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The Psychosocial Impact of Breast Cancer Diagnosis and Treatment in Black and South Asian Women

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Abstract

Breast cancer is the most common form of cancer in women of all ethnic groups. The diagnosis and treatment of the disease can be challenging and distressing for any individual. Research in this area has documented a range of physical, psychological and social consequences. However, very little work within the existing literature captures the experiences of Black and Minority Ethnic (BME) women, especially in the UK. The limited available research, based on American studies, show that while similarities in White and BME women's breast cancer experiences exist, there are also aspects that are unique and specific to BME women, which are influenced by socio-cultural norms, behaviours and beliefs. Therefore, the aim of this research was to explore the psychosocial impact of breast cancer diagnosis and treatment in British Black and South Asian women.

To research this area, a qualitatively driven mixed method approach was adopted. Four studies were undertaken, 3 qualitative and 1 quantitative. The first study was exploratory in nature, in which semi-structured one-to-one interviews were carried out with 11 Black and 11 South Asian women. The findings of this study informed the subsequent studies, the second of which consisted of focus group interviews with 10 Black and 10 South Asian women to explore the ways in which breast cancer experiences are managed. The third study involved interviews with 5 South Asian Indian, Gujarati-speaking women (with limited English proficiency). The findings from these studies show that psychosocial and cultural factors (such as support, appearance concerns, healthcare experiences, cultural beliefs about cancer, understanding of cancer and language barriers) play an important role in shaping BME women's experiences of breast cancer. These findings informed the development of the final questionnaire study. This study investigated the psychosocial impact of breast cancer and aimed to compare breast cancer experiences between White, Black and South Asian women. A total of 173 women participated (80 White, 40 Black and 53 South Asian). The results from this study show that psychological distress, social support and receiving chemotherapy treatment are associated with quality of life. Furthermore, similarities and differences in Black, South Asian and White women's breast cancer experiences (in relation to psychological distress, quality of life, control beliefs (pertaining to cancer), body image concerns and sources of support) are evident.

The findings from this research highlight important implications for policy makers, healthcare professionals and researchers to enhance awareness and understanding, and to ensure the provision of culturally competent care and support to future breast cancer patients.

Introduction

The focus of this thesis is to explore the psychosocial impact of breast cancer diagnosis and treatment in Black and South Asian women. To begin, chapter 1 will provide a literature review of two important areas: ethnicity and health, and breast cancer in ethnic minority women. This provides a clear rationale for conducting this research. The methodological approach adopted for this thesis is then presented in chapter 2, including sampling and researching ethnic minority populations from insider and outsider positions. This is followed by the four studies which comprise the research (chapters 3, 4, 5 and 7). The three qualitative studies (chapters 3, 4 and 5) have produced very similar themes and therefore the findings are discussed collectively in chapter 6. To end, the final chapter of this thesis summarises the research studies, discusses the implications of this research and allows the researcher to reflect on the appropriateness of using mixed methods to research this phenomenon (chapter 8).

Throughout this thesis, key terms are defined. However, medical breast cancer terms are further defined in the glossary (appendix 1).

1 Review of the literature

The aim of this chapter is to provide a framework for the rationale of this thesis. The chapter is divided into 2 parts. The first comprises of a review of the ethnicity and health literature. In this section key terms around ethnicity are defined. The two groups which are the focus of this thesis, Black and South Asian populations, are defined and discussed in relation to their cultural and migration histories. This background information is placed within the health context, placing emphasis on the importance of providing culturally competent care to meet ethnic minority patients' healthcare needs.

The second part of this chapter focuses on a review of the current breast cancer literature. To put this in context, the section outlines the epidemiology and aetiology of the disease before the psychological and social impact is explored. This is discussed in more detail, drawing on the available Black and Minority Ethnic (BME) breast cancer literature. By the end of this chapter, the rationale for researching this topic will become clear.

Part 1 Ethnicity and health

1.1 Introduction

The United Kingdom (UK) is a multi-cultural society, made up of populations from a diverse range of ethnic backgrounds (Sander, 2000). The most recent available figures, based on the 2011 Census, show that more than 9 million people living in the UK are from ethnic minority groups (Office for National Statistics, 2011a). Black and South Asian populations represent the largest ethnic minority communities in the UK (8.8%). These groups are known to be more at risk of some chronic illnesses compared to the White population (i.e. heart disease and some cancers, such as prostate cancer; NHS, 2005; National Cancer Intelligence Network (NCIN), 2009) and they can find it difficult to access healthcare services that are able to meet their needs from a cultural perspective (Atkin, 2003). There is an underlying assumption that policies and healthcare services are appropriate for everyone, that is according to the 'white norm' (Robinson, 2001). Such practices fail to recognise the healthcare needs of ethnic minority communities (Mason, 2000). Ethnic minority groups may differ in the ways in which they communicate and understand illnesses which can be influenced by their cultural norms and beliefs. The NHS is driven to utilise a patient-centred approach, whereby emphasis is placed on providing high quality care and support that meets patients' healthcare needs (Department of Health, 2005). Healthcare professionals therefore need to be aware of the UK's increasingly diverse multi-ethnic society and focus on delivering culturally competent care which has the potential to bridge the health inequalities gap (Department of Health, 2007; Pesquera, Yoder & Lynk, 2006; Szczepura et al, 2005).

Before the provision of culturally competent care is discussed, it is important to understand and define key terminology and classifications of ethnicity and the population under study.

1.2 Definitions

1.2.1 Defining race and ethnicity

The concepts of 'race' and 'ethnicity' are widely used in society under various contexts, including politics, education, research, healthcare settings, and as part of everyday discourse. One of the key goals within health settings is to reduce health inequalities between people belonging to different ethnic groups (House of Commons, 2009). Despite a clear goal, the use of terms such as race, ethnicity and culture have generated a great deal of debate and controversy.

There are no widely accepted standardised definitions of race and ethnicity, and as a result researchers fail to differentiate between these (often described as complex) concepts, resulting in the utilisation of such terms synonymously or as single labels, i.e. race/ethnicity, race and ethnicity, race-ethnicity (Comstock, Castillo & Lindsay, 2004; Pfeffer & Moynihan, 1996). Consequently, this can raise issues in health related research, particularly for researchers investigating health inequalities. For example, researchers may inaccurately attribute health disparities to people based on their race or ethnicity and fail to adequately study and understand the underlying causes of such inequalities that can be determined by other factors such as socio-economic status, lack of education, cultural perceptions of illnesses, racism or the inability to appropriately access health services (Comstock et al, 2004; Jones, 2000). Previous researchers have recommended that these concepts should be clearly defined and differentiated, justified in research studies and other information that may potentially be associated with race or ethnicity (such as socioeconomic status or country of origin) should also be collected (Hahn & Stroup, 1994; Jones, LaVeist & Lillie-Blanton 2001; Senior, 1994; Singh, 1997). However, this is not widely acknowledged. In reviewing 1,198 published articles between 1996 and 1999, Comstock et al (2004) found that 76.7% of the articles referred to concepts of race and ethnicity although the majority of articles failed to describe the rationale for including race or ethnicity in their study and great diversity existed in terminologies between researchers. However, the authors concluded that the diversity in the terms used in relation to ethnicity and race can be due to wanting to include detailed information about a group's background or as a means to ensure that the terms used are politically correct.

1.2.1.1 Race

Race is most commonly defined as a group that one belongs to based on physical characteristics such as facial features, skin colour and hair texture, and have different ancestral roots and origins (Bhopal, 2007). Historically (dating back to the early 19th century), race was understood through a bio-scientific concept; based on the assumption that genetic make-ups differ between different groups of people (Szczepura et al, 2005). This concept has been discredited by many health researchers, including epidemiologists, as evidence shows that 99% of one's genetic make-up is common to all populations and genetic diseases are not confined to specific racial groups (Bhopal, 1997; Pfeffer & Moynihan, 1996; Szczepura et al, 2005).

The modern concept of race has been put forward from a social constructivist perspective, whereby the emphasis is placed on its social origins (Kaplan & Bennett, 2003); although race is still based on

physical factors, this notion is de-emphasised in social epidemiology. Some researchers are reluctant to use the term 'race' due to inaccurate (biological) definitions or because it is viewed as politically incorrect due to its social and historical associations that undermined some races (i.e. slavery of Black Africans or the Nazi's programme of racial hygiene; Bhopal, 2004; Pfeffer & Moynihan, 1996). The two terms most commonly used in relation to race are Black and White. If a person is not White and is of another skin colour, then they are described as being Black (Bhopal & Donaldson, 1998). This can be problematic as referring to non-White people as Black indicates that they belong to a homogenous group and ethnic minority populations are by no means homogenous (detailed in section 1.3). However, in other contexts such as the study of racism, the concept of race is important and needs to be emphasised. Thus the term 'race' is context dependent and while some areas of research may not consider it an appropriate term, other fields (e.g. epidemiologic research) may find it highly relevant.

1.2.1.2 Ethnicity

Within health research, ethnicity is generally the preferred term and is slowly replacing the concept of race (Afshari & Bhopal, 2002; Bhopal, 2007; Smaje, 1995). Ethnicity is not only defined by one's colour or race but by various shared qualities such as religion, language and kinship. It is a multi-faceted construct and because of this it varies in the factors that incorporate its definition. This makes it difficult to determine one set definition, further making it a complex concept (Gill, Kai, Bhopal & Wild, 2004; Bhopal, 2007). At best the term ethnicity can be defined as a "social group a person belongs to, and either identifies with or is identified with by others, as a result of a mix of cultural and other factors including one or more of language, diet, religion, ancestry, and physical features traditionally associated with race" (Bhopal, 2007 p311). People may identify themselves through their ethnicity or through their culture. Therefore, culture and ethnicity are also terms that are used interchangeably (Pfeffer & Moynihan, 1996). Culture, however, is an even broader term, encompassing the shared practices, beliefs, attitudes and rituals that characterise a group (Szczepura et al, 2005). Ethnicity can also include cultural variations and individuals may feel they identify with more than one culture (the process of acculturation is described in section 1.3.1).

1.2.2 Black and Minority Ethnic (BME)

Ethnic groups, as defined by the 2011 UK census, are divided into 5 main categories: White, Mixed/multiple ethnic groups, Asian or British Asian, Black or Black British and other ethnic group. Sub-groups within each category are also included. For example, within White there is the option to select English/Welsh/Scottish/Northern Irish/British, Irish, Gypsy or Irish Traveller or any other White background, and within Asian the options are Indian, Pakistani, Bangladeshi, Chinese or Other Asian (Office for National Statistics, 2011b). The ethnic groups relevant to this thesis are defined below. Before the specific ethnic groups (Black and South Asian) are defined, it is important to understand the term Black and Minority Ethnic (BME).

In the UK, the term ethnic minority refers to a group who differ from the majority of the population because of their non-European origin and non-White status (Bhopal, 2007). Another word often

used to describe ethnic minority people is 'Black'. This term is often used to describe those of African and Caribbean, South Asian and other Asian origins; who have a shared experience of discrimination amongst those whose skin colour is not White (Bhopal, 2004). However, the politically correct term and one most commonly used is Black and Minority Ethnic. The word ethnic suggests that the BME term is not only defined by one's colour or race but by various shared qualities such as religion, language and kinship. This definition is similar to the concept of ethnicity (see above).

Conversely, ethnic majority refers to a group of people who make up the majority of the population. In the UK, this is the White population. The terms Caucasian, indigenous, Western and European are also used synonymously with the term White (Bhopal, 2007). However, the definition of Caucasian has been criticised for being highly ambiguous (Bhopal, 2007). This term derives from the word Caucasus, described as a geographic region which borders Europe and Asia (Bhopal & Donaldson, 1998). Based on the geographical notion, it was previously thought that those originating from countries such as China, India, Pakistan and Iran were Caucasian. The term was also used to refer to Indo-Europeans. Bhopal and Donaldson (1998) conclude that "except as an erroneous euphemism for referring to persons of European descent, the word has little value in race, ethnicity, and health research" (p1304). For clarity purposes the term White will be used to describe the majority of the population throughout this thesis.

1.2.3 South Asian population

The term Asian is often used to refer to a person from the Asian continent. However, this term is often inappropriately used within the media and varies in its definitions in different parts of the world. For example, in the United States, the term Asian is often used to refer to people from East and South-East Asian countries such as China, Japan, Korea, Philippines and Malaysia; while in the UK, the term Asian is used to describe a person from the Indian sub-continent (Bhopal, 2007). This can become problematic for international readers, particularly when generalising findings or when carrying out literature searches. For this reason, it is important to use specific terminologies when possible. For example, if a group being studied belong to a particular sub-group, i.e. Gujarati Indians or Pakistani Muslims, then this should be clarified.

For the purpose of this thesis, the term South Asian is the preferred terminology (unless all the women belong to the same sub-group, at which point the specific sub-group will be named) and will be used throughout to identify people originating from the Indian sub-continent, including countries such as India, Pakistan, Bangladesh, Sri Lanka, Nepal and Bhutan (Bhopal, 2007). Those who were born in or have immigrated to East Africa (mostly from Kenya, Uganda and Malawi) but have ancestry in the Indian sub-continent are also classified as South Asian. These groups can also be known as East African Asians or African Asians (Singh-Ghuman, 1994; Jones, 1996).

1.2.4 Black population

In the UK, the term Black is used to refer to a person whose origins lie in Africa, in countries such as Nigeria, Somalia, Kenya and Uganda. One can self-identify or can be identified as Black, Black African or Black Caribbean. Caribbean people still have African ancestral origins but settled in the Caribbean (such as Jamaica, Trinidad and Barbados) before immigrating elsewhere (Bhopal, 2007). The terms Afro-Caribbean or African-Caribbean are also commonly used. When discussing African and Caribbean populations, the term Black or British Black will be used interchangeably throughout this thesis and when possible, precise terminology such as Black Caribbean and Black African will be used to single out specific groups.

1.3 Diverse BME communities: An in-depth exploration

BME communities are by no means homogenous, encompassing diversity in various domains such as migration history, geographic origins, cultural beliefs, values and attitudes, language, religion and socioeconomic status. While similarities such as ancestral origins, shared cultural norms and practices such as similar lifestyles (i.e. food and clothing) exist, the South Asian community is further divided into various sub-groups (such as Indian, Bangladeshi, and Pakistani) that are characterised by a range of diversities, including religion (Islam, Sikhism and Hinduism), language (Urdu, Bengali, Gujarati and Punjabi), place of origin and cultural beliefs and traditions (Ahmed & Lemkau, 2000). Even within the Black community, faiths, languages/dialects, cultural traditions and beliefs, and lifestyles (i.e. food) will also vary (Guidry, Matthews-Juarez & Copeland, 2003).

1.3.1 Migration history and acculturation

In 2011, an estimated 12% of the UK population were born abroad (Office for National Statistics, 2012). Emigrating to developed countries (such as UK, America and European countries) to seek better opportunities and improve one's way of living, both economically and culturally, has been an on-going occurrence; especially since the Second World War, when the UK was experiencing post-war labour shortages (Mann, 2009). In the 1950s, immigration to the UK was mainly from people living in the Caribbean and India. South Asians from India, Pakistan and East Africa (including double immigrants; often emigrating from the Indian sub-continent, and then from East Africa to the UK) settled in the UK in the 60s and 70s, while Black Africans emigrated from West, East and Southern Africa in the 80s and 90s (Deepak, 2004; Dustmann, Fabbri, Preston, & Wadsworth, 2003; Ghuman, 1994), settling mainly in the London, Birmingham and Manchester areas (Koffman et al, 2008).

Deepak (2004) has outlined two groups of immigrants: those who migrated to the UK or another country, either on their own or with a partner (known as first generation immigrants) or those who came as a family with two or more generations. However, Deepak fails to state whether the latter group would also be categorised as first generation immigrants or the generation status would depend on how many generations moved. For example, if two generations (e.g. mother and daughter) came to the UK, the first generation (i.e. mother) would be known as 'first generation immigrants' and the second generation (i.e. daughter) as 'second generation immigrants'. These

definitions and classifications of generation status would also depend on how one is defining generation. According to Steadman's Medical Dictionary (2002), the term generation can be defined as a group of people born and living about the same time as each other or a group of individuals belonging to a specific category at the same time. If the latter definition was to apply, then those who immigrated with two or more generations would all be classed as first generation immigrants.

Defining individuals based on their generation and immigrant status becomes further complicated and ambiguous when discussing second and third generations. The status 'second generation' is often given to someone who is a citizen of a country, but whose parents were born in another country (Macmillan Dictionary, 2009). Therefore, the individual would be known as a second generation immigrant, although the individual is not actually an immigrant. A preferred (and accurate) term would be second generation [followed by the country of birth/nationality] such as second generation Briton/British born (Suinn, Ahuna & Khoo, 1992; Van Ours & Veenman, 2003). An individual belonging to the third generation would be one who is born in the UK and whose parents were born in the UK but grandparents born in another country (Suinn et al, 1992).

Research exploring generational differences rarely state what they mean when they are referring to first generation or second generation immigrants but employ such commonly used terms on the basis that the reader will understand it to mean the same thing, with little or no justification. For example, some researchers determine one's generational and immigration status based on age. Inman (2006) defined first generation as those who immigrated to the US after the age of 20 and second generation as those who were either born in (second generation resident) or immigrated to another country before the age of 12 (second generation immigrant). Whereas Van Ours and Veenman (2003) conceptualised second generation immigrant as an individual who was born in a country from at least one immigrant parent or those who immigrated to the new country at or under the age of 6.

For clarity purposes (as defined by Deepak, 2004), those who migrated to the UK, either by themselves or as a family with two or more generations will be referred to as first generation immigrants or the older generation. Individuals born in the UK but whose parents are born elsewhere will be known as second generation Britons or the younger generation.

People who have migrated to the UK bring with them their country's cultural values and belief systems. The diversity within the BME communities further extends to the varying demographic status such as occupation and language abilities. For example, many people will have emigrated from villages or small towns where they have spent their time working in manual jobs, having received little or no education, whereas others will have acquired high levels of education and arrived in the UK as highly skilled professionals such as doctors (Deepak, 2004). Arriving in the UK at different points in time, for varying reasons (such as poverty or other political issues), speaking only their mother tongue language or speaking one or more languages (often including English) further demonstrates the diversity of the BME population which has the potential to influence cultural expectations, understanding of health systems and ability to adapt to the new country of residence.

Immigration to another country can be a difficult process, especially if the new country differs greatly from the individual's homeland. Adapting to new cultural norms and ways of living, familiarising oneself with laws, regulations and healthcare systems can be daunting and distressing for any individual (Bhattacharya & Schoppelrey, 2004), particularly for those who are keen to

maintain their cultural traditions and affirm their ethnic culture in the new country (Dasgupta, 1998). The extent to which a person has adopted and adapted to the norms and values of the new culture is known as acculturation (Ahmed & Lemkau, 2000). This can be broken down into four main groups: Assimilation (exclusive identification to the new/dominant culture, completely rejecting their own culture), marginalisation (rejection of both their own and the new culture), separation (rejection of the new culture and sole identification with own culture) and integration (identification with both cultures, also known as bicultural) (Farver, Narang & Bhadha, 2002). Levels of acculturation have the potential to change over time, context and across generations (Phinney, 2003).

Acculturation plays an important role in the adjustment process in first generation immigrants and second generation Britons. The degree of acculturation has been found to influence individuals' experiences in healthcare settings and interactions with healthcare professionals (Anderson et al, 2003). This is also dependent on intra-familial and inter-generational interactions (Ahmed & Lemkau, 2000). First generation immigrants, who have migrated at an older age are likely to find it particularly hard to adjust to the new culture and are keen to maintain their cultural traditions and affirm their ethnic culture in the new country (Dasgupta, 1998). More often than not these groups of individuals find it difficult to engage with the new country's culture due to cultural and language barriers that may make it difficult for them to interact with others and access healthcare services. Therefore, they often associate only with other people from their homeland and are not always keen to assimilate to the new culture (Ahmed & Lemkau, 2000). However, first generation immigrants who migrated at a young age (i.e. before the age of 12) and have therefore spent the majority of their time in the new country may experience intergenerational strains as they become divided between the 2 cultures (Ahmed & Lemkau, 2000). This can also apply to second generation Britons. This is because these individuals are exposed to both the western culture (e.g. dating, partying and love marriages) and their own cultural norms, values and beliefs (which the older generation are trying to preserve). This is especially difficult when both cultures contradict each other. For example, love marriages are a norm in many western cultures, whereas older generations from the South Asian culture believe in arranged marriages (Ahmed & Lemkau, 2000).

Within the health context, differences between generations and levels of acculturation have been found to influence individual's health beliefs, experiences in healthcare settings and interactions with healthcare professionals (Anderson et al, 2003). For example, older generations, recent immigrants and those who are less acculturated may be more likely to internalise myths about diseases such as cancer and believe that 'cancer is contagious'. Ashing-Giwa et al (2004) suggest these individuals are less likely to have a clear understanding of their illness and may not be so proactive in seeking medical help. Whereas more acculturated BME and White individuals are more likely to stress the importance of being proactive in seeking medical help and therefore have better access to care. Attitudes towards cancer also differ between the older and younger generation. The older generation may be more likely to internalise cultural taboos and beliefs that cancer equals death and keep such matters hidden. Conversely, the younger generation may be more open to talk about their illness and often try (without much success) to encourage the older generation to be more open (Deepak, 2004).

Due to the varying levels of acculturation and immigration status, it is important that healthcare professionals do not make assumptions about one's cultural background or on the type of care and support that should be provided.

1.4 Cultural competence in healthcare

The abundance of immigration to the UK from the Asian, African and Caribbean regions has seen a proliferation of cultures and foreign languages. This rise in ethnic and cultural diversity has highlighted the need for healthcare professionals to provide culturally competent care and support to their patients (Szczepura et al, 2005), yet addressing such care has been found to be challenging.

Cultural competence in healthcare refers to the ability to provide care and respect to people of all cultures and take into account ethnic backgrounds, languages spoken, beliefs, values, religions, and other diverse factors (Anderson et al, 2003). For some time now this has been a high priority in closing healthcare disparity gaps in the UK (Department of Health, 2007; National Institute for Health and Clinical Excellence (NICE), 2004). Despite this goal, research suggests that compared to the majority population, BME groups (particularly first generation immigrants) face greater challenges when accessing health care services due to unfamiliarity with healthcare systems, cultural issues and language differences which can result in late diagnosis, poorer uptake of screening and affect one's ability and confidence in accessing healthcare services (Deepak, 2004; Johnson et al, 2004; Lodge, 2001; Papadopoulos & Lees, 2004; Watts, Merrell, Murphy & Williams, 2004).

There exists an inaccurate assumption amongst some healthcare services that low uptake of services in BME communities is due to the lack of interest in health and social care services (Vernon, 2002). However, research has shown that it is cultural and linguistic barriers that affect BME community members' (especially women and the older generation) ability and confidence in seeking care (Cox, Kelly, Talman, & Coutts, 2007; Szczepura et al, 2005; Thalassis & Taha, 2006). Moreover, healthcare professionals often struggle in communicating with BME patients due to language differences and because they lack appropriate cultural awareness and knowledge of the patients that they are treating, making it harder to provide good quality care (Cortis, 2004; Kai et al, 2007).

This has important implications for healthcare professionals in providing care and support that is culturally appropriate. The two widely acknowledged barriers (cultural barriers and linguistic barriers) that contribute to the importance of providing culturally competent care are detailed below.

1.4.1 Cultural barriers

Cultural beliefs, values and customs will influence an individual's health beliefs and experiences including the way in which the disease and its symptoms are perceived and managed, and the type of information needed (Szczepura, 2005). Examples of cultural beliefs on diseases such as breast cancer are based around the belief that it is contagious or a 'White woman's disease' (Balneaves et al, 2007; Watts et al, 2004). Diagnoses of such illnesses can be an isolating time for BME patients as, culturally, the norm is to keep personal issues hidden in order to avoid being stigmatised and to maintain their reputation within their communities. Religious beliefs (strong faith in God) and holding fatalistic attitudes are often used as an effective way in which BME women deal with health related concerns. Such beliefs have the potential to affect compliance to treatments or reluctance in accessing healthcare services (Ashing, Padilla, Tejero & Kagawa-Singer, 2003; Szczepura, 2005).

Prohibition in openly talking about or touching one's private body parts (even as a means of self-examination) are also widely held beliefs and norms that exist in many BME cultures (Ashing et al, 2003). For this reason many find it difficult to access healthcare services due to the issues of modesty and reputation that are emphasised in their cultures. Due to the importance placed on a woman's modesty, many do not find it appropriate to be examined or treated by a male healthcare professional (Lodge, 2001) and therefore reluctance in accessing healthcare services or a preference to be treated by female healthcare professionals exist (Nazroo, 1997).

Other cultural factors such as family dynamics can mean patients may not always be able to seek appropriate care without a family member's support and they may seek help at later stages, particularly in cultures where great emphasis is placed on prioritising family needs before their own (Bottorff et al, 1998; Szczepura, 2005).

