand why the research is being done and what your participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask me if there is anything that is not clear or if you would like more information.

Aim and benefits of the research

The aim of this research project is to understand your perception of various aspects of breast cancer. The reason for trying to understand these issues is because although black women are less likely to develop breast cancer they are more likely to have a worse outcome than white women. This is because black women tend to be diagnosed with breast cancer at a later stage when it is harder to treat. By understanding your views we can better understand factors that may contribute to delayed diagnosis.

You will be asked questions about what you think causes breast cancer, how you feel about breast cancer, who you think is at risk of developing breast cancer, your views on breast cancer prevention, what the signs and symptoms of breast cancer are and what you would do if you noticed any of the symptoms of breast cancer. The benefit of exploring these areas would be to gain a better understanding of the beliefs that black women collectively have about breast cancer and their help seeking behaviour.

Who we are recruiting?

I will be recruiting black women residing in London who are over the age of 25

What will I have to do if I take part?

If you agree to take part, I will ask you to take part in an interview in a place and time of your choosing. The discussion should take about an hour at the longest. The questions will relate to your perceptions of breast cancer, your awareness of the signs and symptoms and what you think you would do if you experienced any of the symptoms of breast cancer.

If I agree to take part what happens to what I say?

All the information you give me **will be confidential** and used for the purposes of this study only. The data will be collected and stored in accordance with the Data Protection Act 1998 and will be disposed of in a secure manner. The information will be used in a way that will not allow you to be identified individually. Interviews will be recorded, subject to your permission. Recordings of the interview will be deleted once I have produced a typewritten copy of the interview; this copy will be anonymised and you will not be identifiable.

Do I have to take part and if I agree now can I change my mind later

Taking part is voluntary. If you decide to take part you are still free to withdraw at any time and without giving a reason. In addition to withdrawing yourself from the study, you may also withdraw any information you have already provided up until it is analysed and about to be written into the final report. The deadline for notifying me should you want to withdraw from the study is 1st Sept 2011. The information you provide will be published as part of the final report and you will be sent a copy. Please **note that confidentiality and anonymity will be maintained** and it will not be possible to identify you from any publications**.**

What do I do next?

Think about the information on this sheet, and ask me if you are not sure about anything. If you agree to take part, I will contact you to make the arrangements, and before the interview commences, I will discuss the study information sheet with you and ask if you have any questions, before I ask you to sign a consent form to participate in the study. The consent form will not be used to identify you. It will be filed separately from all other information. If you do decide to take part you will be given this information sheet to keep. If you want any more information about the study please contact Abi Ajose-Adeogun abisoye.ajose-adeogun@kcl.ac.uk.

If this study has harmed you in any way please contact the study supervisor, Kirstie Coxon, or Chris McKevitt, the post graduate project coordinator; both of their contact details are provided below.

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CONSENT FORM FOR PARTICIPANTS IN RESEARCH STUDIES

Please complete this form after you have read the Information Sheet and/or listened to an explanation about the research.

Title of Study: ____

King's College Research Ethics Committee Ref:_______________

Thank you for considering taking part in this research. The person organising the research must explain the project to you before you agree to take part. If you have any questions arising from the Information Sheet or explanation already given to you, please ask the researcher before you decide whether to join in. You will be given a copy of this Consent Form to keep and refer to at any time.

Please tick or initial

- **I understand that if I decide at any time during the research that I no longer wish to participate in this project, I can notify the researchers involved and withdraw from it immediately without giving any reason. Furthermore, I understand that I will be able to withdraw my data up to the point of publication.** ☐
- **I consent to the processing of my personal information for the purposes explained to me. I understand that such information will be handled in accordance with the terms of the Data Protection Act 1998.** ☐
- **I consent to my interview being recorded.** ☐

Participant's Statement:

I ____

agree that the research project named above has been explained to me to my satisfaction and I agree to take part in the study. I have read both the notes written above and the Information Sheet about the project, and understand what the research study involves.

Signed Date

<u>DELETE IF NOT APPROPRIATE</u>

Investigator's Statement:

I _______________________________________

Confirm that I have carefully explained the nature, demands and any foreseeable risks (where applicable) of the proposed research to the participant.

Signed Date

8.3. Appendix 3: Ethics Approval Letter

14 June 2011

Dear Abi,

BDM/10/11-76 Exploring black women's lay beliefs of breast cancer and their help-seeking behaviour with a view to determining if these factors may contribute to a delayed diagnosis.

Thank you for sending in the amendments requested to the above project. I am pleased to inform you that these meet the requirements of the BDM RESC and therefore that full approval is now granted.

Please ensure that you follow all relevant guidance as laid out in the King's College London Guidelines on Good Practice in Academic Research (http://www.kcl.ac.uk/college/policyzone/index.php?id=247).