Healthcare professionals need to be aware of cultural beliefs and values which have the potential to exert a positive and/or negative impact on people's health perceptions and experiences. For example, an awareness of cultural taboos or showing sensitivity to patients' cultural needs and beliefs (i.e. religious beliefs and practices) can help them to provide appropriate care and support (Ahmed & Lemkau, 2000). An awareness of the diverse religions that exist in the Indian sub-continent is also important and as a result, healthcare professionals should avoid making assumptions based on religious or cultural beliefs amongst the heterogeneous Black and South Asian populations. If patients are hospitalised, healthcare professionals and hospital managers (who dictate the policies that determine patient care) need to be aware of the varying cultural needs such as specific dietary requirements (e.g. Muslims only eat Halal meat) and practices (e.g. Islamic traditions require Muslims to pray 5 times a day) (Ahmed & Lemkau, 2000). This would enable patients to feel comfortable and confident in accessing healthcare services and go a long way in making their experience of the service better.

1.4.2 Linguistic barriers

As well as being aware of the patient's cultural beliefs, norms and values, linguistic competence is also important as language barriers have been known to hinder communication between the patient and the healthcare professional, making it difficult for BME populations to access health care services (Butow et al, 2011; Owens & Randhawa, 2004). Limited proficiency in the English language is particularly evident in South Asian and Chinese populations, especially women and the older generation (Brach & Fraser, 2000; Brenner, 2002; Gill et al, 2004). Differences in English abilities can also exist. An individual may have a good understanding of the English language but may not be confident in speaking or reading it (Szczepura et al, 2005). As a result, health promotion and awareness messages may not always reach BME groups due to unavailability of the information in their own language.

To overcome language barriers, providing interpreters and translating material into the patient's language can help in meeting their healthcare needs, encourage appropriate communication between the patient and the healthcare professional, and enhance the patient's understanding and knowledge of health related issues (Dunckley, Hughes, Addington-Hall & Higginson, 2003; Szczepura, 2005). In cases where information is provided in an individual's mother-tongue language, healthcare

professionals need to be aware that not everyone (particularly first generation immigrants) will be able to read or write in their own language. Research has shown that over half of Bangladeshi and Pakistani women are illiterate in their own language (Rudat, 1994). Other mediums to deliver information, such as television, radio or audiotapes may prove to be better sources of providing information and overcoming language barriers (Szczepura, 2005; Watts et al, 2004). It is also important to note that not all information can be easily translated into another language. For example, there is no acceptable word for 'breast' or 'cancer' in some South Asian languages such as Hindi and Punjabi (Bottorff et al, 1998). Despite this, it is worth noting that various UK cancer charities such as Macmillan Cancer Support, Breast Cancer Care and Cancer Black Care have produced high quality, culturally sensitive information for BME groups, available through various mediums (i.e. audiotapes, videos and DVDs) to aid comprehension about cancer and its treatment (Trevatt & Kelly, 2006).

Appropriate use of interpreters or bilingual/bicultural staff members is another way to overcome language barriers and aid communication between a healthcare professional and a patient with Limited English Proficiency (LEP; Szczepura, 2005). However, working with interpreters can result in additional challenges (discussed in part 2 of chapter 5).

1.5 Implications for healthcare professionals

Based on the barriers outlined above, it is important that the care provided meets patients' needs, culturally. Campinha-Bacote (1994) has put forward a model of cultural competence that healthcare professionals can use as a framework for providing culturally competent care. This model views cultural competence as an on-going process for healthcare professionals in order to achieve competent care within the cultural context. The model comprises of five integrating components: cultural awareness (the process of exploring one's culture and being sensitive to cultural differences), cultural knowledge (developing an understanding of one's cultural beliefs, values and practices), cultural skill (the ability to apply cultural knowledge when assessing and caring for the patient), cultural encounters (the on-going process of engaging with patients from different cultures and continually developing one's knowledge and skills) and cultural desire (the desire and motivation to provide care that is culturally responsive, and wanting to be culturally aware, knowledgeable and skilled in engaging with patients from different cultural backgrounds).

Health inequalities can be reduced by ensuring a delivery of culturally competent care to all patients. Chevannes (2002) conducted an interview study on healthcare professionals' knowledge of BME groups' health concerns before and after taking part in a cultural diversity training programme. Before training, healthcare professionals acknowledged that they lacked knowledge of BME groups' cultural beliefs and values. Cultural specific training and education on BME groups was limited and healthcare professionals stated the need to be trained appropriately in order to meet BME groups' cultural needs. Furthermore, language barriers were a major hindrance in their ability to provide good quality care and they lacked language awareness which made it difficult in knowing what type of interpreters to include in the consultations. However, after the training programme, healthcare professionals were more aware of BME groups' healthcare needs and some mentioned how the training was transferred in their practice.

Other researchers have also provided recommendations on this issue for policy makers, healthcare professionals and researchers (Ahmed & Lemkau 2000; Anderson et al, 2003; Bhopal, 2007; Chin, 2000), including:

- Cultural competence training for healthcare professionals to enhance self-awareness and increase knowledge and understanding about cultural beliefs, attitudes, behaviours and values in different populations.
- On-going education and support for staff in culturally and linguistically competent service delivery.
- Make effective use of cultural and linguistic interpreters for clients with limited English proficiency.
- Make effective use of linguistically and culturally appropriate health education materials.
- Do not assume knowledge without verification.
- Programmes to recruit and retain staff members who reflect cultural diversity of the community.

1.6 Summary

Part 1 of this chapter has defined and clarified key terms that will be used throughout this thesis. The concept of ethnicity in healthcare settings and the importance of providing culturally competent care in order to reduce health disparities amongst BME communities have also been discussed. Culturally competent healthcare systems can promote health and increase quality of life in patients, who in turn will gain trust in the health care system and have the confidence to access them.

Part 2 Breast cancer in Black and South Asian women

1.7 Introduction

This section presents a literature review of the psychosocial impact of breast cancer in BME patients. Breast cancer patients will be referred as breast cancer survivors throughout this thesis. A breast cancer survivor can be defined as an individual “living with or beyond cancer” (Macmillan Cancer Support (2008) p6). This can include an individual who has completed initial cancer management and has no active disease, is living with progressive (but not terminal) disease and may be receiving treatment, or has had cancer in the past (Davies, 2009).

1.8 Epidemiology of Breast cancer

Breast cancer is the most commonly diagnosed cancer worldwide; accounting for almost one-third (31%) of all cancer cases in women in the UK. The estimated lifetime risk of developing breast cancer at any given time is 1 in 8 for women in the UK (Cancer Research UK, 2011). In 2009, 48,417 women were diagnosed with the disease (Cancer Research UK, 2011).

Breast cancer is the second most common cause of death in women, after lung cancer (Cancer Research UK, 2011). While the incidence of the disease is increasing, recent statistics show that the mortality rates of breast cancer have been decreasing since the introduction of the breast screening programme in the UK, in 1988. Early cancer detection and advances in treatments over the last 30 years mean that breast cancer has one of the highest five-year survival rates; reaching 82% for women who were diagnosed with breast cancer between 2001 and 2006, compared to 52% of women diagnosed between 1971 and 1975 (Cancer Research UK, 2011).

There is no one specific cause of breast cancer; although certain hereditary, environmental and/or lifestyle risk factors have been linked to the incidence of the disease (American Cancer Society, 2011). Risk factors can also change over time, due to factors such as age or lifestyle change. For example, breast cancer is strongly related to an increase in age. 81% of cases occur in women aged 50 years and over and almost 50% of cases occur in women between the ages of 50 and 69 (Cancer Research UK, 2011). Other known risk factors include a woman’s family history of the disease. Blood relatives (mother or sister) who have been diagnosed can double a woman’s risk (American Cancer Society, 2011) but it is important to note that 85% of women with breast cancer have no family history of the disease and 85% of women who have a family history will never develop the disease. A woman’s exposure to oestrogen throughout her lifetime can also increase the risk of breast cancer. For example, early menarche, late first pregnancy, and late menopause are linked to increased risk. Lifestyle factors such as alcohol consumption and obesity have also been linked to an increased risk (Macmillan Cancer Support, 2011). The presence of risk factors is not conclusive. Having one or more risk factors does not indicate a definitive chance of developing the disease. Similarly, women who are diagnosed as having breast cancer may not have any related risk factors.

1.9 Psychosocial impact of breast cancer

The diagnosis and treatment of breast cancer can be a challenging and distressing experience for any individual. Within the last four decades, a vast amount of research has documented various physical, psychological and social consequences. Dealing with a life threatening illness, undergoing painful and impairing treatments, and acceptance of a new identity can cause psychological distress, depression, anxiety and affect one's quality of life (Golant, Altman & Martin, 2003; Helms, O'Hea & Corso, 2008). Anxiety and depression have been found to be the two most commonly reported psychological problems experienced by breast cancer patients (Burgess et al, 2005; Deshields, Tibbs, Fan & Taylor, 2006; Knobf et al 2006; Reich, Lesur & Perdrizet-Chevallier, 2008; Shapiro et al, 2001; Thewes, Butow, Girgis & Pendlebury et al, 2004). A diagnosis of breast cancer can also elicit feelings of helplessness and loss of control (Anderson, Kiecolt-Glaser & Glaser, 1994). It is at this point that women have to make decisions on treatment choices (such as surgery and/or adjuvant treatments including radiotherapy and chemotherapy) which can further precipitate increased feelings of anxiety, depression, uncertainty and vulnerability (Knobf, 2007; Reich et al, 2008).

Other psychosocial issues include worry, social stigma, lowered self-esteem, employment factors, impact on family and relationships, an increased sense of vulnerability, uncertainty about the future, and fear of death (Cappiello, 2005; Fobair et al, 2006; Harmer, 2006; Hegel et al, 2006; Schnipper, 2001; Spencer et al, 1999). On a long-term basis, the impact of the threat and uncertainty of recurrence can also cause anxiety and depression (Ferran, 1994; Oh et al, 2004).

Although breast cancer can be an emotional experience, levels of distress vary according to disease severity, treatments and the phase of life one is in. For example, while breast cancer is distressing for women at any age, it has been found that younger women tend to report greater levels of distress than older women (Avis, Crawford & Manuel, 2004; Baucom et al, 2006; Kroenke et al, 2004). However, this does not mean that undergoing a breast cancer diagnosis and treatment is not a distressing issue for older women (Ganz et al, 2003).

The treatment of breast cancer can also elicit concerns regarding one's self concept, body image and sexuality (Kinamore, 2008; Pelusi, 2006). Western societies place great value and importance on physical appearance (Baucom et al 2006), whereby the breast is seen to represent sexuality, attractiveness, desirability and affection (Lamb, 1995). From a symbolic perspective, the breast is also seen to represent feminine identity, womanhood, nurturance and motherhood (Pickler & Winterowd, 2003). Consequently, surgical treatments such as mastectomy, lumpectomy or breast reconstruction can affect a woman's self-image and not only challenge one's perceived levels of attractiveness but can also instigate femininity issues and impact on personal/intimate relationships (Anllo, 2000; Frost et al, 2000; Harmer, 2006). Furthermore, treatments such as chemotherapy, radiotherapy and adjuvant therapy come with adverse side effects such as hair loss, infertility, fatigue, weight gain/loss, decreased libido and menopausal symptoms; all of which can seriously threaten a woman's self-image and feelings of femininity (Shapiro et al, 2001). A study by Bender et al (2005) found that on completing chemotherapy treatment, breast cancer participants reported side effects such as insomnia, fatigue, memory and concentration problems, weight gain and menopausal symptoms. This had a negative psychological impact on the women, increasing feelings of depression and anxiety.

Breast cancer survivors frequently report body image concerns, including dissatisfaction with one's appearance, self-consciousness, feeling sexually unattractive, and loss of femininity and body integrity, (Cohen, Kahn & Steeves, 1998; Ganz et al, 2003; Helms et al, 2008; Hopwood, 1993; White, 2000). There is no general consensus if body image concerns differ according to the type of surgical treatments (Goldberg et al, 1992; Schover et al, 1995); although most studies have found that body image concerns are more frequent amongst women who have undergone a mastectomy compared to lumpectomy patients (Avis et al, 2004; Ganz et al, 1998; Rowland et al, 2000). For example, Ganz et al's (1998) mastectomy participants reported decreased libido, feeling sexually unattractive and feeling uncomfortable with their body image changes both one year and three years post-treatment, compared to those who had a lumpectomy.

The negative consequences of breast cancer can have a detrimental effect on women's overall quality of life (NICE, 2004) and further precipitate psychological distress, which can persist for several years after treatment has ended (Alfano & Rowland, 2006). The current literature suggests that breast cancer survivors' quality of life is perceived to be the lowest after completing treatment (Deshields et al, 2006; Ganz et al 2004). The first 100 days post-treatment are filled with high emotional and psychological distress as women begin to reflect on their overall breast cancer experience and accept their new identity as a breast cancer survivor (Knobf, 2007). During treatment, women typically feel that they are actively doing something to get rid of the cancer. Their emotions become secondary while they strive to get through their treatments (Cowley, Heyman, Stanton & Milner, 2000). However, once treatment is over and regular access to healthcare providers changes to follow up appointments, feelings of worry, vulnerability, uncertainty, distress and mixed emotions are likely to resurface as well as additional feelings of isolation and abandonment (Boyle, 2006; Knobf, 2007). Such responses are further elevated for women who endure long term effects from the treatment such as fatigue, hair loss, weight gain, menopausal symptoms and lymphoedema (Knobf, 2007). A natural response to the completion of treatment is relief that the cancer has been treated and along with that, regular access to support sources such as family, friends and healthcare professionals may reduce as many women attempt to carry on with their life and seek to restore a sense of normality (Knobf, 2007). This has implications for healthcare professionals, whose role involves making breast cancer survivors aware of on-going support networks and in helping them to transition away from treatment and resume their normal lifestyle by ensuring women are well supported, emotionally, psychologically and socially (Maher & Fenlon, 2010).

The majority of the literature has highlighted the negative psychosocial impact of breast cancer but, like any stressful event, negative experiences are often accompanied with positive ones. Breast cancer can lead individuals to re-assess their lives, attitudes and behaviours in a positive manner, thus resulting in a positive psychosocial adjustment to cancer (Andrykowski, Brady & Hunt, 1993). Research within this area has found that women have reported having a different outlook to life, appreciation of life and stronger interpersonal relationships (Collins, Taylor & Skokan, 1990; Wyatt et al, 1993). For example, Collins et al (1990) interviewed cancer patients who were within 5 years of their initial diagnosis and found that the majority reported positive changes in their personal relationships and the way in which they viewed themselves and their life. Similarly, Sears, Stanton & Danoff-Burg (2003) found that 83% reported the emergence of at least one positive outcome from their breast cancer experience, including development of relationships with others, new life possibilities, personal growth, spirituality and an appreciation for life.

Breast cancer survivors have various physical, psychological, social, spiritual, and informational needs. At present, services do not always meet these needs or are poorly integrated (Department of Health, 2007; NICE, 2009). The literature reviewed above has implications for healthcare professionals. An understanding and awareness of the psychosocial factors that impact a woman's breast cancer journey can allow healthcare professionals to develop appropriate care, support and interventions that promotes a positive quality of life.

While the current psychosocial research adds to the breast cancer literature, a serious caveat of this literature is that the majority of the research has focused on mainstream White women. There is very little work within the breast cancer literature that captures the experiences of BME women (Thompson et al, 2008). The specific issues relevant to breast cancer amongst BME women are now considered.

1.10 Epidemiology of breast cancer in BME women

Between 2001 and 2009, the ethnic minority population in the UK increased by 4% (Office for National Statistics, 2011a). According to the latest census data (2011), there are approximately 9.1 million (12.1%) ethnic minority men and women in the UK (compared to 6.6 million in 2001); with half the minority ethnic population describing themselves as British Asian (Indian, Pakistani, Bangladeshi or other Asian) and a quarter describing themselves as Black (Black Caribbean, Black African or other Black) (Office for National Statistics, 2011a). Despite the growing BME population in the UK, very little is known about their breast cancer experiences or the incidence and survival rates within this community.

As mentioned above, breast cancer is one of the most common forms of cancer in the UK. With so many women developing breast cancer, it is the most common form of cancer in women of all ethnic groups, including first generation immigrant BME women (Breast Cancer Care, 2005; Lodge, 2001).

In the UK, the availability of data on breast cancer incidence, survival and mortality rates is limited for the BME population. This is due to the fact that patients' ethnicity is not routinely recorded within all NHS Trusts (Jack et al, 2006). Recording patients' ethnicity (using the classifications provided by the Office of National Censuses) has been mandatory since 1995, as part of the 'admitted patient contract minimum dataset' (National Cancer Alliance, 2001). Despite this, data on ethnicity is often incomplete or of poor quality (Department of Health, 2007). This has implications for NHS Trusts to strive towards collecting such data to allow for more accurate analyses. This information would then help to identify where inequalities exist, and as a result, appropriate measures can be taken to reduce this.

In the absence of recorded ethnicity data, the few studies that have looked into breast cancer incidence rates amongst BME groups have used alternative measures such as identifying South Asians on the basis of their first and/or last name via computer-based name recognition algorithms (such as 'Nam Pechan' and 'South Asian Names and Group Recognition Algorithm'; SANGRA) (Barker & Barker, 1990; Farooq & Coleman, 2005). Such a method can be problematic for three reasons. First, not all South Asian names are distinctive and some South Asians may have westernised names or vary in their spelling which can create false negatives. Secondly, South Asian Christians may share

names with the White population, and thirdly, South Asians may marry out of their communities thus leading to adopting their spouse's name (Bhopal, 2007). These reasons can make it difficult to identify South Asians or cause South Asians to be wrongly identified. Despite this limitation, name algorithms have been the most practical method in gaining such data and potential errors that can occur have been recognised (Farooq & Coleman, 2005). For example, research using the algorithm, SANGRA, has been shown to have a high validity, ranging from 89-96% (Nanchahal, Mangtani, Alston, & dos Santos Silva, 2001). It is also important to note the periods in which the data was collected (i.e. 1976 – 1982 (Donaldson & Clayton, 1984) and 1986 – 1990 (Farooq & Coleman, 2005)) as most of the South Asians would have been first generation immigrants, who would have traditional names relating to religion, occupation and caste (Bhopal, 2007) and cross cultural marriage would have been highly unlikely (Rawaf & Bahl, 1998). Therefore, algorithms like SANGRA were more likely to be a pragmatic approach to accurately identify South Asians via their name(s), though this may not be so feasible now.

At present, data on ethnicity is mainly collected via the Hospital Episode Statistics (HES) dataset. This is heavily dependent on patients self-reporting their ethnicity at admission. Recently, the National Cancer Intelligence Network (NCIN), have combined their cancer statistics with the national cancer registry data, forming a larger database known as the National Cancer Data Repository (NCDR) in order to provide high quality cancer statistics and thus allowing for analyses of epidemiology of cancer according to ethnicity (NCIN, 2009). This is the first national analysis of cancer incidence and survival rates according to ethnicity, covering patients diagnosed in England between 2002 and 2006.

Cancer Research UK and NCIN have gathered data from various sources and aim to present an accurate account of cancer amongst BME communities, in the hope to raise awareness and early detection in communities where incidence rates of cancers are the highest. For example, compared to the White population, Black people have significantly higher rates of stomach cancer. Black men have higher rates of prostate cancer and Black and South Asian women have lower survival rates from breast cancer (NCIN, 2009). Specific to breast cancer statistics, the report states that South Asian and Black women are at a lower risk of being diagnosed with breast cancer compared to White women. However, we need to be aware of the limitations of this data. Information of one's ethnicity was lacking for almost a quarter of cancer patients, questioning the validity of the findings.

Other research conducted in the UK (mainly England and Wales) has also found that South Asians have a lower incidence of breast cancer but a relatively higher survival rate than non-South Asian women (Farooq & Coleman, 2005; Zaman & Mangtani, 2007); although this low incidence of breast cancer is increasing and is expected to increase as BME groups become more acculturated and adopt a western lifestyle (e.g. diet) (Harding, 2005; Kumar et al, 2004; Velikova et al, 2004). It has also been found that breast cancer incidence rates are higher amongst South Asian women living in the UK than those living in the Indian sub-continent (Jain, Mills & Parikh-Patel, 2005) and has been recognised as being the most common cancer amongst first generation immigrant women from minority ethnic groups (Cancer Research Campaign, 1997). Furthermore, data within the UK suggests that South Asian women tend to be diagnosed at a younger age and are more likely to be diagnosed at an advanced stage (larger tumours) than White women (Farooq & Coleman, 2005; Velikova et al, 2004). Rates of mastectomy are also higher amongst South Asian women than non-South Asian women (Velikova et al, 2004).

The term South Asian refers to a heterogeneous population, comprising of various ethnic sub-groups such as Indians, Pakistanis and Bangladeshis. Differences in the incidence rates of breast cancer within the South Asian sub-groups also exist. McCormack et al (2004) revealed that Bangladeshi Muslim women are at a greater risk of developing breast cancer followed by Punjabi Hindu women, Gujarati Hindu women, Punjabi Sikh women and then Pakistani/Indian Muslims.

While figures are available for breast cancer incidences amongst South Asian women, it is unclear exactly how many women from other BME groups are diagnosed in the UK (due to poor data collection). For example, methods of identifying African and Caribbean populations based on their names would not be an adequate approach as many may have traditional Christian or European names which would not be distinctive enough to be detected by name algorithms.

Unlike the UK, the health system in the USA routinely records patients' demographic information, including ethnicity via cancer registries such as the Surveillance Epidemiology and End Results (SEER) cancer registry, allowing analyses of cancer incidence, mortality and survival rates to be produced with ease (Ward et al, 2004). However, there is no one single database. Instead, different hospitals in different parts of America use different programs of data collection to record information (e.g. programs such as the National Center for Health Statistics, National Cancer Data Base and SEER). Nonetheless, research conducted in the USA has shown that, compared to White women, the incidence of breast cancer is lower amongst Black women yet mortality rate is higher (Greenlee, Murray, Bolden & Wingo, 2000; Newman, 2005). Moreover, Black women are diagnosed at a younger age, are more likely to be diagnosed with aggressive forms of the disease and are often diagnosed at a later stage (Hirschman, Whitman & Ansell, 2007; Jatoi, Becher, & Leake, 2003). The limited data from the UK (i.e. Bowen et al, 2008; Jack, Davies & Moller, 2009) mirrors the findings of the American based studies. For example, Bowen et al (2008) found that British Black women were significantly younger at diagnosis and presented with more aggressive forms of the tumour than White women. However, the findings of this study should be treated with caution as it was a small pilot study (with 293; 102 Black and 191 White women) set in one hospital in London.

The lack of figures on breast cancer incidence amongst BME women and the differences in the incidence, survival and mortality rates between BME and White women is worrying and needs to be further explored. It would be inappropriate to assume that BME women's experiences are the same as the experiences lived by White women, especially in groups where mastectomy rates are higher or cancer is presented at later stages. Therefore, further research is warranted. Furthermore, with South Asian and Black communities making up the largest non-White population in the UK, whose incidence rates of breast cancer are increasing, it is important to focus research on these two groups as understanding their experiences and needs will aid in providing appropriate care. BME women's breast cancer experiences before, during and after diagnosis is detailed in the following sections below.

1.11 Pre-diagnosis: Breast cancer detection

Breast screening methods play an important role in detecting cancers early (Lerner, 1999) yet uptake of breast screening is relatively low in BME communities, compared to the White population (Szczepura, Price & Gumber, 2008). This is particularly the case for immigrant women who are

unfamiliar with breast screening procedures due to the unavailability of such services in their homelands (Bottorff et al, 2007).

Reasons behind BME women's lack of participation in breast screening programmes include lack of knowledge and awareness of breast cancer and the importance of screening (Sadler et al, 2001), especially in uneducated women and women who are not acculturated to the western ways of living (Ashing-Giwa et al, 2004). Another reason is that many BME women view cancer as a 'White woman's disease' (Bottorff et al, 1998; Guidry et al, 2003). Scanlon and Wood (2005) investigated breast awareness in a large group of BME (including Black, South Asian, Chinese and Irish) and White population and found that compared to White women, BME women were less aware of breast cancer symptoms and risk factors. The data also revealed that 43% of BME women (compared to 11% of White women) did not practise breast awareness as they did not know what to look for.

Other reasons include language barriers and cultural beliefs (Bottorff et al, 1998; Scanlon & Wood, 2005; Watts et al, 2004). Culturally, South Asian women have been brought up to put their family's needs first and great importance is placed on the preservation of a woman's honour and dignity (Day, 1994). Consequently, research has found that BME women do not engage in breast screening practices as they do not feel comfortable exposing themselves or talking about their private body parts to physicians (especially male physicians). They also avoid self-examinations as they believe it to be inappropriate to touch themselves, even for health reasons (Bottorff et al, 1998; Lende & Lachiondo, 2009). In a qualitative study, Lende and Lachiondo (2009) revealed that their Black participants held a coy attitude about their breasts and therefore did not feel comfortable performing self-examinations or having others examine them. Similarly, Bottorff et al's (1998) South Asian participants explained how a woman should be seen to place her family's needs before her own health needs and therefore practices such as screening for cancer were avoided to protect their family's honour.

This has implications for healthcare professionals looking to raise awareness and increase the uptake of screening by educating BME women about the importance of breast screening and ensuring that it is culturally suitable, for example, by ensuring that the information provided is language specific. Research has also highlighted that family play a significant role in decision making processes within BME communities (Bailey, Erwin & Belin, 2000; Bottorff et al, 1998; Sadler et al, 2001). Therefore, promoting and educating family members on the importance of breast screening may also enable openness and willingness for women to engage in breast screening behaviours (Scanlon & Wood, 2005).

1.12 Post Diagnosis: Psychosocial impact of breast cancer amongst BME women

There is very little work within the breast cancer literature that captures the experiences of BME women (Thompson et al, 2008). Only a handful of studies have explored this phenomenon (Ashing-Giwa et al 2004; Bourjolly, Kerson & Nuamah, 1999; Farmer & Smith, 2002; Gurm et al, 2008; Howard, Bottorff, Balneaves & Grewal, 2007; Moore, 2001; Wilmoth & Sanders, 2001). For example, Ashing-Giwa et al (2004) conducted a qualitative study with 102 breast cancer survivors of various ethnicities (White, African American (Black), Asians & Latinas) and found that concerns around health, cancer recurrence, body image, sexual health concerns and worry related to children and

burdening the family were evident. Additional challenges included lack of cancer-specific knowledge, cultural sensitivity of providers, language barriers and cultural factors related to beliefs, gender role and family obligations. Similarly, Wilmoth and Sanders (2001) conducted two focus group interviews with 16 African American women to explore their experiences of breast cancer. Analysis of their data revealed that the women expressed body image issues based around hair loss, feeling lop-sided in clothes and lack of skin colour matching prosthesis, varying availability of social support from different sources (i.e. family, friends and healthcare professionals), the need of wanting to educate and make others breast aware, menopause and learning to live with a chronic illness. These findings show that while there are experiences similar to White women's (body image, menopause, support), some experiences are unique to BME women (lack of resources such as wigs that do not match their hair colour or texture and appropriately coloured (skin matching) prosthesis, language issues and various cultural beliefs). This has also been reported in other studies (Henderson, Gore, Davis & Condon, 2003a; Moore, 2001). It is important to note that within the handful of research that has been carried out, there is a growing body of literature that explores Black women's breast cancer experiences in comparison to other BME communities, such as East Asian or South Asian women (Knobf, 2007).

The existing, but limited, research within the South Asian communities has been conducted on Canadian Punjabi women (Balneaves et al, 2007; Bottorff et al, 2007; Howard et al, 2007; Gurm et al, 2008). For example, Howard et al (2007) explored the experiences of breast cancer in 12 Canadian Punjabi women by adopting a narrative approach (story telling; an approach that is well suited and a common method of storytelling in South Asian women; Bottorff et al, 1998). Four storylines emerged: "dealing with just another health problem" (downplaying the illness and expressing their ability to get through it), "getting through a family crisis" (the shock experienced by the family and the immense emotional and practical support provided by their family members), "never-ending fear and suffering" (shock and disbelief in their diagnosis and the stigma of the disease), and "a lesson from God" (religious beliefs of fate and karma and enhanced religious faith via prayer). Relying on family members to explain medical advice was also embedded within these women's stories. Another qualitative study with 20 Canadian Punjabi breast cancer survivors (Gurm et al, 2008) also found that women expressed emotional feelings of distress and fear of death. Their experiences were shaped by their cultural background, whereby women felt an obligation to their family to resume daily chores and domestic responsibilities immediately post treatment. Many women wanted to seek support from other breast cancer survivors but felt isolated due to the cultural pressures to keep personal issues private. Women's distress was further exacerbated by judgemental and insensitive comments, often by uneducated and older generation community members. Receiving information and talking to others in their own language was important to the women as was spirituality and religion in managing the experience. These studies show that South Asian women's breast cancer experiences are diverse and more than often are influenced by their cultural norms and beliefs.

It is important to acknowledge that the findings from studies with Canadian Punjabi women cannot be generalised to the South Asian group as a whole. Rather the findings give valuable insight into the experiences of one sub-group. However, it is possible that breast cancer experiences may not differ too much across the South Asian population. For example, similar experiences have been found to exist amongst Pakistani Muslim breast cancer survivors (Banning et al, 2009). Banning et al reported that their participants expressed feelings of shock, disbelief and worry about the diagnosis. The

social stigma attached to cancer in their community resulted in them concealing the illness from friends, relatives and neighbours. Furthermore, cultural specific beliefs that the cancer can affect other family members' future marriage prospects, is God's will and under his control, and the role of religion and spirituality, and support from immediate and extended family members also contributed to the women's experiences. Previous research has also demonstrated how cultural specific beliefs and attitudes can influence women's experiences of breast cancer in other Asian cultures (Ashing et al, 2003; Baron-Epel, Granot, Badarna & Avrami, 2004; Im, Lee, Park & Salazar, 2002).

From the above studies, it is evident that cultural beliefs, values and traditions play a significant role in women's breast cancer experiences. Lay understandings and cultural beliefs of health and illnesses such as cancer exist within BME communities. Limited understanding of the causes of breast cancer include perceptions that cancer can occur due to damage to the breast (via bumps or small hits/knocks), wearing restrictive clothing (including bras) and that it is contagious (Johnson et al, 1999). There is also a lack of understanding of the varying symptoms of breast cancer (whereby many women think that it is related to a pain or lump in the breast). Beliefs that cancer is a White woman's disease are also apparent amongst many BME women (Phillips, Cohen & Tarizan, 2001), as are beliefs that the individual brought it upon themselves due to adopting western ways of living, that cancer is in God's control or a result of intentionally cursing others (via black magic or voodoo) or unintentionally tempting fate by complimenting one on their health or appearance (casting an evil eye) (Johnson et al, 1999). Concepts of fatalism and karma (deeds in present and past lives) are also perceived as influential explanations for developing cancer (Bottorff et al, 1998; Phillips et al, 2001).

Family members are also seen to play an important role in BME (especially South Asian) women's health concerns and experiences. In many communities, there is a high sense of structure and patriarchy within the family based on age and gender. For example, an elder male will be seen as the head of the family and will be influential in making important decisions, including issues related to their own and other family members' health (Ahmed & Lemkau, 2000; Grewal, Bottorff & Hilton, 2005). Many women, particularly first generation immigrants who are unable to communicate in English, rely upon the head of the family to help them make medical decisions. Although in some cases, medical decisions are made by male family members without consulting the patient (Grewal et al 2005; Gurm et al, 2008).

BME populations often hold strong ties with immediate and extended family networks and therefore rely on them for support (Shams, 1994). Consequently, family members are described as being highly supportive; offering practical, emotional and moral support (Ashing-Giwa, 1999; Balneaves et al, 2007; Banning et al 2009; Gurm et al 2008; Henderson et al, 2003b; Howard et al, 2007). However, they may not always be supportive due to the beliefs that cancer should not be openly talked about (Wilmoth & Sanders, 2001). In some families the lack of support is a reflection of family obligations and cultural expectations of the women to fulfil their role of being a good housewife and to resume household chores, immediately post treatment (Grewal et al, 2005; Gurm et al 2008; Wilmoth & Sanders, 2001).

A woman's role within their community (particularly amongst South Asian women) is also seen to be very important. As mentioned above, they are expected to keep their family's honour and reputation intact. For this reason, women are expected to remain quiet and private about their

illnesses in order to avoid being stigmatised by their community members on the belief that illnesses such as cancer can be inherited or is contagious, and as a consequence can negatively affect their children's future in terms of marriage proposals (Bottorff et al, 1998; Guidry et al, 2003). Women are also expected to put their family's needs before their own, whereby they are expected to carry out their traditional housewife duties and household chores, despite any ailments that they may have (Grewal et al, 2005).

The role of the family is an integral part of BME women's health concerns. Health matters are often discussed in a family setting and often women need encouragement or approval from family members to go to the doctors (Grewal et al, 2005). In order to provide appropriate care and support to BME breast cancer survivors, cultural beliefs and the influence that family have on the patient need to be taken into account. Interventions (such as raising cancer awareness) that can help minimise the impact of cultural taboos and misconceptions about cancer, and allow family and community members to talk openly are warranted (Bottorff et al 1998; Grewal et al, 2005).

1.13 BME women dealing with their breast cancer experiences

Just as one's cultural background plays a role in shaping women's breast cancer experience, this can in turn influence the types of strategies that they may adopt to deal with the experience. Research conducted in this area has found similarities and differences in coping styles between BME and White breast cancer survivors (Bourjolly & Hirschman, 2001; Culver et al, 2004; Reynolds et al, 2000). For example, Henderson et al (2003b) conducted a qualitative study assessing African American breast cancer survivors' coping strategies. The authors found that spirituality (in the form of prayers and an increased faith in God) and support networks (family, friends and support groups) played a major role in the women's coping behaviours. Other strategies included positive thinking and avoiding negative people who would make inappropriate comments and bring the women's spirits down. Similarly, Lackey, Gates and Brown (2001) found that their sample of African American breast cancer survivors' relationship with their God helped them throughout their cancer journey.

Furthermore, the small number of comparative studies undertaken has also reported differences in coping styles across various ethnicities (Ashing-Giwa et al, 2004; Bourjolly, 1998; Bourjolly & Hirschman, 2001; Culver et al, 2004; Koffman et al, 2008; Moadel et al, 1999; Reynolds et al, 2000). Much of this literature highlights that ethnic minority groups are more likely to turn to religion and spirituality as a coping mechanism than White women. Seeking social support is a common coping strategy for both BME and White women, although the source of support can vary. For example, in Bourjolly and Hirschman's (2001) study, African American women reported relying more on God for support during their breast cancer experience, whereas White women reported relying more on their husbands. Similarly, a qualitative study (and one of the very few UK-based studies) exploring how religion and spirituality influenced Black Caribbean and White patients' cancer experiences (Koffman et al, 2008) revealed that religious beliefs appeared to be more pronounced among the Black cancer patients compared to their White counterparts. Beliefs in religion and God helped the patients accept the illness and enabled them to receive practical and emotional support from their church communities. Both acceptance and support was described as important in helping the patients deal with their cancer experience positively.

Religion and spirituality have been seen to play an integral role in BME breast cancer survivors' coping processes (Banning et al, 2009; Gurm et al, 2008; Henderson et al 2003b; Henderson, Fogel & 2003a; Howard et al, 2007; Simon, Crowther & Higgerson, 2007). Religion and spirituality are often used interchangeably in health-related studies, although there has been some effort to differentiate the two concepts (Baldacchino & Draper, 2001; McGrath, 2004). Religion has been defined as 'an organised system of beliefs, practices, rituals, and symbols', while spirituality involves 'one's transcendent relationship to some form of higher power' (Thoresen, 1998, p415). Examples of religious coping include attending places of worship, praying, reading and reciting religious scripts and hymns, and seeking emotional support from religious leaders, such as priests/church pastors, and other church members. Spirituality, however, can be understood within a religious context (via religious beliefs and practices) and/or an existential or experiential context (e.g. via transcendence, gaining a profound understanding/meaning to life, reaching tranquillity and inner peace, and finding a greater appreciation for oneself and others). It is possible that some may consider themselves spiritual but not religious and therefore turn to spirituality without any reference to God, which can still act as an important source of coping.

Historically, the church has been an important part of Black people's lives, providing fellowship, education, celebration, place of worship and serving as a source of support and spiritual guidance, not just in the health context but in other aspects of their lives too (Bourjolly, 1998; Lincoln & Mamiya, 1990; Phillips, 1999). For those who hold strong religious affiliations, God is often seen as a healer and great faith (in the form of prayers, attending church) is placed on him to guide, support and provide strength for the individual to get through illnesses such as breast cancer (Culver, Arena, Antoni & Carver, 2002; Lackey et al, 2001). This coincides with other research where Black breast cancer survivors have been found to rely on God as a source of support more frequently than family or friends (Henderson et al, 2003a).

In the same manner, South Asian communities hold strong religious beliefs which can help them deal with different types of life's stressors. Religious beliefs based around fatalism and/or karma (reflection of one's good/bad deeds in past or present life) are widely held amongst South Asian communities (Gurm et al, 2008; Bottoroff et al, 2007; Howard et al, 2007) and reinforce the notion that God is in control of cancer and, as a consequence will guide and protect the patient. These beliefs may help women to understand why they developed cancer in the first instance and may result in active acceptance, allowing them to cope in a positive manner, although, it is possible that such beliefs can result in passive acceptance. For example, women would accept the diagnosis as God's will and therefore choose to do nothing about it, including denying oneself of treatment (Gurm et al, 2008).

Research has shown that, for both Black and South Asian women, religious tendencies and spiritual practices tend to increase in one's time of need, bringing on relaxation and inner strength, and reducing fears and feelings of uncertainty (Banning et al, 2009; Gurm et al, 2008). However, it is worth noting that religion and spirituality may not always act a positive coping mechanism. Feelings of anger towards God or believing that the cancer is a form of punishment from their God can leave people with feelings of helplessness, hopelessness and can have a negative impact on one's physical and psychological well-being (Levine et al 2007; Shaw, Joseph & Linley, 2005).

1.14 Summary

In summary, the literature reported above shows that while there are similarities in White and BME women's breast cancer experiences, there are also aspects that are unique and specific to BME women, which are largely shaped by socio-cultural norms, behaviours and beliefs. With this in mind, it is imperative to conduct further research with BME women in order to understand their unique experiences of breast cancer so as to guide healthcare professionals on providing culturally sensitive care and support. While the above studies contribute to the limited BME breast cancer literature, they have mainly been carried out in America and Canada (Banning, 2011). It would be inappropriate to assume that the findings of American and Canadian based studies can be generalised in the UK, particularly as the healthcare systems are not directly comparable and people in these countries may differ in cultural and lifestyle patterns (Farooq & Cole, 2005). For example, the UK population have access to the NHS service, which is funded through general taxation. Although this is paid for by the UK government, people are essentially paying for their healthcare through taxes. Meanwhile access to healthcare in the US is dependent on health insurance, which are paid through employer and patient contributions, and often only available to those who can afford health insurance (McClintock Roe & Liberman, 2007). Therefore, research in the UK is warranted in order to provide adequate and culturally sensitive care and support to BME women.

Research conducted with BME women in the UK is scarce (Banning, 2011; Watts et al, 2004). To date there is only one UK-based study that has explored BME women's experiences of being diagnosed with, and treated for breast cancer. Blows et al (2009) conducted four focus groups with 20 South Asian and Black women. The women in this study raised concerns regarding communication issues (preference of communicating in their own language), concerns regarding skin care, hair care, prostheses and lymphoedema sleeves, varying availability of support from family and friends, taboos and stigma of cancer as a disease within their cultures and described the negative impact of breast cancer on their body image and femininity. While for some women it was important to be around women of similar cultural backgrounds, others felt it was important to be around women who had been through the cancer experience regardless of cultural background. Furthermore, women felt they had to be proactive in seeking culturally specific information.

Although the study by Blows et al provides valuable information on BME women's experiences, it is not without limitations. Firstly the majority of the South Asian women in this study described themselves as British Indian. Therefore, the findings are not representative of South Asians, particularly as it questions why only these groups of women came forward and not those from Pakistani or Bangladeshi backgrounds. It could be that these women's experiences differ to those of Indian women. Also, those who chose to take part may have differing views to those who did not. With this in mind, further research within the sub-groups is warranted. Also, this study was limited to English speaking women. Therefore, the experiences of non-English speaking women are unknown. Research amongst BME women is typically limited to fluent English speaking women and because of practical reasons (such as difficulties using interpreters or validating questionnaires in other languages) women who do not have a fluent understanding of English are often excluded (Blows et al, 2009). This is unfortunate as non-English speaking women may encounter barriers to accessing healthcare services, affecting their experiences of breast cancer to a greater degree.

1.15 Conclusion

The dearth of research of BME women's experiences of breast cancer, particularly within the South Asian communities, shows that more research is warranted within this group in order to understand the unique experiences that are influenced by one's ethnic and cultural background. To address the above existing gaps, it is imperative that the lived experiences of breast cancer amongst BME women are adequately researched. This is the focus of this PhD. Such applied research can then inform the development of guidelines for the provision of culturally sensitive and appropriate care. The need to meet and improve cancer patients' comprehensive psychosocial needs is a priority of cancer care policy in the UK. In particular, the need to provide high quality cancer care and to improve cancer experiences amongst BME groups was specifically mentioned in the Cancer Reform Strategy (Department of Health, 2007). This further highlights the importance and need to research this group.

This chapter has provided a detailed account of the available literature on ethnicity and health, and BME and breast cancer, thus providing the rationale for conducting this research. To explore this phenomenon in detail, a pragmatic approach is necessary in order to understand the challenges of breast cancer from a cultural perspective. This aspect is discussed in the next chapter.

2 Methodological considerations

2.1 Introduction

In order to set the scene for this PhD, it is important to discuss the methods used to conduct this research, sampling issues, and the issues of insider-outsider roles. This chapter is divided into 3 parts. The first focuses on the decision to use mixed methods as the approach for this research. In order to justify the use of this methodology, the first section begins with a brief description of the two main research paradigms that dominate the research world and how the third research paradigm (pragmatism) emerged. This then leads to why and how mixed methods research are deemed a practical method in applied research settings, followed by an evaluation of this approach. Methods used within the qualitative and quantitative phases of this PhD are reviewed in the appropriate chapters that detail the studies. Another important methodological aspect which needs particular attention is sampling (part 2). This is particularly relevant given the sensitive nature of the research. This section highlights issues regarding hard to reach populations and outlines successful strategies to aid recruitment. Finally, I reflect on my role as an insider and an outsider, and the impact this had on the research process (part 3).

Part 1: Using mixed methods in research

2.2 Mixed methods in health research

There is an increased demand for research findings to inform policy and aid in the development of interventions (in order to improve quality of care), which utilises qualitative as well as quantitative methods (Ritchie & Lewis, 2003). For this reason, mixed method approaches have been well received in applied research settings and have progressively become popular in health research (O’Cathain, Murphy & Nicholl, 2007; O’Cathain, 2009; Tashakkori & Teddlie, 2003), including areas such as cancer (Bertero, 2008; Dubois & Loiselle, 2009; Kubon et al, 2012; Tsai, Morisky, Kagawa-Singer & Ashing-Giwa, 2011). For example, Dubois and Loiselle (2009) and Tsai et al (2011) used mixed methods (quantitative approach to inform the development of the qualitative phase) to understand informational support needs in breast and prostate cancer patients, and the role of acculturation in Chinese-American immigrant women’s breast cancer experiences, respectively, describing the approach to be “a productive way to document the phenomenon of interest in its entirety” (Dubois & Loiselle (2009) p357).

Before discussing the use of mixed methods in the present research, it is important to briefly discuss the research paradigms in relation to their epistemological and ontological positions.

2.3 Research paradigms: Positivism, Interpretivism and Pragmatism

The design of research studies is influenced by their underlying philosophical assumptions in order to answer research questions. These assumptions are heavily guided by the researcher's epistemological (concerning the nature of knowledge; Dures, Rumsey, Morris & Gleeson, 2010) and ontological (pertaining to the view of reality; Dures et al, 2010) stance (Creswell & Plano Clark, 2007). For decades two approaches have dominated the research world: quantitative and qualitative paradigms. Both are seen as two separate entities, presenting contradictory paradigms. This is because they are underpinned by different epistemological and ontological assumptions (Dures et al, 2010; Teddlie & Tashakkori, 2003). Quantitative researchers more often than not tend to adopt a positivist epistemological position. These researchers believe that there is only one truth which is objective, deductive and quantifiable. Research methods are often based on experimental approaches or are operationalised in closed ended surveys/questionnaires, whereby the goal is to test hypotheses and measure relationships between variables (Marks & Yardley, 2004; Maxwell & Delaney, 2004). The focus is on using larger sample sizes so that appropriate statistical analyses can be performed and generalisations can be made (Sale, Lohfeld & Brazil, 2002). However, the ontological assumptions based on naïve realism have been challenged for their rigid beliefs regarding reality as being a fixed entity. A more critical approach of positivism has been termed post-positivism – a preferred term for today's quantitative researchers (Lincoln & Guba, 2003). This paradigm adopts a critical realist ontological position, based on probable truth. This perspective does not deviate greatly from the positivist paradigm. It still acknowledges that an ultimate reality exists but recognises that it is not as straightforward to achieve; thus scientific hypotheses are non-falsified and based on probable facts, as opposed to verified hypotheses that are established as set facts or laws (O'Byrne, 2007; Onwuegbuzie, 2002).

In contrast, qualitative researchers reject the positivist/post-positivist stance and adopt an interpretivist/constructivist epistemological position (Johnson & Onwuegbuzie 2004; Marks & Yardley, 2004). These researchers argue that there are multiple truths based on the way individuals construct their reality according to their lived experiences. Reality is socially constructed, ever changing and the role of the qualitative researcher is very much subjective (Dures et al, 2010; Sale et al, 2002). Research methods include observations, individual semi-structured interviews and group interviews, which have the potential to generate detailed, descriptive and rich data which is open for interpretation (Johnson & Onwuegbuzie, 2004). Sample sizes tend to be smaller in comparison to samples associated with quantitative research, where the focus is on understanding rather than generalising to the wider population (Sale et al, 2002).

Both quantitative and qualitative researchers assert dominance of their position and tend to engage in the paradigm wars debate, that both domains are incompatible, with some believing that the two should not be mixed (Creswell & Plano Clark, 2007; Howe, 1988; Robson, 2002). These types of researchers have been termed purists (Rossman & Wilson, (1985). In contrast to this, Patton (1988) argued for a 'paradigm of choices' and asserted that "there are no logical reasons why qualitative and quantitative approaches cannot be used together" (p117). Hence a third paradigm, mixed methods, has entered the research field, with the aim to bridge the quantitative and qualitative divide (Onwuegbuzie, & Leech, 2005). Mixed methods research has been occurring since the 1950s by researchers known as pragmatists (Cresswell, 2006; Tashakkori & Teddlie, 1998). Pragmatists

believe that multiple paradigms can be used to research a phenomenon, particularly complex, under-researched topics (Creswell & Plano Clark, 2007; Giddings, 2006). This approach has generated a great deal of interest within the last decade and has been advocated for having a paradigm of its own (Creswell, 2003; Gilbert, 2006; Haverkamp, Morrow, & Ponterotto, 2005; Johnson & Onwuegbuzie, 2004; Johnson, Onwuegbuzie & Turner, 2007).

A mixed method approach involves the integration of quantitative and qualitative research. A formal definition of this can be operationalised as a “class of research where the researcher mixes or combines quantitative and qualitative research techniques, methods, approaches, concepts or language into a single study” (Johnson & Onwuegbuzie (2004) p17). This process adopts a pragmatic epistemological position, which offers a logical and practical alternative from dichotomising the quantitative and qualitative approach as being one or the other. It uses multiple approaches to answer a research question and acknowledges that multiple perspectives can be used to understand a phenomenon (Greene, 2008), by being inductive, deductive and abductive (“uncovering and relying on the best of a set of explanations for understanding one’s results” (Johnson & Onwuegbuzie (2004) p17)). Great emphasis is placed on the research question rather than on the method used or the underlying philosophical position (Bryman, 2006; Tashakkori & Teddlie, 1998; Teddlie & Tashakkori, 2003). Pragmatists do not commit to any one system of philosophy and reality, and reject the notion of discovering absolute truth. Instead the flexibility of this approach allows researchers to draw upon quantitative and qualitative assumptions of reality and access multiple truths and meanings, which are accepted to be provisional and subject to change (Creswell, 2003; Johnson et al, 2007; Maxcy, 2003). Pragmatic researchers are free to use multiple methods to collect and analyse data that can provide optimum results and understanding of the phenomenon being researched (Johnson et al, 2007).

2.4 Mixed methods: Rationales, typologies and research questions

Pragmatism has been described as the best paradigm for utilising a mixed methods approach (Johnson & Onwuegbuzie, 2004). However, the rationale for using a mixed methods approach is not always clearly explained or the data obtained from both methods are not always clearly communicated or integrated (Barbour, 1999; O’Cathain et al, 2007). It is therefore important to be explicit when stating one’s choice or reasons behind using mixed methods (Bryman, 2006) and how the qualitative and quantitative aspects of the research relate to each other (Denscombe, 2008). Greene, Caracelli, and Graham (1989) put forward five main rationales for adopting a mixed methods approach: triangulation (combination of different methods to study the same phenomenon), complementarity (seeking elaboration and clarification of the results produced from the different methods to generate complementary insights and create a bigger picture), development (using the findings from one method to inform or develop the other method), initiation (discovering paradoxes and contradictions from one method that can lead to new perspectives and result in re-framing research questions that can be researched using a different method) and expansion (expanding on the breadth of the research by using a range of different methods). All of these rationales can aid in greater understanding of a research phenomenon than the use of a single methods approach (Johnstone, 2004). Complementarity and expansion have been

found to be the two most common rationales for justifying the use of mixed methods (Bryman, 2006; Greene et al, 1989; Niglas, 2004).

The reason for employing a mixed methods approach for this research was to gain a detailed understanding of a topic that has received very little attention in the breast cancer literature. The aim was to achieve triangulation, complementarity and development in order to gain a comprehensive understanding of the psychosocial impact of breast cancer in BME women.

When conducting mixed methods research, it is important for the researcher to consider the research design in relation to the time ordering (whether the qualitative and quantitative research is to be carried out sequentially or concurrently) and paradigm emphasis dimension (deciding whether to give the qualitative and quantitative components an equal status or give dominance to one approach over the other) (Johnson & Onwuegbuzie, 2004).