For your information ethical approval is granted until **14 June 2012**. If you need approval beyond this point you will need to apply for an extension to approval at least two weeks prior to this explaining why the extension is needed, (please note however that a full re-application will not be necessary unless the protocol has changed). You should also note that if your approval is for one year, you will not be sent a reminder when it is due to lapse.

If you do not start the project within three months of this letter please contact the Research Ethics Office. Should you need to modify the project or request an extension to approval you will need approval for this and should follow the guidance relating to modifying approved applications: http://www.kcl.ac.uk/research/ethics/applicants/modifications.html

Any unforeseen ethical problems arising during the course of the project should be reported to the approving committee/panel. In the event of an untoward event or an adverse reaction a full report must be made to the Chairman of the approving committee/review panel within one week of the incident.

Please would you also note that we may, for the purposes of audit, contact you from time to time to ascertain the status of your research.

If you have any query about any aspect of this ethical approval, please contact your panel/committee administrator in the first instance (http://www.kcl.ac.uk/research/ethics/contacts.html). We wish you every success with this work.

With best wishes
Yours sincerely

Joni Browne – Senior Research Ethics Officer

c.c. Kirstie Coxon

8.4. Appendix 4: Literature Search Key Words

1. Breast cancer AND beliefs AND black women
2. Breast cancer AND lay beliefs AND black women
3. Breast cancer AND beliefs AND black British women
4. Breast cancer AND lay beliefs AND black British women
5. Breast cancer AND beliefs AND African American women
6. Breast cancer AND lay beliefs AND African American women
7. Breast cancer AND health belief AND black women
8. Breast cancer AND health belief AND black British women
9. Breast cancer AND health belief AND African American women
10. Breast cancer AND help seeking behaviour
11. Breast cancer AND help seeking behaviour AND black women
12. Breast cancer AND help seeking behaviour AND African America women
13. Breast cancer AND help seeking behaviour AND black British women
14. Lay Beliefs AND health
15. Lay Belief AND illness
16. Help Seeking Behaviour
17. Care Seeking Behaviour

8.5. Appendix 5: Topic Guide

BDM 1011-76

Exploring black women's lay beliefs of breast cancer and their help-seeking behaviour with a view to determining if these factors may contribute to a delayed diagnosis

Dissertation: Topic Guide

Summary of the Structure of the Interviews

A qualitative study involving in-depth, part semi-structured/part structured, recorded, face-to-face interviews will be conducted. The interviews will consist of three sections as detailed below.

The first section will be a semi-structured segment that explores the beliefs of black women with respect to various aspects of breast cancer. It will focus on four areas: beliefs about breast cancer causation, the nature of breast cancer, risk perception and breast cancer prevention.

The next section will be the structured section of the interview. It will evaluate the accurate identification of the signs and symptoms of breast cancer. To explore the accurate identification of the signs and symptoms of breast cancer the structured segment of the interview will utilise the Cancer Awareness Measures (CAMs). The CAMs are a validated collection of questions designed to assess the level of awareness of cancer of a given population. The CAMs were developed by Cancer Research UK, King's College and the University of Oxford and have been successfully implemented in a number of studies to evaluate the public's level of awareness of cancer. There is a specific Breast Cancer CAM and this will be downloaded from Cancer Research UK's CAM page for use in this dissertation. Domain 1 of the Breast Cancer CAM, which is entitled 'Knowledge of Symptoms' will be used.

Once the level of awareness of the signs and symptoms of breast cancer has been evaluated then the anticipated help seeking will be explored through the final section, a semi-structured segment. This section will explore how black women would feel if they experienced any of the symptoms of breast cancer and how long it would take for them to seek help through contact with their GP. In addition, any barriers or motivators to seeking help will be explored.

Topic Guide

The topics below will be covered. The bullet points serve as prompts and sub questions to ensure each area is explored as fully as possible.

1. Lay beliefs about breast cancer
    - Exploration of their lay beliefs about breast cancer causation:

- Participants' views about the nature of breast cancer
- Participants' views about risk perception and breast cancer prevention (e.g: who might be at risk, and whether there are ways of reducing risk)

2. Awareness of the signs and symptoms of breast cancer
    - Tested through domain 1, Knowledge of Symptoms, of the breast cancer CAM (Cancer Awareness Measure, a validated set of questions designed to reliably assess cancer awareness.)

3. Help Seeking Behaviour
    - What would be their response if they found a lump in their breast or discovered a rash on their breast

    - If they noticed a lump or rash who would they talk to first

        - Determine at what point professional medical help would be sought
        - Determine if there are any barriers to seeking help, or if there is anything in particular that may motivate them to seek help promptly