Within the sequential design, one type of data is collected and analysed first, followed by data collection and analysis from the other research approach. For example, qualitative data can be collected and analysed in the initial stage followed by conducting the quantitative phase of the research method (sequential exploratory) or the quantitative phase of the research can be conducted first, followed by the qualitative research phase (sequential explanatory) (Creswell et al, 2003). In contrast, a concurrent design involves simultaneous use of both research approaches (qualitative and quantitative) (Creswell et al, 2003).

With regards to the paradigm emphasis dimension, both research approaches can be given equal status (QUAN + QUAL or QUAN → QUAL – *the '+' sign indicates a concurrent design whereas the arrow indicates a sequential design*) or one research approach is given dominance over the other (e.g. QUAL + quan or quan → QUAL – *upper case letters indicate the dominant paradigm*) (Johnson & Onwuegbuzie, 2004). Here, the appreciation lies in the acknowledgment that the adjunctive (less dominant) research approach will benefit the overall research, by enhancing understanding (Johnson et al, 2007). Furthermore, Creswell and Plano Clark (2007) argue that within mixed methods, quantitative researchers recognise the important role that qualitative data can play in their research in order to get an in-depth understanding. Similarly qualitative researchers recognise the importance of mixing research with quantitative data in order to generalise the findings to the larger population. The latter point is particularly important for stakeholders such as policy makers, funding bodies and practitioners who are likely to rely on medical, scientific and post-positivistic paradigms. Therefore, a quantitative approach will be more likely perceived to be credible to stakeholders such as the funders for this research (Breast Cancer Campaign) and healthcare professionals and managers who are in a position to act on research findings and recommendations (Johnson & Onwuegbuzie, 2004).

In mixed methods research, it is also important that the research question is driven by appropriate methods. This can depend on whether the research adopts a concurrent or sequential design. In concurrent studies, research questions are often framed from the start, whereas in sequential studies, research questions from the second phase of the project emerge as a result of the findings from the first phase (Tashakkori & Creswell, 2007). Tashakkori and Creswell (2007) highlight three possible ways of formulating robust research questions in mixed methods research: a) separate qualitative and quantitative questions are written, followed by an explicit mixed methods question, b) an overarching mixed research question is written which is broken down into separate qualitative and quantitative questions to answer in each strand of the study (frequently used in studies with a

concurrent design), and c) research questions are written for each phase of a study as the overall project evolves (frequently used in studies with a sequential design).

In line with the above, this research has adopted an exploratory sequential design, whereby the research dominance is given to the interpretivist/qualitative paradigm (QUAL → quan). This design was adopted due to the limited research conducted in the area of breast cancer in BME communities. Qualitative research based on the interpretive epistemological stance has been found to be a valid method, allowing for exploration in areas where little is known (Liamputtong & Ezzy, 2005). Therefore, it was deemed appropriate to start with an exploratory qualitative nature to gain a deeper understanding of BME women's breast cancer experiences. The findings from the qualitative data were then used to inform the design of the quantitative research, which aimed to further examine specific variables that were obtained from the qualitative findings. This allowed the researcher to examine similarities and differences amongst a larger cohort of Black, South Asian and White breast cancer survivors so that appropriate generalisations can be made. In order to answer the broad research question, specific research questions were developed for each phase of the study as the thesis evolved (Tashakkori & Creswell, 2007). Therefore, the qualitative research questions were developed from within the qualitative framework and quantitative research questions were developed within a quantitative framework; although the research questions for the quantitative phase were guided from the findings of the qualitative. The findings from both approaches were then integrated to gain enhanced, insightful knowledge on the psychosocial impact of breast cancer in Black and South Asian women (Moran-Ellis et al, 2006).

2.5 Evaluation of the mixed methods approach

Acknowledging the strengths and weaknesses of the methods can help researchers plan and conduct robust research when using a mixed methods approach (Castro, Kellison, Boyd & Kopak, 2010; Johnson & Onwuegbuzie, 2004). Before they are listed, the strengths and weaknesses of quantitative and qualitative methods are briefly outlined.

The strengths of quantitative approaches include the following: a) testing hypotheses and validating theories about a specific phenomenon, b) capacity to make comparisons across groups and examine relationships between variables, c) use of large samples allows for findings to be generalisable, c) data collection (i.e. questionnaires) can be relatively quick and d) data analysis is based on numerical data which is less time consuming to process (Castrol et al, 2010; Johnson & Onwuegbuzie, 2004). Weaknesses of this approach include: decontextualisation - where the findings may be too abstract and detached from its real world context (Viruel-Fuentes, 2007), and the rigidity of focussing on theory or hypothesis testing (as opposed to theory or hypothesis generation) can result in the researcher missing out on important aspects of the phenomenon being studied (Johnson & Onwuegbuzie, 2004).

The strengths of qualitative approaches include: a) generation of rich detailed accounts based on meanings and experiences, allowing for a contextualised approach, b) allow researchers to carry out in-depth analysis to fully understand often complex phenomena, and c) enable idiographic causation of a particular event (Ashing-Giwa et al, 2004; Gelo, Braakman & Benetka, 2008; Dwyer & Buckle, 2009; Plano Clark et al, 2008; Johnson & Onwuegbuzie, 2004). The weaknesses of this approach

include: a) findings are unique to the participant group and therefore not generalisable, b) data collection and analysis are often time consuming and c) the research is subjective in nature thus findings are influenced by the researcher's personal biases and idiosyncrasies (Johnson & Onwuegbuzie, 2004).

Like any approach, mixed methods will have its advantages and disadvantages. Mixed methods allow researchers to be flexible in the way they want to research a phenomenon, having the ability to address a range of research questions via various research methods (Onwuegbuzie & Leech, 2005). Johnson and Onwuegbuzie (2004) provide a list of strengths and weaknesses of mixed methods. These include:

Strengths

- Allows researchers to draw on the strengths and minimise the weaknesses from both quantitative and qualitative research approaches.
- Combination of both approaches can generate new perspectives and produce complete knowledge and understanding of a phenomenon which can inform theory and practice.
- Researchers are not confined to a single method or approach and therefore can answer a broader and more complete range of research questions.
- In sequential designs, findings from one approach can be used to develop and inform the second stage of the research using another approach.
- A stronger, more concrete conclusion can be established through convergence and corroboration of the findings.
- Findings from a combination of both approaches can increase generalisability of the results.
- Provides insights and understanding that may not be obvious when using a single method.

Weaknesses

- Traditional methodological researchers believe that researchers should use either a qualitative or quantitative approach.
- It can be time consuming for a researcher who would have to learn multiple methods and approaches to understand how to mix methods appropriately.
- A single researcher would find it difficult to carry out both research approaches, especially if the researcher adopts a concurrent research design.

The goal of mixed methods is not to replace the two well established paradigms but to allow the researcher to carry out good quality and rigorous research by drawing on the strengths and minimising the weaknesses that comprise the two paradigms (Castro et al, 2010). It can be clearly seen that mixed methods research is valued in applied health settings and forms a strong rationale in this research. As well as clarifying the methods approach, it is also important to discuss sampling within this chapter. This was a very important issue as the BME population have been known to be difficult to recruit (Ashing-Giwa, Padilla, Tejero & Kim, 2004). The next section will discuss this in more detail.

Part 2: Sampling

2.6 Researching hard to reach populations

Within the health context, hard to reach groups are often those who are underserved and seen as 'slipping through the net' (Doherty, Stott & Kinder, 2004). The BME community are often under-represented in health research, particularly in the UK and specifically when researching sensitive topics such as cancer (Ashing-Giwa et al, 2004; Heiat, Gross & Krumholz, 2002; Knobf et al, 2007; Stirland et al, 2011). This is because they are seen as 'hard to reach' or referred to as the 'hidden population' because they are not easily accessible, unwilling to participate and often do not wish to be found (Ashing-Giwa et al, 2004).

Reasons for lack of participation in research can include the topic being studied, particularly if it is associated with generic and cultural taboos and stigma (e.g. cancer is associated with negative connotations of fear and death), the topic is sensitive and therefore individuals do not want to re-live the experience, issues of trust (i.e. fear they will be misinterpreted), personal circumstances (i.e. work commitments, childcare demands, proximity of research location), or simply because they want to keep their personal affairs private (Knobf et al, 2007; Michalec et al, 2004; Marpsat & Razafindratsima, 2010; Rooney et al, 2011; Underwood & Alexander, 2000). On exploring barriers to participation in research amongst the South Asian population, Rooney et al (2011) found that reasons for lack of participation included: having little understanding of the research, not being told about the research, stigma of being labelled with an illness (asthma), unfamiliarity of the research process, language barriers (i.e. lack of translated material to aid understanding), fear of being misinterpreted, and time and location of the research (due to personal commitments such as family, work and/or education).

Not knowing about the research can be the result of researchers excluding potential participants, whether it's due to language barriers or because researchers assume that BME groups will not be willing to participate (Wendler et al, 2006). Interestingly, Wendler et al found very little difference in willingness of ethnic minority groups (mainly African Americans and Hispanics) to participate in health studies (ranging from interviews to clinical trials in a broad range of conditions, including HIV infection, cancer and cardiac diseases), concluding that health researchers need to ensure that choice to participate in research is also given to ethnic minority groups. It is important to note that willingness to participate may differ in the US and the UK, especially as there is greater emphasis on health insurance in the US and therefore participation in research such as clinical trials can be an opportunity for participants to access free medical care (Wendler et al, 2006).

Researching 'hard to reach' or 'hidden populations' can be very challenging (Lindenberg, Solorzano, Vilaro & Westbrook, 2001; Penrod, Preston, Cain & Starks, 2003). Nonetheless, it is important to include them in order to close the health inequalities gap (Nelson, Smedley & Stith, 2003). In order to maximise participation, a variety of sampling strategies need to be considered. Community networking and snowball sampling have been found to be successful sampling strategies in gaining access (Aitken, 2005; Black, Frisina, Hack & Carpio, 2006; Knobf et al, 2007).

An initial barrier for researchers can be not knowing where to start recruitment or who to approach. Establishing relationships and collaborating with community members and leaders, who can act as important gatekeepers, are vital in helping researchers access hard to reach populations (Alvidrez & Areal, 2002; Benoit, Jansson, Millar & Phillips, 2005; Black et al, 2006; Keval, 2009; Lindenberg et al, 2001). Although this can be a time consuming process, it allows researchers to earn the community's trust, gain a better understanding of the community and the research group, and consequently increase participation rates (Lindenberg et al, 2001). Engaging with the community can involve community outreach, volunteering for health fairs and giving educational presentations at community events (Heiney et al, 2006; Stirland et al, 2011; Sun, 2006).

Recent research exploring recruitment strategies amongst BME communities has demonstrated a variety of ways to increase participation (Lloyd et al, 2008; Rooney et al, 2011; Stirland et al, 2011). For example, Stirland et al (2011) interviewed UK and US researchers to explore recruitment strategies when researching BME groups. The authors found that researchers reported effective strategies including: establishing trust and relationship with gatekeepers/community leaders, effective communication (clearly explaining the research to participants can diminish any trust issues or suspicion that participants may have, and providing translated materials to enhance understanding of the research aims and objectives), personal touch (e.g. face to face contact), offering incentives and reimbursements (as a way of showing participants that their time is valued and they are in no way out of pocket for participating in terms of travel costs and providing refreshments), cultural sensitivity and understanding (based around gender (e.g. ensuring a female is present with a male researcher when researching female participants), and understanding cultural beliefs and influences such as religion), targeting areas that have a high BME population (and choosing a venue that is convenient for them) and persistence (e.g. follow up phone calls and reminder emails to participants and gatekeepers regarding the study). Additionally, Rooney et al (2011) and Lloyd et al (2008) found that use of interpreters to overcome language barriers and providing an audio version of the information sheet can also increase participation rates. The latter is particularly useful for community members who are not literate in their mother tongue language or where there is no written form of their language available (such as Sylheti).

For populations where a sampling frame is not readily available, and therefore the size of the population is unknown, snowball and chain referral sampling have been found to be highly successful strategies in the recruitment of hidden/hard to reach populations, under the assumption that peers (who associate with or are well known to the community) are better placed to recruit hidden populations than the researcher (Aitken, 2005; Benoit et al, 2005). Snowball sampling is based on a process of referrals, whereby one participant refers potential participants, who can then refer other potential participants, and so on (Vogt, 1999). An advantage of this method is that it can be a quick process as trust amongst individuals belonging to the same group will already be established (Atkinson & Flint, 2001). However, a disadvantage of this strategy is that the sample size acquired may not be representative and has the potential to cause bias sampling since it is possible that only those who are similar or share the same social networks are approached (Penrod et al, 2003). Combining sampling techniques, for example with chain referral sampling, can reduce this bias.

Chain referral sampling (or multiple snowballs) is very similar to snowball sampling, whereby it seeks to recruit participants through participant referrals but via multiple social networks and therefore is

not confined to just one social network (Penrod et al, 2003). However, a weakness of chain referral sampling is that it still has the potential of bias sampling, especially if the participants are recruited via similar social networks, such as support groups. Therefore, those who do not attend support groups are still hidden and under-represented and potentially the ones who are most in need of getting appropriate care and support (Penrod et al, 2003).

Finally, using a multi-recruitment approach can increase participation (Knobf et al, 2007). These can include all the strategies mentioned above and additionally sending out personalised letters to potential participants and media presentations (e.g. radio, television, newsletters and magazines – specifically mediums that are aimed at or are regularly accessed by BME communities). However, the success rates of these approaches can vary with specific ethnic minority populations and can be dependent on the topic being studied (Ashing-Giwa et al, 2004; Yancey, Ortega & Kumanyika, 2006). Insider-outsider status can also impact the researcher's ability to access hard to reach populations. This is of particular relevance to the current research and is discussed in more detail in the next section.

Part 3: Insider-Outsider dichotomy

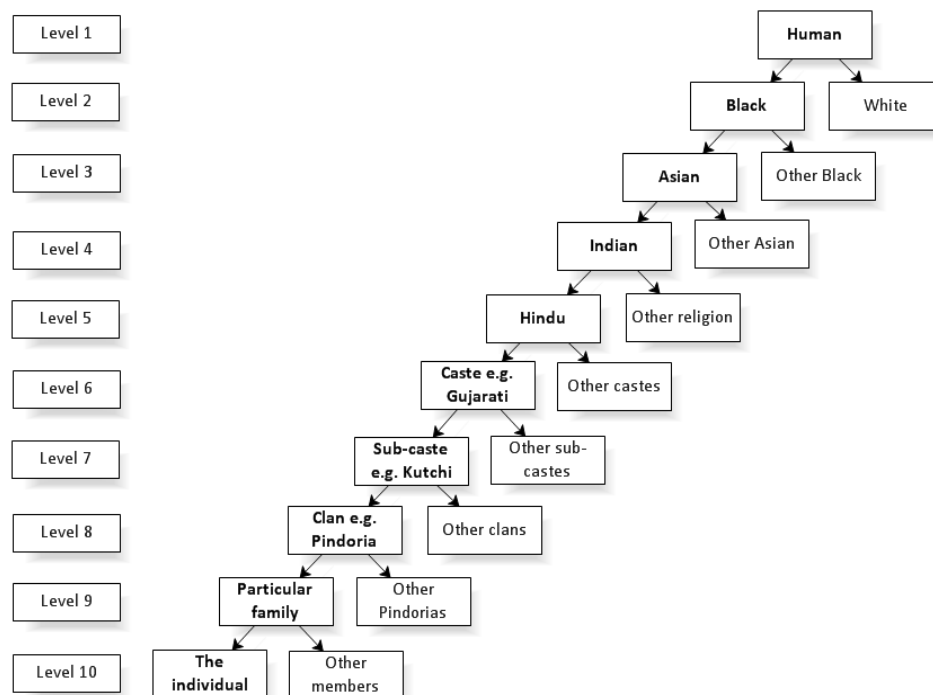
2.7 Insider-outsider roles in qualitative research

Many qualitative researchers have written about how their characteristics, beliefs and knowledge can result in positioning themselves as either insiders or outsiders, which can influence the recruitment, data collection and analysis phase of the research process (Bhopal, 2001; Bonner & Tolhurst, 2002; Dwyer & Buckle, 2009; Etherington, 2004; Gunaratnam, 2003). Insider researchers can be described as those who are familiar with the population they are researching and share the same or similar characteristics as them, such as gender, age, sexuality, ethnic identity, language, religion, and/or experiential base (Asselin, 2003). An outsider is one who is different to the research group and unfamiliar with the research area they are about to study (Louis & Bartunek, 1992).

The dynamics of insider-outsider positions are not simple and instead of being dichotomised as either/or, they should be placed on a continuum, making it possible for researchers to be both an insider and an outsider, often at the same time or with the roles changing throughout the research process (Ritchie et al, 2009; Wray & Bartholomew, 2010). Adopting both an insider and outsider role has been termed role dualism (Hurworth & Argirides, 2005). This can be a valuable tool when “interacting supportively with informants and at other times stepping back to interpret the data more broadly” (Ritchie et al, 2009 p109). As a British born South Asian, female researcher who has not directly experienced breast cancer, I feel I was both an insider and an outsider and this status changed at varying stages of the research.

It is also necessary to consider the extent to which one can be an insider and/or an outsider, and the impact this can have on the research process. Singh-Raud (1999) believes that “one can always be regarded as an outsider unless one is researching oneself... only a degree of ‘insiderness’ can be claimed” (p11). He goes on to explain this concept via the ‘insiderness’ and ‘outsiderness’ model (figure 2.1). While shared ethnicity (thus insider status) gave me more of an advantage than it would a White researcher, a closer look at ethnicity and the varying levels can question my level of ‘insiderness’ and deem me an outsider. The model is outlined below and adapted to demonstrate the details of how my ethnic identity is classified.

Figure 2.1: The 'insiderness' and 'outsiderness' model adapted from Singh-Raud (1999)



The model shows how one's ethnicity can be broken down into micro levels which can determine the degree to which a researcher can be an insider and an outsider. It can be said that when researching Black women, I was an outsider at level 3. Yet when researching the South Asian women, this varied. For example, I was an outsider in cases where I differed to the participants in terms of religion (level 5) or even caste (level 7). Therefore, as an Indian researcher, it can be implied that I would have had less of an understanding or cultural knowledge of the South Asians who were Pakistani or Bangladeshi and even less of an understanding of the Black culture. This was particularly evident when I had to identify names of potential participants for the quantitative study (chapter 7). As mentioned in chapter 1 (part 2), ethnicity is not routinely recorded within the healthcare services. One way to identify ethnic minority patients is via their names. In some instances, I was required to attend the hospitals to help with recruitment while other times, the research nurses attempted to identify potential participants via their names. Whilst more errors were made by the research nurses when identifying foreign names (often resulting in Non-South Asians completing the questionnaire), there were times when I too was also guilty of doing this. While I was able to identify potential participants (via surnames) who belonged to the same caste as myself with relative ease, names from other sub-castes or other sub ethnic groups became less familiar to me. For example, initially I read the surname 'Gill' with a soft G, assuming it to be an English surname. It later became obvious that Gill, pronounced with a hard G is a highly common Sikh surname. As a consequence, I double checked the patient list to ensure I had not missed any potential South Asian participants.

However, as the levels ascend (from 1 to 10), the differences become less obvious (e.g. religious beliefs are not so varied, or the language varies due to varying dialects, which are subtle), yet can have the potential to impact my stance as an insider. While an interesting point, and shows my level of 'outsiderness' with even the South Asian participants, it did not seem to affect recruitment, data collection or data analysis. In fact responses yielded were very similar across the sub-groups in terms of the cultural influences, which were probed and analysed appropriately (see chapters 3-5 for details).

2.7.1 Accessing participants

Sharing characteristics such as age, gender, ethnicity, religion or language with the researched group do not always guarantee access to the research group, but for some researchers such characteristics have proven to be powerful tools in the research process (Keval, 2009). When researching topics concerning race and ethnicity, matching the researcher and participant by ethnicity and cultural traits such as shared language, beliefs, knowledge or religion has been perceived as being favourable (Sin, 2007). It is generally assumed that insider status allows quicker and easier access to potential participants due to the concept of there being an element of 'sameness' between the researcher and the participant. This can mean that less time is needed to develop trust and rapport with the research group and participants may be more open to talk based on the assumption that the researcher will be able to relate to them better than an outsider would; thus allowing for the generation of in-depth data (Bhopal, 2001; Breen, 2007; Dwyer & Buckle, 2009; Mercer, 2007; Temple & Edwards, 2002).

However, it has also been argued that insider status does not always guarantee access to the research group (Bhopal, 1995; Wray & Bartholomew 2010). This is because the research group can be worried about the way they will be portrayed in the research. Potential participants may also decline being interviewed by an insider because of the fear of being judged and therefore unwilling to openly talk about their experiences (Shah, 2004). Similarly, despite shared characteristics such as ethnicity, if one does not belong to the group's local community, they can be treated with suspicion and seen as a threat (Bhopal, 1995). Initially I thought my shared ethnicity (Gujarati Indian background) would grant me instant access to the breast cancer survivors in my local community. While shared ethnicity enabled me to recruit a few of the South Asian women through my local and extended community group, this was not always the case. One woman refused to take part. To my knowledge, this particular woman was very private and had kept her cancer hidden from the community for a very long time. Furthermore, when asked if she would be willing to share her experience, she said she would not feel comfortable talking about this issue. It is possible that she did not want to talk about her experiences with anyone or specifically me as we were from the same community and may therefore have had concerns around anonymity, confidentiality and how she may be perceived.

In this light it can be argued that participants may feel more comfortable talking to an outsider on the basis that they are less likely to be judged (Tinker & Armstrong, 2008). Therefore, shared ethnicity may not always be necessary. Although broadly speaking, my belonging to a BME community gave me insider status; I was an outsider when researching the Black women. Despite

this, I was able to access the Black breast cancer survivors just as easily as the South Asian ones. This is similar to Egharevba (2001), a Black researcher researching South Asian women, who managed to access her South Asian participants. Although she had limited understanding of the South Asian culture, her participants were described as being open and willing to disclose their personal experiences. However, in both my and Egharevba's case, it is possible that while the participants did not see the researcher as the same (Black in my case with the Black breast cancer survivors and South Asian in Egharevba's case), we were also not seen as totally different, thus BME status was the shared trait at a macro level (Song & Parker, 1995).

To further support this argument, sharing the same ethnicity may not always ensure an insider guaranteed access to the research group, particularly if the group do not see shared ethnicity as important and place greater importance on other characteristics such as gender or socioeconomic status (Culley, Hudson & Rapport, 2007). For example, Culley et al (2007), a team of White researchers, were able to access their South Asian participants as their gatekeepers placed more importance on the research team being 'experts' than on ethnicity. Therefore, the research team's association with a known university and funding from a well-known public body assured trustworthiness and helped in building a rapport and gaining access to their research group.

With regards to accessing the BME community for my research, the majority of the women were recruited via support groups. Initial contact was made with the support group facilitators who acted as key gatekeepers. The gatekeepers played a very important role in helping me gain access to my participants. These gatekeepers were also BME women and therefore shared ethnicity could be a possible reason for developing a rapport and gaining their trust straightaway. This was particularly the case with one of the South Asian support group co-ordinators, who specifically told me that she was willing to help me over other non-South Asian researchers who had approached her because of my ethnic background. The gatekeepers may also have had an invested interest in the research as working in the area of cancer, they would appreciate the importance of conducting this research. This can explain why gatekeepers of cancer-specific support groups were willing to help me compared to the other generic church and community organisations that I approached. Similar to Culley et al, it may have also worked to my advantage that I was part of an academic setting and my research was funded by a well-known breast cancer charity, thus coming from a reputable background.

While my ethnic identity placed me as an insider, not being a breast cancer survivor placed me as an outsider. Whether an insider and/or an outsider, researchers need to establish trust and rapport with their participants in order to obtain good quality data (Cohen, Phillips & Palos, 2001). The gatekeepers played a key role in recruitment, and their established trust and rapport with the women may have encouraged the women to take part. However, some element of trust in the researcher would need to be present even if participants are recruited through gatekeepers (Clingerman, 2008). This was achieved during the initial phone conversations (made to explain the research in detail and arrange a suitable time for interview) and the rapport further developed between the researcher and participant during the interviews, which resulted in the participants sharing their experiences at great depths.

2.7.2 Shared knowledge

An advantage of being an insider can mean having a greater awareness/understanding of the research group's culture (Jaspal, 2009; Le Gallais, 2003). It can also make it easier to establish a rapport and interact more naturally if the researcher is familiar with the research group's language and cultural idioms (Bonner & Tolhurst, 2002).

Before I started this research, my awareness of my own culture was rather basic. It was only after taking on this research that I started showing more of an interest and started to participate in conversations about the general beliefs and traditions we hold and reasons behind it. I became more aware of the South Asian, specifically the Gujarati Indian culture, and aspects of the women's breast cancer experiences (i.e. cultural taboos around cancer, language barriers) started to make more sense to me as I realised that I had witnessed such cultural beliefs and behaviours in other contexts. With regards to the Black community, my understanding of cultural backgrounds, religion, language and geography was initially limited but increased as I interacted more with the group through the interviews and based on the background reading I had done to understand their culture better. Therefore, as I became more familiar with not just the South Asian culture but the Black culture too, I felt I was becoming more of an insider from this perspective.

Initially, my limited cultural understanding and knowledge placed me as an outsider. Though while reflecting on this, I came to conclude that insider knowledge develops as you begin to research the phenomenon in more detail and therefore making you an insider to some extent. This notion supports the argument that insider-outsider roles are better placed on a continuum and the roles change and develop throughout the research process (Wray & Bartholomew, 2010).

However, my prior (though basic) understanding of the BME community did work in my favour in many cases. For example, having shared language with my Gujarati speaking participants allowed me to pick up on the interpreter's erroneous translations (discussed in detail in chapter 5, part 2). There was one particular incident when the interpreter gave an inaccurate answer. She told me that one of the participants was married when I could clearly see that she was a widow. This was culturally obvious to me due to the participant's 'plainness'. Within the South Asian culture, there are certain signs that indicate whether a woman is married or a widow. For example, widows are no longer allowed to adorn themselves and are required to live a very simple life (Mastey, 2009). Furthermore there was a garland of flowers placed around her husband's photograph. In the Hindu culture, a garland of flowers is only placed on a photograph of the deceased as a sign of respect. Later in the interview, the participant stated that she was a widow. My prior cultural knowledge and the participant's confirmation enabled me to ask appropriate and relevant questions. Furthermore shared language also worked to my advantage whilst interviewing English speaking South Asian participants as in some instances the women would often revert to their mother tongue language when sharing aspects of their experiences.

From the breast cancer perspective, I was more of an outsider as apart from shared ethnicity, I had very limited knowledge of breast cancer experiences and how one lives with such a disease. As I started to read around the breast cancer literature and began to conduct the interviews, I became more confident of my knowledge in this area and was moving along the continuum, no longer feeling like a total outsider. However, being an outsider from the cancer perspective did not impede

the research process as the participants were all still willing to share their experiences. This shows that you do not always need to be an insider or have been through an incident in order to access the research group. If the group are keen to voice their stories, then they will talk (Breen, 2007). However, it is also important that the researcher is able to establish trust and rapport with participants in order for them to feel comfortable enough to share their experiences with ease (Keval, 2009).

It has also been argued that greater familiarity and having prior knowledge of the research group's cultural beliefs and values can put the researcher at risk of losing objectivity (Hewitt-Taylor, 2002). While shared knowledge can be seen as an advantage, there is a risk on both the researcher and participant's part of making assumptions about knowledge. For example, the participant may not go into too much detail about their experiences under the assumption that the researcher already knows. In a similar manner, the researcher may take their insider knowledge for granted and fail to further probe or ask questions as they may feel the answers are too obvious (Dwyer & Buckle, 2009; Tinker & Armstrong 2008; Young, 2004), whereas an outsider can embrace this lack of cultural knowledge and ask questions more freely. Furthermore, an outsider's lack of cultural knowledge can be empowering for the participant, as they would see themselves as the expert and therefore provide detailed accounts, eliciting in-depth data (Tinker & Armstrong, 2008).

I felt it was important to have some prior awareness within the BME culture and cancer context before conducting the interviews so that I did not overlook or misinterpret the participants' responses. It has been recommended that researchers ought to keep an open mind to differing and unexpected perspectives/responses when conducting their research and not assume that everyone will share the same attitudes as each other or even the researcher (Le Gallais, 2003). Due to my initial outsider status, I avoided having any cultural assumptions when interviewing my participants. Even if the answer was obvious to me, I made sure that I asked further questions and encouraged participants to elaborate on their experiences in general and from their cultural perspective (Fielding, 2008). For example, I did not just assume that all the South Asian women were Indian and even if this was obvious from their name, I probed them in a way that I hoped did not come across as patronising. I was also careful not to impose my perceptions on the participants by using a mix of positive, negative and neutral vignettes to elicit responses. My outsider position from a generation status, particularly with first generation immigrants, also proved to be an advantage in this situation. This is because it allowed me to show my ignorance about the South Asian cultural beliefs and values, and place the participants as experts which resulted in them giving detailed responses regarding cultural influences in relation to their cancer experiences.

As well as ethnicity, I feel being an insider from a gender point of view was important in this research. Gender can play a big role when researching BME communities. In some cultures it is not acceptable for men and women (especially married women) to interact in any situation. Even during events such as weddings, or going to places of worship, men and women are partitioned and often in different rooms altogether. In these situations it would be difficult for male researchers to research females (Egharevba, 2000). Many BME cultures place great emphasis on modesty regarding the body and therefore issues related to private body parts are not openly discussed. Given the sensitive nature of this research and conducting it on BME women, my gender allowed me to gain access to this research group more so than if a male wanted to research this area.

2.7.3 Analysing data

While it can be argued that an insider is closer to the data and can present the participants' perceptions and experiences in an accurate manner, there is a risk that they can become too close to the data, hindering their ability to remain unbiased in the analysis process (Dwyer & Buckle, 2009). This can be especially true if the researcher knows the participant personally or has gone through the actual experience, impeding their ability to remain objective. It is also possible that an outsider, who is unfamiliar with the participant's world, is able to maintain a distance, enabling a critical analysis of the data (Tinker & Armstrong, 2008; Young, 2004). Whether the research and analysis is carried out by an insider and/or an outsider is not such a main concern as qualitative researchers have the potential of being subjective in their own right, regardless of the position they adopt (Pike, 2003). To ensure that participants' accounts are construed accurately, they can be verified by having other researchers check their interpretations and validate their findings (Tinker & Armstrong, 2008).

Ritchie et al (2009) state that it is valuable having a research team made up of insiders and outsiders as this can help develop good quality research with credible data. My supervisory team was an example of this, comprising 3 supervisors: my first supervisor has substantial expertise in the field of breast cancer, but limited knowledge of ethnicity, the second has expert knowledge in the research of ethnicity and health and the third has great experience in supervising PhD students in various health and appearance related projects. Therefore, I was able to seek advice from each supervisor accordingly. Furthermore, my findings were verified by various researchers, who were outsiders to both the ethnicity and cancer field. This was in order to ensure that my analysis portrayed an accurate account of the women's experiences which were not clouded by my cultural knowledge as an insider (Cohen et al, 2001).

The insider-outsider position is not a simple one. At first I felt my positioning was rather straightforward, an insider from an ethnic minority perspective and an outsider from the cancer perspective. As I continued to delve into this, I found that it was more complex, where in some cases I was both an insider and an outsider, and at other times I was more of an insider than an outsider. Furthermore, my level of 'insiderness' was very much context dependent. To conclude, it is better to place the insider-outsider position on a continuum, allowing one to appreciate the complexities, and value the pros and cons of being both within various contexts (Mercer, 2007).

Regardless of one's position, it is important to be reflexive throughout the research process in order to ensure the research is conducted in a rigorous manner (Etherington, 2004; Ritchie et al, 2009; Wray & Bartholomew, 2010). Furthermore, Dwyer and Buckle (2009) state that "the core ingredient is not insider or outsider status but an ability to be open, authentic, honest, deeply interested in the experience of one's research participants, and committed to accurately and adequately representing their experience" (p59). Therefore adopting one position over the other does not make you a better or worse researcher but a different type of researcher (Dwyer & Buckle, 2009).

2.8 Conclusion

This chapter has covered three crucial methodological aspects that form an important part of this thesis. The approach used to conduct this research has been placed within a pragmatic

epistemological position as the use of mixed methods was deemed practical and appropriate within this applied health context. The rationale for this approach and need for a qualitatively driven approach has also been clearly justified. The second part of this chapter has drawn attention to the challenges of researching BME populations and provided strategies that can promote effective participation. Finally, the insider-outsider dichotomy has been discussed in relation to: a) the importance these roles have on the research process with regards to having prior or acquiring knowledge on the research group and topic of study, b) accessing the research group, and c) analysing data. This section also allowed me to reflect on my direct position on the research and the extent to which I see myself as an insider and an outsider.

The next few chapters (chapters 3-5) present the qualitative studies of this research which helped to guide the development of the quantitative study (chapter 7).

3 Study 1: Black and South Asian women's experiences of breast cancer

3.1 Introduction

This chapter presents the first study of this thesis.

As highlighted in chapter 1 (part 2), research documenting the experiences of breast cancer in Black and South Asian women is limited; particularly in the UK. Existing published research concludes that the experiences of ethnic minority women with breast cancer show some similarities to White women's experiences (e.g. body image concerns and social support). However, unique experiences amongst ethnic minority women are also captured and warrant further research (Ashing-Giwa et al, 2004; Blows et al, 2009; Thompson et al, 2008). The aims of this study were two-fold:

- To explore in detail the experiences of breast cancer diagnosis and treatment in Black and South Asian women in the UK. Due to the dearth of previous research available, an exploratory nature was deemed necessary.
- To inform the development of subsequent studies in this research.

3.2 Method

3.2.1 Design

In order to gain an in-depth understanding of BME women's experiences of breast cancer, a qualitative approach was undertaken (the rationale for adopting a qualitative approach is described in chapter 2). A qualitative approach is particularly recommended when researching an under-researched phenomenon (Waxler-Morrison, Doll & Hislop, 1995). Specifically, one-to-one semi-structured interviews were used to explore breast cancer experiences in detail. The process of one-to-one interviews allows "the emergence of the individual experience and the creation of a combined understanding of the phenomenon" (Darlaston-Jones (2007) p24), and are particularly beneficial when exploring sensitive topics (Reid, Flowers & Larkin, 2005). The semi-structured nature allows the researcher to probe and further explore issues that arise during the interviews, which may not have been considered in the initial interview schedule (Britten, 2006).

3.2.2 Recruitment strategy

This study adopted a purposive sampling technique, whereby "particular settings, persons, or events are deliberately selected for the important information they can provide that cannot be gotten as well from other choices" (Maxwell (1997) p87). Sampling strategies and maximising recruitment with BME communities was discussed in detail in chapter 2, part 2.

It was decided that participants would be recruited through community groups/organisations rather than through the NHS. The main reason for this was to gain a retrospective understanding of women's experiences of their breast cancer journey and not of those who were currently undergoing treatment, as these women's experiences would differ to those who have completed their main treatments. Also, on seeking advice from the Frenchay breast cancer centre, based at Frenchay Hospital, Bristol, the researcher was informed that a very low number of ethnic minority women attend the clinic. Therefore, recruitment of participants via the NHS would not be feasible as the probability of BME women attending these clinics is not very high. Furthermore, snowball sampling and recruitment via community groups have proven to be successful strategies when recruiting 'hard to reach' populations (Ashing-Giwa et al, 2004).

With this in mind, various support and community organisations (appendix 2) around the Bristol and Cardiff areas were approached via letters, telephone calls and posters which were written in English (appendix 3 and 4). This area was initially targeted as Bristol has a fairly large Black Caribbean and South Asian community (Bristol City Council, 2012). Cardiff is where the researcher resides and therefore links within some of the South Asian communities were already established; taking advantage of the insider researcher status (discussed in part 3 of chapter 2). The researcher also made direct contact by attending various community groups within the Cardiff and Bristol areas to talk about the study and the importance of this research. Follow up calls were made a few weeks later to see if any interest had been generated. However, it soon became clear that this was not a very helpful recruitment strategy as only 3 breast cancer survivors showed an interest in taking part.

Recruitment via the media was also attempted. Local and national press releases about the study were distributed, and the research was advertised on websites and in newsletters of relevant organisations such as Breast Cancer Campaign and The Haven Breast Cancer Centre. The press releases were picked up and further promoted on a number of local radio stations. However, this method of recruitment was unsuccessful, generating no interest from potential participants.

Therefore, cancer support groups in areas that have the highest ethnic minority populations were sought. Previous research has tended to concentrate on areas with the largest BME populations such as London, Bradford and the West Midlands (Kai et al, 2007; Rhodes & Nocon, 2003; Stirland et al, 2011). Thus cancer support groups in areas such as London and Birmingham were approached (appendix 2). The researcher liaised with many support groups and visits were made during support group hours in order to recruit women for the study. This proved to be a highly successful recruitment strategy. Due to the initial difficulties of recruitment and after consulting with the chairperson from one of the support groups (Asian Women's Breast Cancer Group; AWBCG), it was decided that offering a £20 Marks and Spencer gift card to show appreciation of the women sharing their personal experiences would act as an incentive for women to take part (as this was not originally offered, an amendment to the university ethics committee was submitted and approval gained). Offering incentives and subsidising costs such as travel have been found to be successful strategies in increasing participation rates (Stirland et al, 2011). This proved to be a very successful recruitment strategy, with 90% of women recruited via support groups. This strategy resulted in 34 women showing an interest in taking part. Women were interviewed until the researcher got a sense of reaching data saturation. The remainder of the women were thanked for their interest and asked if they were happy to be contacted to participate in future studies.

The inclusion criteria were Black and South Asian women over the age of 18, diagnosed with breast cancer (at least 6 months post diagnosis) and have completed their main treatments (surgical, chemotherapy and/or radiotherapy). At this stage, English speaking women and women with Limited English Proficiency (LEP) were included; although a separate study was later designed to gain a detailed understanding of breast cancer experiences amongst women with LEP (chapter 5, part 1). Due to the initial difficulties in recruitment, no upper limit for time since diagnosis was set. However, women who were diagnosed within the first 6 months and/or still undergoing treatment were excluded because they may be less able to reflect on the whole experience and it was important to be sensitive to their needs whilst they were undergoing treatment and/or still coming to terms with the disease.

3.2.3 Participants

Overall, 27 women came forward to take part in this study. However due to other illnesses and various family commitments, 3 were unable to participate. With the women's permission, their contact details were kept in the hope that they may be able to participate in future studies. Of the remaining 24 participants, two were non-English speaking and wanted the interview to take place in their mother tongue language (Gujarati and Urdu). However, the interpreters that were used (family member and community member) proved to be inaccurate in their interpreting and translating skills (discussed in part 2 of chapter 5). For this reason their data was not analysed. Therefore, a total of 22 women took part in the study; 11 South Asian women (including East Africans originating from the Indian sub-continent) and 11 Black women. Twenty of these women resided within the outer areas of London (n = 20), one woman lived in Birmingham and one woman lived in Cardiff. The majority (n = 20) were recruited via three cancer support groups (Asian Women's Breast Cancer Group (AWBCG), Cancer Black Care (CBC) and Cancer You Are Not Alone (CYANA). One woman was recruited via a snowball technique and one woman (known in the community) was approached by the researcher. Table 3.1 provides a summary of the participants' demographic and breast cancer information.

Age: The age of participants ranged from 43 – 75 years (mean age – 54 years).

Ethnicity: Ten of the women described themselves as Indian and one as Pakistani. All the South Asian women were first generation immigrants and have been living in the UK for an average of 32 years (range 9 – 42 years). Four of these women were from India and seven from East Africa (namely Tanzania, Uganda and Kenya). Of the Black women, nine described themselves as Caribbean, one as African and one as mixed (White and Black Caribbean). Two of the Black women were born in the UK (England). The remaining nine women were first generation immigrants and had been living in the UK for an average of 30 years (range 9 – 50 years). Eight of these women were from the West Indies (namely Jamaica and Grenada) and one woman was from Kenya.

Employment status: Just over half of the women were in full time employment (n = 13). Seven were retired and two women were unemployed.

Marital status: Nine of the women were married, three were single, two were in a relationship, one was separated, two were divorced and five described themselves as widows. All but one woman had one or more children.

Breast cancer diagnosis and treatment¹: Women's age at initial diagnosis ranged from 42 – 60 years (mean age – 48 years) and time since initial diagnosis ranged from 1 – 15 years (mean time – 5 years). Twenty women had primary breast cancer and two had secondary breast cancer. With regards to surgical treatment, ten of the women had undergone a mastectomy and fourteen a lumpectomy. Of the ten mastectomy patients, one woman opted for immediate breast reconstructive surgery. The majority of the women had undergone adjuvant therapy (n = 18) and 4 underwent neo-adjuvant therapy, in the form of chemotherapy (n = 14), radiotherapy (n = 16), Tamoxifen (n = 14), Arimidex (n = 4) and Herceptin (n = 2). Two of the women who were on Arimidex had been initially prescribed Tamoxifen and had to switch to Arimidex due to side effects from the Tamoxifen.

3.2.4 Interview schedule

A semi-structured interview schedule was developed using the existing BME breast cancer literature as a guide (appendix 5). A semi-structured approach was employed as it was important to ensure that the participant had the flexibility to discuss their experiences in detail, the interviewer could probe for details further and wording of questions could be omitted and adapted accordingly. The interview schedule was developed by firstly listing the issues previously highlighted in the literature. This resulted in formulating appropriate questions and probes which were placed in a logical order. Due to the exploratory nature of the study, the topics were kept broad to allow women to share their experiences. The interview schedule was divided into 3 parts: a) diagnosis and treatment experiences (e.g. thoughts and feelings at diagnosis and during treatment, healthcare experiences, impact on others (i.e. family) and body image concerns), b) experiences of breast cancer in relation to ethnicity (e.g. cultural thoughts and beliefs, including the role of religion in relation to illnesses), and c) overall thoughts (e.g. reflection on overall experience and thoughts/concerns about the future). Before conducting the interviews, the interview schedule was reviewed by all the supervisors and changes were made according to the feedback received. This included adding and rewording some of the questions and probing techniques.

3.2.5 Procedure

Ethical approval was obtained from the School of Life Sciences Research Ethics Committee at the University of the West of England, Bristol.

Support group leaders/facilitators approached members of their support group (on behalf of the researcher) to take part in the study and briefly explained the aim of the research and what taking part would involve. On agreeing to take part, the support group leaders/facilitators forwarded the

¹ Some participants had more than one treatment.

Table 3.1: Study 1: Demographic and breast cancer information (n = 22)

Pseudonym	Age (years)	Ethnicity	Country of origin	Time in the UK (years)	Marital status	Children	Employment status	Age at diagnosis (years)	Time since diagnosis (years)	Treatment (in order)	Primary/secondary cancer
Anna	51	African	Kenya	11	S	1	U	49	2	M, IR	Primary
Jean	47	Caribbean	Jamaica	10	R	2	E	43	4	L, C, R; M	Secondary
Corinne	50	Caribbean	Jamaica	21	M	1	E	46	4	M, T	Primary
Amanda	43	Caribbean	Jamaica	25	S	1	E	42	1	C, O, R, T	Primary
Isabelle	49	Caribbean	Jamaica	9	D	2	E	48	1	C, M, R, T	Primary
Julia	51	Caribbean	UK	51	S	0	E	43	8	L, C, R, T, A	Primary
Alexandra	57	Caribbean	Granada,	44	M	2	E	46	11	C, L, T	Primary
Rachel	43	Mixed White & Caribbean	UK	43	R	2	E	42	1	L, C, R, T, H	Primary
Angie	65	Caribbean	Jamaica	48	W	4	R	58	7	L, R, T	Primary
Denise	75	Caribbean	West Indies	50	W	5	R	60	15	L, C, R, C, R, T	Primary
Lauren	71	Caribbean	Jamaica	48	W	7	R	56	15	M, T	Primary
Mina	52	Indian	India	42	S	2	R	49	3	M, C, R, T	Primary
Vanita	63	Indian	Kenya	27	W	1	R	55	8	M, R, T	Primary
Sanjani	57	Indian	Kenya	9	M	1	E	56	1	L, C, R	Primary
Anu	51	Indian	Tanzania	36	M	3	E	47	4	L, M	Primary
Fahima	62	Indian	India	39	W	1	R	47	15	L, R; M, C, T	Secondary
Savita	48	Indian	India	39	M	1	E	45	3	L, C, R	Primary
Tanuja	50	Indian	Tanzania	32	M	1	R	46	4	Bilateral M, T, A	Primary
Nashida	50	Pakistani	Kenya	24	D	2	U	47	3	L, C, R, A	Primary
Raaksha	47	Indian	Uganda	37	M	2	E	44	3	C, L, R, H	Primary
Kaveeta	53	Indian	Kenya	41	M	2	E	50	3	L, R, T	Primary
Hema	50	Indian	India	25	M	2	E	49	1	L, C, R, A	Primary

Marital status: S = Single; R = In a relationship; M = Married; D = Divorced; W = Widow

Employment statuses: E = Employed; U = Unemployed; R = Retired

Treatment: M = Mastectomy; IR = Immediate Reconstruction; L = Lumpectomy; C = Chemotherapy; R = Radiotherapy; H = Herceptin; T = Tamoxifen; A = Arimidex; O = Other [Full axillary clearance]

women's contact details to the researcher. The researcher then contacted each potential participant to explain the study in more detail and to arrange a suitable time and place to conduct the interview.

A one-to-one semi-structured interview was conducted with each participant. All participants preferred to be interviewed in English; although there were times when some participants shared aspects of their experiences in their own language. At the beginning of each interview, the participant was given an information sheet to read (appendix 6). This sheet outlined the purpose of the research and nature of participation in detail. Once they had read the information sheet, participants were given the opportunity to ask questions and were reminded of the rationale of the study and their right to withdraw. Confidentiality of their responses was also reiterated. Participants then read and signed the consent form (appendix 7). Demographic details were collected and the interview between the researcher and the participant commenced. On completion of the interview, participants were thanked for their time and given a £20 Marks and Spencer gift card as a way of thanking them for sharing their experiences. All the interviews were audio-taped and lasted between 37 and 135 minutes (mean – 78 minutes). It was also noted if participants were interested in receiving a summary of the findings.

3.2.6 Data Analysis

The interviews were transcribed verbatim by the researcher. Comments made in the women's mother tongue language (mainly Gujarati and Hindi) were translated into English and also transcribed by the researcher. The accuracy of this translation was validated by a community member who is fluent in Gujarati and Hindi.

The dataset was analysed via inductive thematic analysis (Braun & Clarke, 2006). Thematic analysis is a "method for identifying, analysing and reporting patterns (themes) within data" (Braun & Clarke (2006) p79). This analysis was used because it allowed the researcher to carry out a detailed analysis of the data and identify relevant themes that can capture the women's experiences. Thematic analysis is not linked to one particular theoretical framework, thus justifying its use in this exploratory study. The reported BME breast cancer studies (described in part 2 of chapter 1) show that women's society is influential in the way that they experience illnesses. With this in mind, the thematic analysis adopted a contextualist epistemology; whereby the researcher was required to make sense of the women's experiences within a personal and broader cultural context. The analysis was also conducted at a semantic level, whereby the themes identified reflected the surface meanings of the data. This required the data to be described, summarised, and then followed by an interpretation of the data in relation to the broader meanings and implications; which would be supported by previous research (Patton, 1990).

Also, due to the large dataset, thematic analysis was deemed appropriate over analyses such as Interpretative Phenomenological Analysis (IPA), which requires a thorough understanding of the way in which the individual understands their reality and the world around them (Smith & Osborn, 2003). This approach will be used and explained in greater detail in chapter 5 (5.3.2).

Using a bottom up approach (themes are closely related to the data), Braun and Clarke's (2006) step by step guide was utilised to analyse the data. Firstly, each transcript was read thoroughly, several

times, whilst making notes where appropriate (phase 1: familiarising self with data). Whilst reading and re-reading the data, interesting aspects were noted. This was first done by hand (on the transcripts) and then via the qualitative software program, QSR NVivo. This software enabled the data to be analysed and managed in an organised manner. Although time consuming, this ensured that during the coding process nothing had been missed out (phase 2: generating initial codes). On producing a list of codes, a closer look at the codes was sought in order to group the codes into potential themes (phase 3: searching for themes). This was done by creating a map of the codes and themes and generating themes and sub-themes. These themes were then reviewed in great detail and further refined to ensure that the codes were relevant to each theme (phase 4: reviewing themes). At this stage, each transcript was re-read to check for additional coding and to check that nothing had been missed out in the earlier phases. Finally, the themes and sub-themes were checked to make sure they told a clear story and captured the depth and breadth of the data. They were then given a concise name and defined to capture each theme (phase 5: defining and naming themes). See appendix 8 for a worked example.

The findings were also verified by two objective qualitative researchers (experienced in thematic analysis) as a means of validating the accuracy of the interpretations (Mays & Pope, 1995). This was carried out in two ways. One researcher went through 6 of the transcripts and cross referenced them to the codes and themes that were produced. The second researcher was given another 6 transcripts to analyse. This was done to see if another researcher produces similar themes. The transcripts were randomly selected. Meetings with each researcher were arranged to talk through the datasets and to iron out any disputes. Both additional researchers were in full agreement of the researcher's interpretations. A summary of the findings (appendix 9) was also sent to participants and support group facilitators (so that they can circulate the findings to participants who could only be accessed by the support group facilitator) for member checking. This is considered an appropriate technique to check whether the findings 'ring true' (Ziebland & McPherson, 2006).

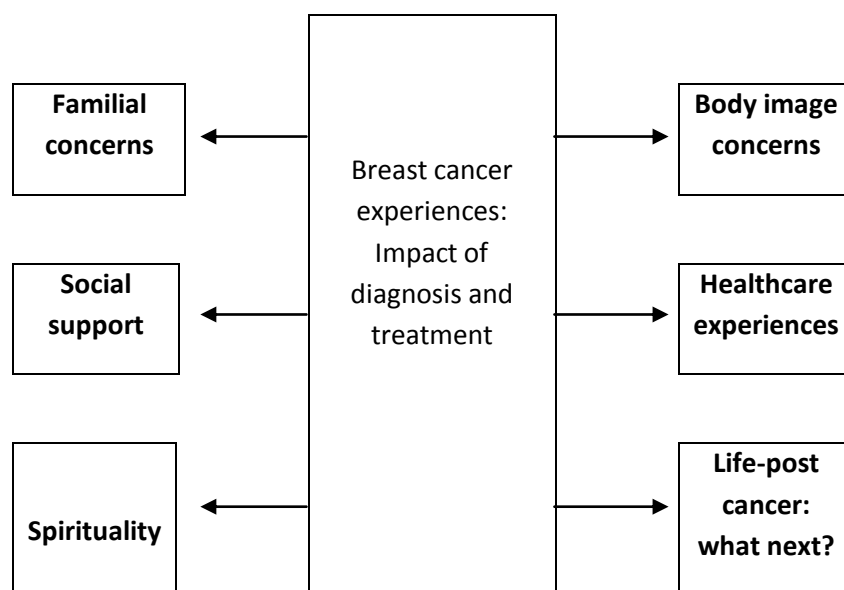
3.3 Findings

Thematic analysis of the data revealed six main themes with sub-themes emerging within each. The six main themes were: familial concerns, social support, spirituality, body image concerns, healthcare experiences and life post-cancer. These themes are related to the psychosocial impact of breast cancer diagnosis and treatment (figure 3.1).

On the whole, all the women found their breast cancer experience to be physically and mentally draining. Women were very emotive in the way they described their experiences and expressed feelings of shock, devastation, worry, distress, anxiety, depression and anger. There was an instant association with death and many felt they were not going to live for long. The shock of the news made it hard for the women to accept their diagnosis, although this changed over time. It was a life altering experience and one that will not be easily forgotten.

Each theme is described in detail below. *Italicised fonts* represent the sub-themes that emerged. Participant quotations are also used to verify the identified themes. All names quoted in the text are pseudonyms.

Figure 3.1: Diagram illustrating the 6 themes



3.3.1 Familial concerns

This theme highlights how the cancer was not limited to the breast cancer survivors but outlines the concerns pertaining to family members. The experience as a whole was an emotional time for everyone around them, particularly their family.

'Impact on family members'

All the women emphasised how their breast cancer had an adverse impact on their family members. On hearing of the diagnosis family members expressed great concern and were deeply shocked. Children and partners in particular found it difficult to accept their loved one's cancer diagnosis and seeing them undergo treatment. While some tried to remain positive, many reacted by closing up, suppressing their feelings and constantly fearing the worse. A few women even explained how their children gave up their studies because they could not cope.

"The younger one took it really badly. He was at *** University. He was just there for 6 weeks and came back. He just wanted to be... he kind of wanted to be near me but he was in denial. He would do crazy things like bring different girlfriends around. I don't know he was just... I think he was thinking it's not fair, why has mum got it. And the older one was at ***** University in his last year and he reacted completely differently. He cried and he would phone me etc. But my [other] son dropped out of university and he didn't go back."** [South Asian; Kaveeta, aged 53]

One family member found it so hard he insisted that his mother and aunt did not display their bald heads.

“We understood what he meant, what he was thinking, how it made him feel all in that little phrase that he said and so I said, “oh he doesn’t like to see us like this”. It told me in one sense that he cared so much for us that it was hard for him. I looked at it that way, but all in all... it told me well when you say youngsters don’t really care, they care.” [Black Caribbean; Julia, aged 51]

For those who had young children, one of the most immediate reactions at diagnosis was worry for their children’s wellbeing. This was particularly evident in women who were divorced or separated. However, married women were also worried as they saw themselves as their children’s main carer, and did not believe they would survive. Many women also expressed their worry for older family members, such as their parents, and how this would affect them.

‘Staying strong for the family’s sake’

The worry of how the cancer diagnosis was affecting family members resulted in many women putting family members’ needs before their own. This often took the form of downplaying the personal and physical impact of diagnosis and treatment, and supporting the family during the illness. Staying strong for their family enabled the women to instil confidence and assurance. It was important to the women to remain optimistic for their and their family’s sake by keeping things as normal as possible and to avoid the constant reminder of the cancer. This involved resuming domestic roles and for some, continuing to work during treatment. Although it was hard to stay strong, this technique acted as a positive coping mechanism as whilst assuring others that they will fight this disease, the women internalised this belief and were determined to get through this.

“Life goes on you know and um I felt that was really important to um to let my kids know that life went on and that you still had to work hard and do the best you can and I needed to prove to myself that I could still do it.” [Mixed raced; Rachel, aged 43]

While resuming normality helped women feel useful, a few of the South Asian women found it difficult to fulfil their previous domestic roles, feeling an obligation to put their family’s needs before their own. These particular women did not have their family’s full practical and emotional support and had to continue upholding household chores of cooking, cleaning and, for some, looking after their young children.

“Obviously even after I came back from the chemo[therapy] it was difficult to keep up with making meals, keeping the house clean, making sure the kid’s homework was done.” [South Asian; Raaksha, aged 47]

‘Being a burden’

Women also spoke of how they did not want to worry or burden family members with their problems. Many chose to go for their treatments by themselves rather than inconvenience others. This made them feel as if they were in control of their lives and the illness.

“My sister-in-law did offer [to take her for the chemotherapy] and I think...because it

was the first time I said I don't know what I was going to be like and what the side effects would be so she came with me. But I told them not to because I didn't want to be a burden. I just wanted to cope with it myself. Maybe it was that... something that... they were there to help me, they were getting the time, free time and everything but I just felt that I shouldn't be hassling anybody else, not even my husband at times." [South Asian; Savita, aged 48]

3.3.2 Social support

Being well supported was imperative during the women's experience. Women talked about the vast amount of support they received from various sources and how this allowed them to deal with their diagnosis and treatments; particularly those who were open to talk and tell others about their cancer.

'Unlimited support'

The majority of the women spoke of receiving unlimited support from their family members, friends, work colleagues, church members and support groups. These women described their sources of support to provide invaluable practical (people helping with household chores such as shopping, cooking and cleaning), emotional (listening ear, words of encouragement and positivity), moral (visiting the patients at hospitals and/or their homes and going to hospital appointments with them) and informational support (advice/leaflets about breast cancer).

"I can't grumble... I really can't grumble. I was supported at church, I was supported at home, I was supported, can't grumble, I really can't grumble." [Black Caribbean; Julia, aged 51]

Interestingly, only the Black women spoke of their community church members to be very supportive and caring. Church members would comfort the women by praying for them and/or with them. Conversely, many of the South Asian women expressed how unsupportive members of their community were and would often make inappropriate remarks, resulting in women being private about their cancer and wanting to avoid such negativity.

"Somehow I thought I don't want to move towards that person, she's going to ask me something and she did. "I thought you had it chopped off you know you're just running around like normal" I said "what's wrong with that they haven't chopped my leg off"." [South Asian; Anu, aged 51]

Although sources of support varied, family members and partners played a key role in supporting the majority of the women. Some women's family members (i.e. sister, mother or in-laws) moved in to support and care for them. Partners were described as doing more around the house and were understanding to the women's emotional and practical needs throughout their cancer experiences. This on-going support was very helpful for many women (especially those who had a mastectomy and were limited in their levels of physical activity, post-surgery) as they did not need to worry about anything; allowing them to focus on getting better.

“When I was in hospital, he [partner] was there for me. During my sickness he was there you know. Even though I get mad at him he was still always there you know. He’d do the housework, he’d do everything. He always encourages me, even when I get mad; he was still there, encouraging.” [Black Caribbean; Jean, aged 47]

Whilst the majority of the women were very well supported; a few talked about how they had no family to turn to and, in some cases, their work colleagues were not understanding or supportive. This had an adverse psychological impact on them as they felt that they had to be proactive in finding appropriate care and support. A few women even found that not all their friends were supportive and some did not bother at all due to the possible fears and taboos associated with cancer.

“Well the fact that I’m on my own... that ... I know people who went through it with the support of family, a partner um and I think for them it was easier. It was more manageable because they had you know people who loved them, family and you know a partner who was supportive.” [Black African; Anna, aged 51]

On the other end of the scale, a small number of women felt smothered by the amount of support they were getting and felt they wanted to be left alone in order to deal with their cancer diagnosis in their own way. Being overwhelmed by an excessive amount of support appeared to instigate feelings of helplessness and they felt that the overwhelming care and support was a constant reminder of their illness. Before the cancer, many were independent working women. Therefore, a large majority felt their treatment had compromised their independence and ability to do things. This left the women feeling helpless in their own homes, which was extremely frustrating for them.

“They [family] would be overprotective and too fussy and you can’t cope with that. It becomes more stressful.” [South Asian; Savita, aged 48]

“I didn’t want anybody to touch me or anything like but then I didn’t have a choice and I used to cry. I really used to cry because I didn’t want everybody... I didn’t want help from all these people, never expected... even in my kitchen they would just get on with it.” [South Asian; Tanuja, aged 50]

‘Support from similar others’

Attending support groups was a great source of support for the majority of the women, whereby emphasis was placed on being around other breast cancer survivors who could understand what they were going through. Moreover, support groups that were designed to provide culturally specific support were found to be highly beneficial in addressing the women’s cultural needs and concerns. Many of the South Asian women spoke of a six week workshop (Naya Rasta – *New way*) which was only available in one hospital in London. Here, the women were given the opportunity to gain and provide emotional support to other Asian cancer patients. From a cultural perspective, they were taught how to cope with the taboos and stigma that Asian communities attach to cancer. They received informational support regarding the Asian diet (e.g. the right foods to eat and where to get this from) and psychological support (e.g. ways of managing any body image concerns and dealing

with feelings of depression and other anxieties).

“They [support group] gave us things and they catered for our colour.” [Black Caribbean; Julia, aged 51]

“They [Naya Rasta workshop] were able to say well you know you can buy this from here and this from there, you don’t have to cook [laughs], there were short cuts and you could still get healthy meals from the supermarkets and nowadays you can get all Indian food as well. You can get ready made chapattis, you can get Tiffin delivery and these are the sort of things I needed to know from them, to guide me in the right direction and um ... that really helped.” [South Asian; Raaksha, aged 47]

“They [Naya Rasta workshop]... um... taught us about depression. We discussed this depression, how to get around it, um the Asian diet, the vegetarian diet. What it’s lacking in. What you can do to overcome that. It’s like you need protein because you don’t eat meat so don’t have watery *daal* [lentil curry dish], have it thick so you can get enough protein inside you. Things like that you learn from there.” [South Asian; Sanjani, aged 57]

While many women found it helpful being around breast cancer patients who shared the same ethnicity, other women found that knowing other breast cancer patients who were similar to them in age or shared similar circumstances (i.e. single mothers) to be most helpful. Women often compared their own cancer experiences with other people’s experiences. This made them feel better and appreciate their illness, particularly when comparing themselves to people who were worse off. However, this was not always the case and some women felt better about their cancer when comparing themselves to those who were living proof that they had overcome the disease. This instilled confidence in the women that they too could get better and a breast cancer diagnosis is not a ‘death sentence’.

“It makes you feel better when my buddy, um had an infection after her radio[therapy] and her skin split open and it went septic and that made me realise that if I think I’m going through hell, what about her. So calm down, it isn’t that bad so in that respect it also helps. You just compare and you think what are you moaning about? They have it a lot worse.” [South Asian; Sanjani, aged 57]

“Then the Macmillan nurse would suggest you know oh we have this group and would you like to come and that was very very encouraging. And I went along and there was this air hostess, very glamorous and you know sort of looking where was it [cancer]? And that gave me a lot of hope” [Black Caribbean; Alexandra, aged 57]

3.3.3 Spirituality

This theme focuses on the varied spiritual attitudes that influenced the women’s experience and aided acceptance and understanding of their cancer.

'Spiritual faith and beliefs'

All the women (bar one) spoke of holding spiritual beliefs in one form or another and discussed how this had played an important role in helping them understand and deal with their cancer. Some women turned to spirituality in the form of meditation (yoga) and Reiki. Engaging in such relaxation methods helped the women connect with their inner self, control their emotions and avoid negative feelings of depression, anger and distress. However, the majority of the women placed great emphasis on being religious and explained how their faith had helped them through their cancer journey. All but one of the women had a strong belief in God and were religious before their cancer diagnosis. Therefore, praying to their God and attending a place of worship was already a big part of their lives. However, after being diagnosed, the women's faith in their God increased and they turned to more religious/spiritual activities. For example, they were praying more, reciting mantras, reading holy books, and listening and singing religious hymns. When the women would be feeling low, engaging in these activities helped to lift their spirits, gave them a peace of mind and increased feelings of serenity.

"I'm a Christian and I believe in God and I know it was my faith that kept me going through it." [Black Caribbean; Amanda, aged 43]

"While I was going through my treatment I was at home and all that time I was not watching television and films but I used to listen to Bhagavad-Gita [Hindu scriptures] and all that sort of things. And it does help, it gives you a peace of mind, it does." [South Asian; Savita, aged 48]

While most women's faith and belief in God strengthened, one woman spoke of how she blamed God for what happened to her and was bitter and angry towards him. This resulted in her temporarily losing her faith as she felt he was not hearing her. Nonetheless, meditation and the above religious references helped the majority of the women to deal with their cancer in a positive way.

"I always, regardless of how negative I'm feeling, always revert back to going to church. It's just a part of me and um ... I think with time, no I had to talk with my vicar as well because it got so intense that towards the end of last year, I just stopped going to church." [Black African; Anna, aged 51]

'Fatalistic beliefs'

Another way women dealt with their cancer was by internalising a fatalistic attitude. From a religious perspective, some of the women believed that their cancer was predetermined by forces beyond one's control, such as their God. It was not in the women's nature to blame God but they believed that it was something that was meant to happen. Holding such a belief reduced anxieties and worries and helped many women accept the cancer.

"I've never questioned why me you know." [Black Caribbean; Lauren, aged 72]

“As far as I know if I did anything it might have been unwittingly or maybe in my last incarnation, I don’t know but um they’re all question marks and there are no answers to it so there isn’t much point brooding over it and telling yourself why why why, why me? It’s God’s wish.” [South Asian; Sanjani, aged 57]

‘Punishment’

While some women engaged in positive fatalism, other women questioned why they had developed cancer and thought of it as a punishment from God. These women felt that they had done something wrong in life and were being punished for their bad deeds. This belief was further encouraged by members of their community who, on visiting them, would insinuate that they must have done something to deserve it. This resulted in many women internalising this cultural belief.

“I used to think oh why God has done this to me. Look he chose me, what crime have I committed? What crime have I done that he chose me to give me this and all that.” [South Asian; Nashida, aged 50]

“You have got some people who say “holier than holy”, they will turn around and say what did you do to get, you know what I mean, it’s more from what people say.” [Black Caribbean; Julia, aged 51]

“I thought yeah they [community members] could be right, they are right. I thought like that. Sometimes I do feel like that and I think no it can’t be. It’s not linked but back of your mind you think I must have done something.” [South Asian; Tanuja, aged 50]

Another cultural belief that members of the women’s community would often speak of, and the women themselves internalised, was that of karma. A few women spoke of how they believed that their cancer was a consequence of having done something bad in their present or previous life and felt they had to go through this journey as a way of repenting for their past mistakes.

“I’m quite spiritual I believe in karma philosophy and you know you might have gone through something in life which you have to pay for now so it was part of payment to go through torture that I had probably created to somebody else.” [South Asian; Raaksha, aged 47]

However, one woman rejected beliefs centred around karma and held a fatalistic attitude, without making any references to God or spirituality.

“I believe that doesn’t happen. This um anybody and half of the world are suffering with cancer; they are not doing everything bad. It just happens.” [South Asian; Hema, aged 50]

3.3.4 Body image concerns

This theme highlights the impact that surgical and adjuvant treatment(s) had on the women's body image.

'Altered appearance'

Many of the women spoke about the negative impact of an altered appearance on their body image. The majority of the women who underwent a mastectomy (compared to lumpectomy), chemotherapy and/or radiotherapy spoke of the devastating impact of losing their breast and/or hair, and changes to their skin (e.g. skin tightening or becoming discoloured). Furthermore, side effects from hormonal therapy resulted in many having to deal with gaining weight. Women reported feelings of depression, distress, shame, embarrassment and loss of self and body esteem. Women often tended to compare how they used to look before their cancer and how they look now, both during and after treatments; which further decreased their confidence levels. Some of the single and divorced women voiced their concerns of feeling conscious about getting into a new intimate relationship.

"My nails got black, all my nails got black. I got so dark you know and some like rashes and things like that all over my skin. Oh Lord, I just wanted to crawl under somewhere honestly and just hide you know." [Black Caribbean; Jean, aged 47]

"I was putting on weight like anything... my face was round and I had really really put on weight and I thought God what am I going to do? Oh God, I really started to hate myself" [South Asian; Tanuja, aged 50]

"Well for one, I'm very um conscious of the fact that I have had the mastectomy so you know the thought of meeting somebody new scares me because then I have to tell them I've had a mastectomy and then they have to see the difference so you know I'm conscious of that." [Black African; Anna, aged 51]

Women also explained how they were really self-conscious of the way they looked and due to feelings of shame and embarrassment avoided looking in the mirror, being around family and friends and going out in public. Women's feelings of self-consciousness and anxiety were particularly elevated when people made negative remarks about the way they looked. One woman spoke of how she never went out for two years because she was too nervous to face anyone. Another woman did not go out for at least six months.

"After I had my operation I never went out for at least six months cos I was thinking how would I look and if anyone, you know is going to say something and as I say, when I used to go out during that time and if anyone looks at me, I used to feel a bit conscious." [Black Caribbean; Lauren, aged 72]

"People are telling me in church which is where I'm conscious about it. You can see you've had something done with your breast. One's bigger, one's lopsided and I'm so conscious of it. I say I haven't fixed myself properly this morning" [Black Caribbean; Julia, aged 51]

Although changes to appearance had an adverse impact on them, some women psychologically prepared themselves by taking control of the illness. This included getting appropriate information from others, maintaining their appearance (regardless of the changes), and being proactive in managing the side effects of treatment (e.g. exercising to control weight gain and shaving their hair off rather than waiting for it to fall out).

“I felt good. I said I'm in charge here. It's [hair] going to fall out and I'm going to get used to seeing myself in the mirror with a bald head.” [South Asian; Sanjani, aged 57]

'Use of appearance-related products'

Women engaged in appearance concealing behaviours by equipping themselves with products such as wigs, scarves, prosthesis and make-up. This helped to boost their confidence. By covering up their altered appearance, women felt they were able to carry on as normal and avoid the taboos and stigma that are associated with cancer. Although products were available to help women deal with their altered appearance, many women expressed their dissatisfaction with the limited range of items such as wigs, prosthesis and lymphoedema sleeves and felt that culturally, they did not meet their needs. For example, some women explained how wigs were designed for White women and therefore did not look natural on them. Wigs designed specifically for South Asian and Black women were limited and not readily available on the NHS and women found they had to go elsewhere to buy a suitable wig. Women also complained that they had problems getting a breast prosthesis and lymphoedema sleeves that matched their skin colours. However, not everyone voiced their dissatisfaction with these products. Some women understood that it's difficult to find a prosthesis and/or lymphoedema sleeves that match their exact skin colour so were content with them being similar to their skin colour. A few women also explained that they were not too concerned that their prosthesis did not match their exact skin colour as the prosthesis is worn inside the bra and is therefore not seen by everyone.

“They [wigs] were horrible. I think they need to look at um the wigs because as a Black person I feel that those wigs don't suit Black people. They're more of European type. And we're the Caribbean people, I'm speaking from Caribbean side of people, them type of hair is not for us.” [Black Caribbean; Amanda, aged 43]

“I don't know what the fuss is about this getting the colours right. Even if I was dark, you don't see them [breast prosthesis]. You don't see the prosthesis. They're inside your bra for God's sake. I've read everywhere with women saying oh they couldn't find my colour and in the end they found my colour. I think they're just being daft.” [South Asian; Mina, aged 52]

'Clothing issues'

Changes to the women's appearance also left many feeling angry and frustrated as they felt limited in their choice of clothing. Women stated that they could no longer wear low neck and sleeveless tops/dresses and found they tended to cover up more by wearing high neck and long sleeved

clothes. Some of the South Asian women mentioned the additional difficulties of wearing traditional clothes. Responses varied here, where a few felt they were restricted in what they could wear as it attracted more attention to the chest areas thus limiting attendance to cultural/religious functions. While others felt that, in comparison to English clothes, wearing a prosthesis was not so obvious in traditional South Asian clothes (i.e. saris; long material that is draped around the waist and over the shoulders, and salwar kameez; a long tunic worn over a pair of baggy trousers).

“This blouse is okay cos you can’t see anything but I can’t wear it too low you see. Things and appearance like that bothers me sometimes. If I go to buy a top or you know... and I see, and I say oh that’s nice but then I got to think oh no, I can’t wear that or if I do buy it I have to put a camisole inside so that it doesn’t show.” [Black Caribbean; Lauren, aged 72]

“See those little dots there [shows her leg] they’re not everywhere, just here and that’s caused by the drugs I’m taking. Hopefully it’ll go away when I stop and that’s another thing I can’t wear dresses and short skirts. Forget about the top half being problematic, I can’t wear anything that shows my legs because I don’t like the way it looks ... I think it looks nasty,” [South Asian; Mina, aged 52]

The above comment (by *Mina*) shows that appearance changes were not just confined to the breast regions but side effects from the medication had the potential to affect other parts of the body too.

‘Health Vs Appearance’

There were a small number of women who did not seem to be highly concerned by their appearance changes as they placed more importance on health than appearance. They were thankful to be alive and reassured themselves that appearance changes such as hair loss were temporary. Some women described how they had chosen to undergo a mastectomy as they put more emphasis on wanting to survive and diminish any possibility of recurrence.

“Yeah I’m not worrying about my looking, I worry about my health. Health is important; if you are healthy then everything will come back.” [South Asian; Hema, aged 50]

‘Femininity issues’

Changes to the body raised issues of femininity for many of the women, which had an adverse affect on their self-confidence. Women explained how things that they believed defined them as a woman had been negatively affected by treatment and consequently felt like less of a woman (e.g. going into early menopause, losing a breast and hair).

“Prosthesis or not... when you undress fully, you are not a full woman.” [South Asian; Mina, aged 52]

Yet a minority of the mastectomy patients did not feel that a loss of a breast defined their femininity in any way and continued to see themselves as complete women. Similarly, many women spoke about the importance of their partner's support and attitude towards their appearance changes. If the partners were not bothered by the women's appearance changes then the women were less affected. Similarly, if men did not find them attractive, the women believed that they would have felt like less of a woman.

3.3.5 Healthcare experiences

This theme outlines how healthcare issues were embedded in the women's stories.

'Satisfaction with healthcare'

The majority of the women were extremely satisfied with the healthcare that they received. All the healthcare professionals, particularly the breast care nurses, were described as being caring, sympathetic and very supportive. Consultants and nurses clearly explained all aspects of the breast cancer process including treatment side effects. These women were assured at each stage of their illness and felt the nurses were invaluable in the informational, practical and emotional support they provided. Some women explained how their nurse would make home visits, listened to their concerns and referred them to relevant people according to their needs such as to support groups and counsellors. All the women who underwent a mastectomy and were wearing breast prosthesis spoke very highly of the care and support they received from the prosthesis fitters. Fitters made women feel comfortable, gave them their undivided attention and were very empathetic of their needs. Being well supported, particularly the aftercare received, played a crucial role in boosting the women's self and body esteem and helped them to understand and accept their illness.

"I was scared myself looking in the mirror, for a week I didn't even look at myself in the mirror after surgery. It was horrible but then slowly and gradually the breast care nurse helped me." [South Asian; Tanuja, ages 50]

Some women mentioned that they were given the opportunity to attend a one day 'look good, feel good' workshop, which they found to be very useful. This workshop was available at some of the hospitals that the women were being treated in. Here, they were shown how to apply make-up and wear suitable wigs to make them feel good about themselves and not shy away from society because of their appearance changes.

"In a sense with the chemo[therapy] when you say your hair falls out, your eyebrows and eyelashes also vanish and the rest of the hair vanishing is a bonus but you feel that your eyebrows and eyelashes make a difference and your skin colours are different so this is where the look good, feel better comes in. They teach you how to do make-up while you're going for the chemo[therapy] and it's all out there for people with cancer. Just advice is there, booklets are there, DVD's are there." [South Asian; Fahima, Aged 62]

However, not all the women were satisfied with their healthcare experience. Some women felt that their healthcare team were not always supportive or attentive to their needs. Women felt that information regarding treatment was not clearly explained. Some also felt that nurses were mechanical in the way they treated them and lacked empathy. These women found their breast cancer experience to be very challenging and they had to be proactive in getting emotional and informational support (regarding support groups, treatment options and lymphoedema sleeves). A few women discussed how treatment errors such as nurses not reading information correctly or administering wrong drugs had an additional adverse psychological impact on them.

“The consultants were very aloof. There was one consultant, I cannot remember. The first consultant I ever saw was an Asian consultant at *[hospital]*** but the rest after that, the second consultant I saw at ***[hospital]*** and the one I saw at ***[another hospital]*** was so aloof that you know you just don’t feel comfortable talking about anything. Not empathetic, very aloof, very dismissive of any concerns you bring up and very detached from the patients. They just don’t show any human feelings.”** [Black African; Anna, aged 51]

“Unfortunately in the very first session, there was a mistake and the steroid was going through to me but it was for a very short while and they rectified it very quickly and the doctor came to reassure me and on every page of my file it said no steroids and how come someone makes a mistake? After that they said you should say yourself I said how do I know what things are going in, how do I know what to control but anyway after that session... every time, NO STEROIDS! I had to.” [South Asian; Fahima, Aged 62]

(This woman previously experienced a negative side effect from the steroid during her chemotherapy session, which resulted in her experiencing a psychotic episode. Fahima experienced breast cancer three times. The above quote is in reference to her secondary breast cancer).

‘Type of Care: Private Vs NHS’

Women who received private care were impressed by how well and efficient everything was. Women felt that they were treated ‘like royalty’ and avoided the hassles of moving to different rooms or hospitals as opposed to those who were treated by the NHS. However, the shortfall was observed with the lack of aftercare received during these women’s private care treatment. These women felt that while they were treated well medically, there was a limited amount of emotional and informational support available to them. Information regarding support groups and how to access products such as wigs and prosthesis was not fully available and when it was, they were being introduced to expensive resources – while wigs and prosthesis were free on the NHS. These women felt that they had to be proactive in getting appropriate support and approached the NHS for help. One woman talked about how she could not afford a prosthesis and had to stuff her bra which affected her self-confidence. It was not until she approached the NHS and was fitted with a prosthesis that she was able to turn her life around and gain the confidence to face the public.

“When you are having private treatment, they expect you to find your way with

everything else like wigs, scarves. When you're going through the National Health Service, they help you." [South Asian; Mina, aged, 52]

Not being able to afford a prosthesis on private care raised financial concerns for one of the women. Even women who received NHS care spoke of their worries and struggles in paying taxi fares and parking tickets whilst going for treatment. Fortunately some women had their transportation to and from hospital paid for, which helped reduce some of their anxieties.

'Gender of the healthcare professionals'

Cultural specific experiences regarding healthcare were also mentioned. This was only talked about by the South Asian women. Interestingly, South Asian women were uncomfortable being treated by male nurses. This was something that they had to get used (as even though they requested them, there were no female consultants/nurses available) but they found it very embarrassing and shameful the first time they had to expose themselves to male healthcare professionals. These women were also aware that reluctance of wanting to be examined by male healthcare professionals was a commonly held belief within their culture; which often resulted in women avoiding examinations and sometimes even treatment.

"Radio[therapy], there are times when there are only men there and you know... us Indians are a shy race and when it comes to sort of exposing your body in front of men it's a bit... but I said they are treating me so... it's not very pleasant." [South Asian; Sanjani aged 57]

"Thank God there were ladies over there because you have to take your top off." [South Asian; Nashida, aged 50]

While wanting to be treated by females appeared to be a cultural issue, one South Asian woman stated that for her it was more of a preference as you feel more comfortable being treated by another woman. Preference of being treated by female consultants was not mentioned by any of the African or Caribbean women.

While some women voiced their embarrassment of being treated by male consultants, two felt that their GPs were uncomfortable examining them. These women felt it was because they shared the same ethnicity as the doctor or because they both belonged to the same community. These women were angered by the way their GPs were dismissive and not willing to examine their breasts.

"Sometimes with our... sometime, Indian GP, because they don't have a lady doctor and the male doctors feels ... especially if you know the doctor, they feel that they send you to the nurses and nurses these days, they said they not supposed to touch you like you know you're supposed to be examined by the doctors. So if they are a doctor whether you know them or not, they should do their job like you know. That was the annoying part" [South Asian; Anu, aged 51]

"I went to see my GP and my GP was a man and um he didn't examine me and he goes to me "you're too young, you can't have a lump you don't need to know." I said "I

want to go for a mammogram” he said “you don’t need to” and he sent me home. I was well angry” [South Asian; Tanuja, aged 50]

3.3.6 Life post cancer: What next?

This theme outlines how the women viewed their life after going through a traumatic incident, including reflecting on their life once the treatment was over.

‘Fear of recurrence’

Fear of the cancer recurring was a constant worry for the majority of the women. Often, the slightest bodily twinge would be enough to worry the women that the cancer had returned. However, they were determined not to let this worry take over their life and tried to remain as optimistic as possible.

“Sometimes I do feel because whenever, if I’m bleeding or something, little bit or something different happens in my body, at that time I think has it [cancer] come back again or what. For a fraction it will be there, right at the back of my mind it might be still there but then I try to forget it you know,” [South Asian; Vanita, aged 63]

‘Changes to quality of life’

The side effects of treatments had a negative impact on quality of life (QOL) for many women. Some of these women spoke of additional chronic illnesses that they developed during and/or after their treatment. Chronic illnesses such as arthritis, weak bones and lymphoedema further induced adverse psychological feelings of depression, anger and frustration. For example, women with lymphoedema found it difficult to be in public places like busy shopping malls or on buses because they would get pushed and knocked. Moreover, their condition limited daily chores and activities such as cooking and long distance driving. Many women stated that their life will never be the same again.

“People don’t realise it but half of your life is gone after this treatment. Your self-confidence, your mentality, your thoughts, you’re in pain constantly and you always worry that you’re going to die.” [South Asian; Mina, aged 52]

However, not everyone let the change to their QOL bother them. Many remained positive, carried on with their life and were logical and practical about the adjustments they made to improve their QOL. Women emphasised the need to be more attentive to preserve their body by engaging in healthy behaviours. Women took up healthy eating practices and exercise and avoided anything that could provoke recurrence (i.e. chemicals, body products, and certain foods).

“They say okay avoid putting plastic in the microwave so I’m going to steer clear of those things. I don’t drink in a plastic bottle anymore I drink in a glass bottle. And they say sugar is a cancer cell feeder so I’ve cut out all the added sugar, all the desserts that I used to love. All my chocolate cakes; Indian sweets I never liked anyway so doesn’t

matter. I don't take my tea with sugar anymore and um yeah I avoid sugar." [South Asian; Sanjani, aged 57]

'Thankful to be alive'

Women also attempted to find possible meanings to explain the cause of their cancer. A common belief was that breast cancer was a result of being stressed thus many women tried their best to avoid anything that would cause them stress, worry and tension. All the women took the time to reflect on this life threatening experience and stated having a newfound appreciation for life. Many women realised that life was too short to worry about trivial things and while it was in their nature to think of family before themselves, they learnt that it was also important to put themselves first. They were listening to their body, enjoying and living life to its fullest and became more caring and compassionate towards others.

"I'm quite happy cos I go out dancing, go on holidays and things like that and enjoy my life while I can." [Black Caribbean; Lauren, aged 72]

'Altruistic tendencies'

One of the positive things that came out of the women's traumatic cancer experiences was the engagement of altruistic behaviours. Women were highly motivated to help support other cancer patients. Women did this by providing other cancer patients with moral, practical and emotional support. They would accompany patients to hospital appointments, visit patients at home or in hospital and instil confidence in them. Furthermore, all the women acknowledged the cultural taboos and stigmas attached towards illnesses such as cancer; which result in women being very private about their illness and even reluctant in seeking medical help (due to shame, embarrassment and fear). This in turn motivated the women to abolish such cultural perspectives and raise awareness of breast cancer by educating others. Breast cancer survivors would attend conferences, community events and places of worship to share their experiences and encourage others to be open about their cancer. Some women saw the need to start up support groups and took part in fund raising events to raise awareness in their communities. All this was carried out voluntarily and knowing they were making a difference made women feel good about themselves.

"I actually spoke at 2 women's lunches... where they asked me to talk about my breast cancer and I talked about it and I said look, people don't take it seriously, they just think oh I don't bother examining my breast. I said you have no idea how important it is and you really should and when it comes from somebody who is going through it I think it carries a bit of weight and I said if my being honest, perfectly honest about myself, if it saves one life, it'll be worth my while." [South Asian; Sanjani, aged 57]

3.4 Conclusion

This exploratory study helped to encapsulate Black and South Asian women's breast cancer experiences; providing an insightful understanding of how psychosocial aspects such as family, level of support, cultural attitudes and beliefs, and healthcare professionals, play an influential role in shaping the overall breast cancer experience. Furthermore, the treatment of cancer can have a negative impact on a woman's body image. The findings of this study are discussed in detail in chapter 6.

One of the aims of this exploratory study was to guide the development of the rest of the studies in this research. The six main themes that emerged from this study were: familial concerns, social support, spirituality, body image concerns, healthcare experiences and life post-cancer. Within these themes, references were often made to how women tried to deal with certain aspects of the cancer experience. The way in which women manage their experiences is an important strategy that shapes the overall cancer experience. Thus a detailed account of how women manage this was deemed necessary (chapter 4).

All the women who took part in the present study were English speaking. These women were able to clearly articulate their experiences, though some women spoke at times in their own language, particularly with reference to cultural sayings. The researcher's understanding of the Gujarati and Hindi language allowed the women to share their experiences in words that best expressed how they felt and allowed a natural conversation to flow. While a few women with limited English proficiency took part in the present study, their data was omitted from the analysis due to the inaccuracies observed by the researcher in relation to the interpreter's role in the interview process (discussed in part 2 of chapter 5). Consequently, a limitation of this study is that it did not capture the experiences of women who are not fluent in the English language. It is possible that this group may face additional barriers compared to English speaking South Asian women. Therefore, a third qualitative study transpired: to explore breast cancer experiences in Gujarati speaking Indian women with a limited English proficiency (chapter 5, part 1).

Finally, it is necessary to understand Black and South Asian women's experiences of breast cancer on a larger scale and include the White population to determine how ethnic minority women's experiences differ or are similar to White women's breast cancer experiences. Therefore, the findings of the qualitative studies helped to inform the development of the final quantitative study (chapter 7).

4 Study 2: Black and South Asian women's experiences of managing the psychosocial and cultural impact of breast cancer

4.1 Introduction

This chapter presents the second study of this thesis.

The exploratory study in chapter 3 revealed how Black and South Asian women's experiences are shaped by socio-cultural factors (i.e. the role of family and community members, and negative cultural beliefs around cancer). Furthermore, the adverse psychosocial and physical impact of breast cancer diagnosis and treatment also contribute to the women's experience. The ways in which women's breast cancer experiences are managed play an important role (Culver et al, 2004). This was embedded in the women's stories in study 1. Part 2 of chapter 1 highlighted the importance of family and the role of religion/spirituality in helping BME women manage their cancer experiences. Therefore, having explored BME women's breast cancer experiences, it was deemed important to understand how this was managed.

The aim of this study was to

- Explore in detail how Black and South Asian women manage the adverse impact of their breast cancer experiences.

4.2 Method

4.2.1 Design

Similar to study 1, this study also used a qualitative design in order to gain an in-depth understanding of ways in which breast cancer experiences are managed. However, the method of data collection differed in that semi-structured focus group interviews were utilised. Focus groups are "a form of group interview that capitalises on communication between research participants in order to generate data" (Kitzinger (1995) p299). It is a method used to seek opinions, experiences, and beliefs pertaining to a specific issue, in a collective and mutually supportive environment (Morgan, 1997; Krueger & Casey, 2000). While one-to-one interviews are better suited when exploring personal and private issues, it is now more widely acknowledged that focus group interviews are also more likely to facilitate rather than prevent disclosure of personal issues (Culley et al, 2007). However, researchers need to be aware that not everyone will be willing to disclose private information in a group setting (Farquhar, 1999). Just like one-to-one interviews, focus group interviews are ideal when conducting research of an exploratory nature (Culley et al, 2007).

Focus group interviews were employed for this study as this method of data collection also encourages self-disclosure and has been known to stimulate discussion amongst people who share similar experiences and serve as expert informants (Krueger, 1988). This method of data collection has been particularly successful when researching ethnic minority women as they are more likely to

participate in settings where there is potential to meet other members who share similar experiences of a personal nature (Culley et al, 2007; Ruff, Alexander & McKie, 2005; Wilmoth & Sanders, 2001). Being in a group setting also has potential to reduce pressures and anxieties on participants that a one-to-one interview can potentially produce (Culley et al, 2007). Furthermore, it has been reported that a focus group methodology can increase the likelihood of reaching data saturation due to the number of participants engaging in the discussions (Ruff et al, 2005). With this in mind, using a focus group method was deemed suitable for this study. Furthermore, findings obtained from this study (thus the use of different methods: one-to-one interviews and focus group interviews) can help to triangulate the findings from study 1 (Campbell & Fiske, 1959).

4.2.2 Recruitment strategy

As with study 1, snowball sampling and chain referral sampling (see chapter 2, part 2) were the main recruitment strategies. Women who were interested in participating in the first study but were unable to find the time to take part were contacted to see if they were able to participate in this study. Cancer-related support groups who helped with recruitment of breast cancer survivors in study 1 were also approached; namely Asian Women's Breast Cancer Group and Cancer Black Care. Additional support groups in cities with a high ethnic minority population (i.e. London, Birmingham and Manchester) were also approached (i.e. White House Cancer Support Centre, Dudley; The Haven, London; Paul D'Auria Cancer Support Centre, London; and Naya Rasta, London). Support group leaders/facilitators were first contacted via a telephone call to assess their interest and willingness to involve their group members in research. They were then emailed details of the study and sent posters to display in their centres (appendix 10). The support group leaders assisted with recruitment by contacting their group members to see if they would be interested in taking part. Announcements about the research were also made at their meetings. Posters were also distributed at relevant cancer and ethnic minority related conferences and workshops (e.g. 'Raising awareness of cancer in BME communities', Nottingham and 'Looking beyond cancer survivorship', Leeds) where there was an opportunity to meet potential contacts (or Black and/or South Asian breast cancer survivors) who would be willing to promote recruitment of the study.

The same inclusion and exclusion criteria as study 1 (chapter 3) was used for this study, with the exception of language. Participants were required to be English speaking as it would not be possible to run a focus group with people speaking a mixture of languages, particularly if this was not a shared language amongst the group.

4.2.3 Participants

A total of twenty breast cancer survivors took part in four focus group interviews (five women in each group); ten Indian and ten Black Caribbean women. All the women were English speaking and recruited via cancer support groups. The South Asian women were recruited via the Asian Women's Breast Cancer Group (AWBCG) and through a cancer workshop Naya Rasta (translated to mean 'new way'); both based in North London. The Black women were recruited from two separate support groups; Paul D'Auria cancer support centre in South-West London and the Whitehouse Cancer

support centre in Dudley. Two of the Black women who took part in the Dudley focus group were recruited through snowball sampling (via study 1). None of the women had taken part in study 1. Table 4.1 provides a summary of the participants' demographic and breast cancer information.

Age: The age of the participants ranged from 32 – 72 years (mean age – 56 years).

Ethnicity: All the South Asian women were Indian. Nine described themselves as Hindu and one as Sikh. They were all first generation immigrants. Four of these women were from India and six from East Africa (namely Tanzania (n = 1), Malawi (n = 1) and Kenya (n=4)). Eight of the Black women described themselves as Black Caribbean and two described themselves as mixed (White and Black Caribbean). Seven of these women were first generation immigrants, all from Jamaica and three were born in the UK (England).

Marital status: Nine were married, five single, one in a relationship, one separated, one divorced and three women described themselves as widows. Fifteen of the twenty women had one or more children.

Employment status: Seven women were in full time employment. Eight were retired, two unemployed, one was a student and two women did not state their employment status.

Breast cancer diagnosis and treatment¹: Women's age at initial diagnosis ranged from 28 – 67 years (mean age – 52 years) and time since initial diagnosis ranged from 6 months – 16 years (mean time – 4 years). Nineteen women had primary breast cancer and one had secondary breast cancer. With regards to surgical treatment, eight had undergone a mastectomy and thirteen women had a lumpectomy. Of the eight mastectomy patients, three underwent breast reconstructive surgery. The majority of the women had undergone either adjuvant therapy (n = 19) in the form of chemotherapy (n = 11), radiotherapy (n = 20), Tamoxifen (n = 9), Arimidex (n = 6) and Herceptin (n = 1).

4.2.4 Interview schedule

A semi-structured interview schedule was developed using the existing BME breast cancer literature and findings from the first study as a guide (appendix 11). The interview schedule was designed to explore how women manage their breast cancer experiences. Four vignettes were included to encourage discussions. The use of vignettes, in conjunction with other data collection methods such as one-to-one or focus group interviews have been found to be successful methods to facilitate discussions (Barter & Renold, 2001); particularly when researching sensitive topics (Bailey, 2008) and when vignettes are depicted from real life events (Poulou, 2001). The vignettes were developed based on the findings of study 1 and included examples of issues pertaining to support and healthcare needs as a way of managing the cancer experience. The interview schedule (including the vignettes) was reviewed by one of the supervisors, prior to conducting the interviews and changes were made according to the feedback received. The vignettes were adapted again after the first focus group interview to avoid biased responses. This was because it was observed from the first focus group interview that the biased scenarios elicited biased responses.

¹ Some participants had more than one treatment.

Table 4.1: Study 2: Demographic and breast cancer information (n = 20)

Pseudonym	Age (years)	Ethnicity	Country of origin	Marital status	Children	Employment status	Age at diagnosis (years)	Time since diagnosis (years)	Treatment (in order)	Primary/Secondary Cancer
Jaya	63	Indian	Kenya	W	1	R	55	8	M, R, T	Primary
Sunita	53	Indian	India	S	1	R	48	5	M, C, R, A, T	Primary
Vilash	53	Indian	India	M	2	E	52	1	L, C, R, A	Primary
Daksha	54	Indian	Kenya	S	0	E	53	1	C, L, R, H	Primary
Anita	57	Indian	Kenya	M	2	R	56	1	O, R	Primary
Bina	60	Indian	Kenya	M	1	E	58	2	L, R	Primary
Minal	68	Indian	India	M	3	R	67	1	L, R, T	Primary
Bhavna	70	Indian	Tanzania	W	0	R	66	4	M, C, R	Primary
Anisha	47	Indian	Malawi	M	0	E	45	2	L, C, R	Primary
Kiran	52	Indian	India	M	2	E	41	11	L, R, T	Primary
Liz	69	Caribbean	Jamaica	M	0	R	54	15	L, R, T; M, A	Secondary
Shontelle	40	Caribbean	Jamaica	S	2	O	36	4	M, C, R, T, A, DR	Primary
Fran	64	Caribbean	Jamaica	D	5	U	64	6 months	L, R, A	Primary
Rebecca	51	Caribbean	England	R	1	U	48	3	L, C, R, T	Primary
Stella	66	Caribbean	Jamaica	M	2	R	63	3	M, C, R	Primary
Theresa	72	Mixed: White and Caribbean	Jamaica	M	3	R	66	6	L, R, A	Primary
Beverley	59	Caribbean	Jamaica	W	0	E	55	4	L, C, R, T	Primary
Lydia	47	Caribbean	UK	S	3	O	43	4	L, R	Primary
Tessa	32	Mixed White and Caribbean	UK	S	2	S	28	4	M, L, C, R, DR	Primary
Joanna	50	Caribbean	Jamaica	S	2	E	48	2	M, C, R, T, DR	Primary

Marital status: S = Single; R = In a relationship; M = Married; D = Divorced; W = Widow

Employment statuses: E = Employed; U = Unemployed; R = Retired; S = Student; O = other (unspecified)

Treatment: M = Mastectomy; DR = Delayed Reconstruction; L = Lumpectomy; C = Chemotherapy; R = Radiotherapy; H = Herceptin; T = Tamoxifen; A = Arimidex; O = Other [Reduction mammoplasty]

4.2.5 Procedure

Ethical approval was obtained from the School of Life Sciences Research Ethics Committee at the University of the West of England, Bristol.

Support group leaders approached members of their groups to take part in the study and briefly explained the aim of the research and what taking part would involve. On agreeing to have their details passed on, the support group leaders forwarded potential participants' contact details to the researcher. The researcher then contacted the potential participants to explain the study in more detail and to arrange a suitable time and place to conduct the group interview. Reminder calls were made to all the participants as the group interview date approached. This approach has been known to increase and maximise the likelihood of attendance (Gurm, 2000).

All the focus groups were conducted by the researcher and arranged to be held at a time and place that was convenient for the participants. Four focus group interviews were conducted with five women in each group (2 focus groups with Indian women and 2 with Black Caribbean women). Small groups were used as it is easier to manage the discussions and to make it comfortable for the participants (Kreuger, 1988).

Before starting the interviews, participant information sheets and consent forms (appendix 12 and 13) were distributed to the participants. The information sheet outlined the purpose of the research and nature of participation in detail. Once they had read the information sheet, participants were given the opportunity to ask any questions. Participants then read and signed the consent form. Demographic information was also collected (appendix 14). The group were then verbally reminded of the rationale of the study and were encouraged to respond to all the issues raised. The confidentiality of their and the group members' responses was also reiterated.

To create an informal and relaxed atmosphere that would encourage an open discussion, participants were seated in a circle and refreshments were provided (Basch, 1987).

To start, each participant was asked to introduce themselves to everyone and state when and how their cancer was diagnosed. The researcher then started the group interview. All the interviews were audio-taped and lasted between 88 and 100 minutes (mean - 94 minutes). The researcher also made notes during the interviews, for example, the order in which each individual spoke and when general consensus was shared to main discussion points. This was to make the subsequent transcription process easier. All the interviews were conducted in English; although there were occasions when women in the Indian focus group made a few references in their mother tongue language (Gujarati). This was dependent on which language the women felt best expressed their experiences.

At the end of each session, the participants were thanked for their time and given a £20 Marks and Spencer gift card to show the researcher's gratitude for sharing their experiences. All the participants had the option to have their travel expenses reimbursed. It was also noted if participants were interested in receiving a summary of the findings.

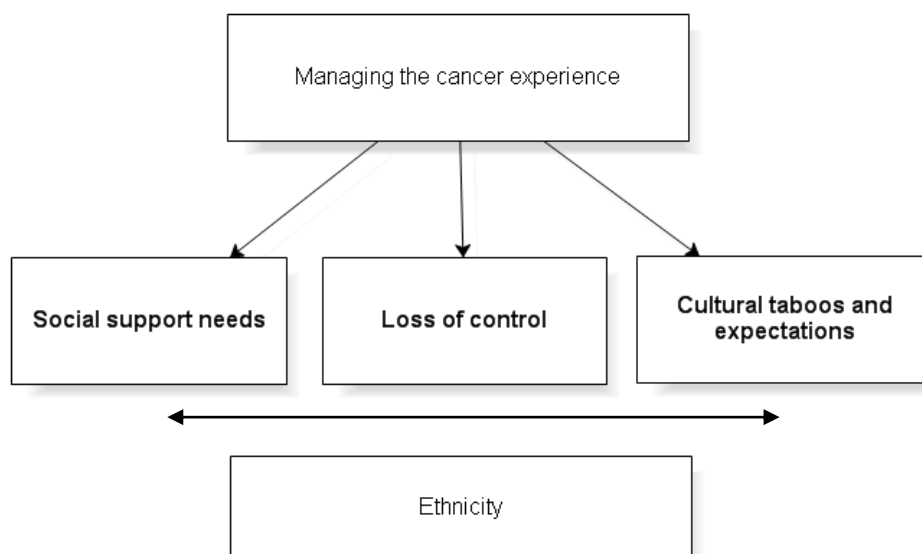
4.2.6 Analysis

The interviews were transcribed verbatim by the researcher and the same approach of data analysis was used as in study 1 (inductive thematic analysis using QSR NVivo to analyse and organise the data). Any comments in their mother tongue language was translated and transcribed in English. The accuracy of this translation was validated by a community member who is fluent in the Gujarati language. The findings were verified by an independent qualitative researcher (experienced in thematic analysis). The independent researcher was given 2 randomly selected transcripts (one South Asian and one Black dataset) to see if similar themes were produced. Any concerns were discussed but on the whole, the independent researcher was in full agreement of the researcher's interpretations. A summary of the findings was also sent to participants who wanted to receive a copy of this (appendix 9).

4.3 Findings

Thematic analysis revealed 3 main themes with sub-themes emerging within each. The three main themes were: social support needs, loss of control and cultural taboos and expectations. These themes capture the women's breast cancer experiences and the ways the women managed this. The women's ethnic identity and cultural background is embedded within and across the themes (figure 4.1). Each theme is described in detail below. Italicised sub-headings represent the sub-themes that emerged. Participant quotations are used to verify the identified themes. All names quoted in the text are pseudonyms.

Figure 4.1: Diagram illustrating the 3 themes



As a whole, undergoing the cancer experience had an adverse psychological and emotional impact on the participants. The women discussed the many negative feelings that occurred during their breast cancer diagnosis and whilst undergoing treatment. Feelings of shock, devastation, depression, confusion, uncertainty, fear, anger and distress were described in great detail. This aspect was described in very similar ways to the women's breast cancer experiences in study 1. This was in relation to the impact on family, support, positive and negative healthcare experiences, limited availability of appearance-related products (i.e. wigs, breast prosthesis and lymphoedema sleeves), cultural expectations/obligations of upholding housewife duties, quality of life and new life perspective after cancer, and cultural beliefs and attitudes. While some of these experiences are captured in this study, a specific account of the way in which they were managed will be provided.

4.3.1 Social support needs

The women in the focus groups acknowledged the importance of receiving appropriate care and support during the diagnosis and treatment phases, in order to manage their cancer experience in a positive and effective manner.

'Getting the right balance'

All the women expressed their views on the importance of having the right amount of support to cope with their cancer experience. The majority of women felt that they were well supported and spoke of the ample support received from their family members, friends, work colleagues and healthcare professionals. It was mainly family (particularly the female members) who were described as providing practical, moral and emotional support, whereby their partner, children or siblings would help with the domestic responsibilities (i.e. cooking, cleaning, ironing and shopping), accompany them to their hospital appointments and provide a listening ear when they wanted to talk about how they were feeling. Being well supported made the women realise how much they were cared for by many people. Furthermore, not having to worry about their domestic responsibilities or work commitments enabled them to recover and get through their experience more effectively.

Vilash: I was lucky to get away for a couple of days to my sister's after my chemotherapy. So um my husband and kid, they took over everything in the house, cleaning. Even now, they do cleaning, washing up and all that. So that's good. Ironing, they do it themselves... Even my future daughter-in-law was fantastic. She used to visit me every single day and her mum used to send us food as well so it was good. (Aged 53)

[Indian focus group 1]

Anisha: All in all, family, friends, work colleagues, all more than I ever imagined. So I think I feel really grateful and I didn't realise I had such good friends and colleagues around me until this happened. I think it did bring out another sort of like angle of perspective to people who are in my life. Umm... so yeah I do feel really grateful that I had such great support for me, and it made everything easier. (Aged 47)

[Indian focus group 2]

Healthcare professionals were also viewed as a vital source in helping women deal with the cancer experience. Women were looking for assurance and comfort, and spoke of the importance of having a supportive healthcare team who took the time to explain all aspects of the cancer diagnosis and treatment in sufficient detail.

Bina: The consultant was there and the nurse was there. So they gave some information and whatever the consultant wanted to tell me, he told me. Then I went into another room to see the nurse who had been sitting there and she gave me all that information. And she also gave me lots of Macmillan's booklets, which are very informative. So I found *** hospital, at that time, were quite organised and gave the information. (Aged 60)**

[Indian focus group 2]

However, a small number of women explained how some aspects of their support needs were not fully met. This was mainly in relation to not receiving enough emotional or moral support from family, friends or members of their healthcare team. There was a particular reference to lacking emotional support from partners by several women. Some expressed the negative impact of not receiving adequate work support, whereby colleagues were unable to empathise with them and managers were pressuring them to return to work. Two women mentioned how they had very minimal support from family members. One spoke of how all her energy went into caring for her chronically ill husband. The women found the limited support rather upsetting and this affected the way they managed their experiences, resulting in caring and supporting themselves. Some women tried to do this with a positive attitude by taking everything within their stride and 'got on with it'. Some of these women compensated for the lack of family support by finding support from within (spiritually) or external sources such as support groups.

Vilash: Like my sister, my sons and my husband were fantastic but one friend, like you know we were quite close – couple of friends, and they didn't want to know." (Aged 53)

Daksha: That's right when they [friends] need support you are there but they don't want to give you that. (Aged 54)

Vilash: And then finding excuse "oh I would've taken you for the day, but oh I'm not feeling well", "I'm going here, I'm doing this". Excuses. (Aged 53)

Jaya: Even if they don't understand what you are going through, they can at least support. (Aged 63)

Sunita: Its individual isn't it? You can't pinpoint anything... I don't even want to go there because I'll be very upset if I start talking about it. But it was really tough. I was just on my own. I was in my room and that's it. I would wake up in the morning, hoping that I would pull through the day, go to sleep and just pray that I would wake up the next morning." (Aged 53)

[Indian focus group 1]

Liz: He [husband] did some cooking as well but not so much the emotional side of it you know where you can sit and talk about it. That was very, very distant. (Aged 69)

[Black Caribbean focus group 1]

There were also instances where many women felt over-supported and were trying to manage the support they were receiving along with dealing with the cancer experience. Family members were described as fussing too much, over-pampering and over-protective. Although the women understood that people around them had the best intentions, they found this to be rather frustrating. The constant fussing made these women feel as though they had lost some element of control and independence from their lives (discussed further in theme 2: Control over life Vs Control over cancer).

Joanna: It's so emotionally draining though, this is the thing. And I know people think they are doing it for the best intentions but it can drain you. It tires you. It's not just the treatment that tires you, your mind is tired. And you just haven't got the energy to cope with all these people. (Aged 50)

[Black Caribbean focus group 2]

'Having information is important'

The importance of receiving breast cancer information was expressed by all the participants. The women particularly relied on healthcare professionals to provide them with information about the cancer treatment and related side effects, after-care and ways to improve their quality of life after treatment. Healthcare professionals were seen as pertinent in signposting women to information about support groups (especially culturally specific support groups), availability of financial support and where to get appropriate products such as wigs and prosthesis. Support groups were another place where many women received adequate information. Although the women in this study did not have any problems accessing information, they did highlight the need for healthcare professionals to provide sufficient informational support that is culturally appropriate (e.g. in mother-tongue language) to ethnic minority women who do not speak English or those who may not be aware of financial benefits that they may be entitled to, especially to women who are unable to actively seek information themselves.

Joanna: I personally feel sorry for people who don't speak English. You know I don't know how they cope to find information, where to go and get it and tell them what they're entitled to and things. You know when I went to get my, cos I'm on Tamoxifen, and I went to get my Tamoxifen and she's [pharmacist] saying to me "you have to pay" and I'm saying I don't have to pay you know I've got an exemption. And I thought what if it was somebody who didn't speak the language and she [pharmacist] says you've got to pay for these drugs and they'd be forking out £7 a time. And it's all these little bits of information that people don't receive. (Aged 50)

[Black Caribbean focus group 2]

'Once I found the group, I have not looked back'

Women in each focus group stated that cancer-related support groups were one of their biggest sources of support. The groups offered a place to receive on-going and unlimited support, whenever they needed it. This was very important for some women who felt very overwhelmed when their hospital appointments finished as support from healthcare professionals was no longer readily available and they felt they were left to get 'back to normal'. These women stressed that it was after treatment that they felt vulnerable and uncertain as to what would happen next. This was especially true for women whose quality of life was negatively affected from the side effects of treatments. It was at this point that women needed help with how to cope with life after cancer and how to minimise the negative side effects that they were experiencing.

Lydia: I felt really scared after the hospital visits had finished. I thought...what if it comes back? what am I going to do? how am I going to cope? Because you know if you get a little twinge and when you go to the hospital you can tell somebody [all agree]. But it's... right that's it now. You've got your medication in place, it's more or less a goodbye and don't come back and it was really frightening so to have the support groups, it's like you know... that extra you know, extra um ... security that you really need [all agree]. (Aged 47)

[Black Caribbean focus group 2]

Support groups were also described as giving women a sense of belonging, which helped them realise they were not alone. There was a sense of shared assurance and comfort in being around other breast cancer survivors whom they can relate and identify with, especially on an emotional level. While many of the women received a lot of support from their family members, they expressed the difference in the depth of the support provided. This was especially true in families where ample practical support would be provided but, due to the taboos of cancer, emotional support would often be lacking. Attending support groups and being around similar others promoted positivity and a sense of survivorship. It helped women see that cancer is not an automatic death sentence.

Anita: After a year I was introduced to the Asian Women's Group, and I think that helps as well because there you meet people who have gone through similar sort of circumstances, similar situations and it helps that you're not alone and there's a lot of support. (Aged 57)

[Indian focus group 1]

However, a small minority of women mentioned that initially, during the time around diagnosis, they did not want to be around other breast cancer survivors as they needed time to digest the diagnosis themselves. Nevertheless, when they felt ready, they attended support groups and spoke very highly of these resources in helping them to deal with their breast cancer experience. Women in the discussions did acknowledge that support groups are not suited to all cancer patients' needs, for example, some women prefer to deal with their situation by avoiding other cancer patients because they do not want to be reminded of their cancer or be identified as a cancer patient.

There were also discussions around the type of support groups that women preferred to attend. Many expressed their preference of being around other breast cancer survivors with whom they shared an ethnic identity. Culturally specific support groups gave women the opportunity to learn how to deal with their cancer from a cultural perspective and talk about their experiences with other women in their own language. Some of the women from the Indian focus groups discussed the value of a culturally specific workshop that they attended: Naya Rasta (New Way), a 6 week course, learning to live with cancer, whereby sessions on the Asian diet and ways to deal with the taboos of cancer from a cultural perspective were covered.

Kiran: After my treatment, you're looking for support groups but there weren't any support groups for us Asian women and that is where I thought no I want to talk to somebody. Because the thing is, within the Asian culture, it is all hidden underneath and because it's sort of personal and it's to do with your body and your breasts, you can't really talk to anybody and if it's cancerous they just want to brush it. (Aged 52)

[Indian focus group 2]

Anita: It [Naya Rasta workshop] is quite good because they cover quite a lot in the sense that um ... like today they covered diet, the Asian diet and um... last week I couldn't attend and they covered fatigue. So I think what they aim to do is give you a lot of information about how to accept cancer um... what goes on when you have cancer and you know sort of not to shy away from it but to accept it. (Aged 57)

[Indian focus group 1]

'God was with me'

The majority of participants, who stated that they were religious or had a strong belief in God, described this as a major source of support. This increased their faith and many women engaged in religious activities on a regular basis such as praying, listening to preaching's/mantras and going to the temple/church. Interestingly, a lot of the women in the Black Caribbean focus groups spoke about being part of a church community. They described how they would have their pastor to talk to and their church members would also offer emotional, practical and moral support. This helped the women manage the negative aspects of the breast cancer experience in a positive and useful way.

Jaya: My support was my temple. I used to go to my temple, listen to the prayers, preaching. That was my ...support, main support. (Aged 63)

[Indian focus group 1]

Stella: I find my church really um ... very supportive because they prayed openly for me. And um I think... it's what you believe in and I BELIEVE that it did help. (Aged 66)

[Black Caribbean focus group 1]

4.3.2 Loss of control

Another theme that dominated the focus group discussions was talk over how much the cancer consumed the women's lives, and how this loss of control made them feel. Women felt they needed to be able to understand why they had developed cancer and how to take proactive steps in order to accept and manage it.

'Why me?'

With regards to looking for the cause of their cancer, women's discussions varied in how much control they felt they had over it. For many women, their cancer diagnosis put their lives in great turmoil and the unexpected news produced feelings of frustration and confusion. This was especially true for women who felt they were in control of their lives and led a good, healthy lifestyle, and therefore struggled to understand why they had developed cancer. These women tried to gain some control and understanding over the cancer (and their lives) by looking for causes and explanations. For example, some questioned their lifestyle and proactively sought out information to see how the cancer could have been avoided or how to prevent chances of recurrence.

Kiran: I'm young, because it was in my 40s when I had it, and because I'm a Biologist and it was even more tough because I knew what was going inside my body but I couldn't control it. And um ... the other thing was that you know usually women over 50, that's when you really start getting the symptoms if you're going to get breast cancer or if its running in the family so it was none of these and I wasn't smoking or anything of that nature, even though there is plenty of stress you know but I didn't think about it as stressful of anything that it can cause. And I thought I jog, I do exercise, I'm vegetarian, I eat healthily and as a Biologist I KNOW what to do and what not to do and WHY sort of thing. (Aged 52)

[Indian focus group 2]

Many felt that the cancer was pre-determined by an external force such as their God's will and accepted it as part of their fate. Some women described how they put their faith in their God and felt that God was putting them through this with good intentions (i.e. to cleanse them). The focus groups also involved discussions based on women's beliefs of karma. In this case some of the women felt that they did not deserve to get the cancer as they were decent people who often led a healthy lifestyle. These women's search for answers almost insinuates that they did not think they deserved to be punished with cancer.

Rebecca: I do pray but it doesn't mean I still don't say to God wasn't there any murderers or Mr Fritzel, who locked his daughter away? Didn't he need cancer more than me? You know, so sometimes I do have this banter with God and say you know what's going on here? (Aged 51)

Fran: Not one day I ever said why me. I never said that. I never said why me. Never. (Aged 64)

Rebecca: Well I'm saying it to him loud and clear. Didn't he have anybody else? Didn't Raoul Moat need it more than me? So yes I will ask the question. (Aged 51)

Shontelle: I've said it. I have said it. (Aged 40)

Liz: Exactly. I've said it. (Aged 69)

[Black Caribbean focus group 1]

'I'm taking control now'

While many women adopted a fatalistic attitude whereby they believed that their cancer was a result of God's will and accepted it was written for them, they tried to gain some perspective and control by dealing with the cancer in a positive manner. For example, one lady spoke of how she accepted the cancer as God's will and then took control of the situation by preparing herself and her daughter whilst drawing up her will. Whereas a few women who had to undergo chemotherapy treatment expressed their agony in losing their hair and took control by cutting their hair short rather than waiting for it to fall out. Other women took control by engaging in activities like meditation, yoga, positive thinking and avoided negativity. Over half the participants also made very strong references of how engaging in meditative type activities put them on a path of self-discovery and allowed them to get in touch with their inner selves (particularly those who really struggled with coming to terms with the illness or had no other sources of support). By using spiritual well-being as a coping mechanism, these women were able to reach tranquillity, gain some perspective and take control of their lives and the cancer which helped them to cope in an effective manner.

Daksha: I had very long hair and when I was diagnosed and I was told that once I have chemo[therapy], I'll lose my hair. I decided to have my hair cut and donated that to Great Ormond Street Hospital (Aged 54)

[Indian Asian focus group 1]

Lydia: Yes because that [meditating], for me, that then helped me to deal with other aspects of my life. Like lifestyle um eating, exercise because once you're functioning up here [points to her head] you can deal with other aspects of your life. Even when things seem you know impossible, once you tune in to yourself, well for me I just feel you know that hurdle is a little bit easier to jump over. (Aged 47)

[Black Caribbean focus group 2]

'I found that loss of control was very, very difficult for me'

All of the participants described themselves as strong, independent women who were used to being in control of their lives and not having to rely on anyone else. Many women discussed, at great lengths, the impact the treatment had on their sense of independence.

As mentioned in the support theme, many women discussed the importance of having support that was balanced; not too much and not too little. Consequently, the over-fussing and being treated like a fragile patient was very frustrating as they did not feel in control of the cancer or themselves. Women were already feeling vulnerable on hearing the cancer diagnosis and whilst undergoing treatment. These feelings were further exacerbated for those who were unable to continue their daily chores. Many felt they had lost their independence and had to rely on others to help them with household chores such as shopping, cooking and/or washing.

Women also talked about how they did not want their cancer to disrupt others around them. In order to try and maintain their independence, women tried to stay in control of the situation by downplaying their illness so as not to worry anyone and avoiding further fussing. A few women also said they would attend appointments by themselves. Being able to maintain their independence allowed the women to preserve as much normality in their lives as possible and not let the cancer consume them. For example, they would keep busy and continue to do what they did before they got the cancer such as going to work.

Tessa: I'm so independent and I'm always, I'm very ... I had a lot of people around me who wanted to support me but I think I found that loss of control was very, very difficult for me and I found that I wanted to do everything on my own just to keep some sort of control and some form of normality. (Aged 32)

[Black Caribbean focus group 2]

4.3.3 Cultural taboos and expectations

A recurrent discussion within all the focus groups was based on how the community and family members' cultural beliefs and attitudes affected the women's breast cancer experience. This often resulted in women being frustrated with the perceived narrow minded views, which enhanced feelings of isolation. Again, the women managed this in a productive manner by being open about their cancer and re-interpreting the negative attitudes in a positive light.

'She's got the big C'

Both the Indian and Black Caribbean focus groups acknowledged that within their communities, life threatening illness such as cancer can be a very private matter and is not openly talked about. Some women also mentioned that there were times they wanted to talk about their cancer with their family but family members would often put up a barrier. Conversely, other women felt their cancer was a private matter and wanted to avoid negative comments and reactions.

Lydia: I do think that a lot of people from our culture are in-denial about it. They don't want to talk about and they think if they don't talk about it, it doesn't exist. We have a few who are open or brave enough to discuss it, but in general I think no. You know, they'll see you and smile and they will not say "how's treatment?" or ask you what's going on? ...it's very closed and you do feel isolated and that's why I just wanted to shout about it because I was just fed up of knowing about people who'd had it prior to

me getting it and it would be [whispers] “have you heard about so and so, she’s got the big C” and it was all very closed and Theresa said it’s meant to be very private because it’s embarrassing and its associated with death. So it’s not openly talked about. (Aged 47)

[Black Caribbean focus group 2]

Additional cultural taboos were discussed within the Indian focus groups which contributed to the reasons why cancer was not so openly talked about. Here, women discussed how culturally, it is not acceptable to talk about a private body part (especially in front of male relatives). Asian women have been brought up not to reveal their body to anyone but their husband. This was an additional embarrassment factor for a few women who were treated by male healthcare professionals. Other reasons for not openly talking about the cancer included not wanting the news to spread in the community and be idly gossiped about which would result in community members judging them and making negative remarks. Also, one of the Indian women’s focus groups highlighted that illnesses such as cancer are often hidden because it can damage the family’s reputation, especially if there are daughters involved as it can hinder future marriage proposals.

Bhavna: Only in the last year, 2009 onwards maybe you can talk about breast. The word breast... You feel ashamed, even to a woman. If you say breast cancer [whispers breast cancer], she has no shame “she’s talking about breast” and your family members also, they are so orthodox. (Aged 70)

[Indian focus group 2]

Many negative consequences of not openly talking about the cancer also emerged. A few women mentioned that due to the taboos and private nature of cancer, people are unsure of how to react and for this reason had to endure negative comments and sometimes even avoidance. Some women in the Black Caribbean focus groups stated that when community and even family members are private about their cancer, it means that others are unaware of their actual family history; which was voiced as being very important when needing to relay information about their medical history to healthcare professionals. Women who were unable to talk about their experience within their family or did not know any other cancer survivors described feelings of loneliness, isolation and were made to feel abnormal for having cancer.

However, the general consensus across the focus groups was that these cancer taboos and stigma are more apparent amongst the older generation, who are therefore more closed about it and were viewed as not knowing how to be tactful and sympathetic. This often resulted in women having to put up with insensitive comments (particular within the South Asian culture). Whereas the younger generation were described as being supportive and understanding that cancer does not always result in death.

Jaya: I think elderly ladies sometimes; they don’t know how to say it. One of the elderly lady that I experienced, she told one of her friends...just introducing as “oh she had cancer, and hers is chopped off”, “it’s cut off” [laughs in disbelief]... I didn’t know why she had to specify it that way. She could’ve said it another way, any other way,

but they don't know how to. (Aged 63)

[Indian focus group 1]

Joanna: I think down the generation...my kids were like... it was kind of weird, I was quite upset cos they weren't flippant but they were quite matter of fact about it you know. They were like alright mum, fine, we'll deal with it. You know you get treatment and they've been through the Kylies and the Trisha's and all of that you know and seeing people of a younger age who have been diagnosed with and have just got on with their lives. So it was a different reaction, from a generational thing, it was completely different. (Aged 50)

[Black Caribbean focus group 2]

The women in the focus groups were keen to abolish these taboos and show that as survivors, cancer does not always equal death. Some women demonstrated this by setting up culturally specific support groups for ethnic minority women so that others can gain support from other cancer survivors and not only understand but also talk about their experiences openly. Other women felt that being diagnosed with cancer was an educational experience for both them and their family and as a consequence learnt how to accept and deal with the cancer.

Sunita: I am now doing so much to run that group so any other woman, like myself, would come in and who has been isolated, would find support. Doesn't matter if it's not at home or with friends but she will have support at the group. (Aged 53)

[Indian focus group 1]

Throughout their discussions, many women acknowledged that over time, attitudes and awareness towards cancer have changed and people are more accepting of the illness now than they were 5-10 years ago. The fact that there was a lack of support groups specifically for Black and South Asian women over 10 years ago contributes to the cultural taboos and stigma pertaining to cancer, thus increasing feelings of isolation.

'She must have done something wrong in life'

Many women said that they had to listen to various remarks from people of their community and sometimes even family members who would impose their negative cultural beliefs upon them. One of the common cultural beliefs associated with cancer is conveyed within a religious context. From a karmic perspective, a lot of people believe that cancer is a form of punishment from God; either for current deeds or for something done in their past life. This resulted in many women feeling that they were being culturally judged and had to endure various negative taunts. Even though women did not internalise these beliefs, some women explained how they managed such negative attitudes by keeping the cancer to themselves. Interestingly, all the Indian women in the first focus group discussed how they resented such comments and did not believe this was the case. For these women, having a strong faith in their God helped them to view their cancer in a positive light; that they were chosen for a reason, to be cleansed or because they are God's favourite.

Anita: Especially in our Indian community like you know it's the sins which you have committed and that's why you're paying for it. (Aged 57)

Sunita: When someone tells you that, that you've done something wrong and that's why you got cancer...it's when you're ill and you're praying...that's when God is actually channelling through you. So it's the other way around. When you are suffering, God is the nearest to you. (Aged 53)

Daksha: That's what they say that you are God's favourite and that's why. (Aged 54)

Vilash: You got this and you are closer to God. That's what people tend to say. (Aged 53)

[Indian focus group 1]

Similarly, women in the Black Caribbean focus groups also described how community members try to impose religious beliefs upon the cancer survivors. Women described having to listen to comments that they are the 'chosen ones' and they need to convert and be baptised to repent for their sins and be saved by their Lord. Many of these women were already religious and had their own faith in their God and therefore did not appreciate other people's religious beliefs being forced upon them.

Fran: She [step-mother] said oh give your heart to the lord. Give your soul to the lord [laughs]. You know become Christian is what she's trying to say to me. So I says but I do go to church when I want to. I says I do believe in God. I says I don't have to go to church to be a Christian. (Aged 64)

[Black Caribbean focus group 1]

4.4 Conclusion

This study further illustrates Black and South Asian women's breast cancer experiences and how the adverse impact was managed. In summary, women used a variety of methods and sources to deal with the issues they faced. Support was described as an important aspect. This included the need to be well supported (not too little and not too much), mainly by family members. Support groups (particularly culturally specific support groups) and the women's religion were also described as a major source of support, which helped them manage the negative aspects in a positive way. Another aspect that helped women deal with their experience was by gaining an understanding, accepting their new cancer identity, and taking control of the illness; allowing them to re-gain a sense of independence. Women also spoke of what they found to be less helpful and how they managed this in an appropriate manner. For example, the negative cultural beliefs, often instigated by their community members, were re-interpreted with a positive attitude or such negativity was avoided altogether. The findings of this study are discussed in chapter 6.

5 Conducting research with women with limited proficiency in English

This chapter is divided into 2 parts. The first presents the third study and the second discusses issues of working with interpreters within health and research settings.

Part 1: Study 3: Exploring the lived experience of breast cancer in Gujarati-speaking Indian women

5.1 Introduction

It has been recognised that the majority of research with BME groups is typically limited to English speaking participants (Marshall & While, 1994). To date there is no UK based research that has explored the experiences of breast cancer in women with Limited English Proficiency (LEP). Some American based studies have recognised this limitation and included women with LEP (Ashing et al, 2003; Bottorff et al 2007; Gurm et al 2008; Howard et al, 2007). Participants who are not fluent in the English language are often excluded from research due to language barriers and practical reasons, such as lack of financial resources, difficulties using interpreters or validating questionnaires in other languages (Blows et al, 2009; Stirland et al, 2011). This is unfortunate as women with LEP may encounter barriers to accessing healthcare services that further hinder their ability to communicate their concerns and health problems clearly or even avoid seeking medical advice, affecting their experiences of breast cancer to a greater degree (Deepak, 2004). As shown in chapter 1, a significant number of the ethnic minority population are first generation immigrants. English literacy and language abilities vary considerably between this group, with many who are not comfortable or fluent in the English language (Ahmed, 1998). Therefore, it is important to include them in research and understand their experiences which can guide healthcare professionals in providing culturally competent care and aid in reducing inequalities in healthcare.

Study 1 (chapter 3) included South Asian breast cancer survivors with LEP but due to the inaccurate and unreliable information that was provided by the interpreters, their data was omitted from analysis. Therefore, it was decided that only Gujarati speaking Indian women with LEP would be included as this is my mother tongue language and allows me to gain greater control of the interview process. However, as my understanding of Gujarati is better than my ability to speak the language fluently, a professional interpreter was needed to help with relaying the interview questions to the participants and aid in translating unfamiliar words and phrases when interviewing women who speak a different dialect of Gujarati to me.

Therefore the aim of this study was to:

- To explore Gujarati-speaking Indian women's (with LEP) experiences of being diagnosed and treated for breast cancer.

5.2 Method

5.2.1 Design

The design of this study mirrors the design of study one (chapter 3). One-to-one semi-structured interviews were used to explore women's breast cancer experiences in detail.

5.2.2 Recruitment strategy

As with studies 1 and 2, snowball sampling and chain referral sampling were the main recruitment strategies. Women who were interested in participating in the first study but wanted to be interviewed in Gujarati were contacted by telephone to see if they were still able to participate in this study. This contact was made by the researcher and the conversations took place in Gujarati. Various Gujarati communities in London and Cardiff were approached to see if they knew anyone with breast cancer and would be willing to pass on their contact details to the researcher or inform women about this research. The researcher was a member of the community groups (locally and nationally) that were approached and was therefore able to access them with relative ease. The researcher also went to meetings and events to get to know the community members and establish a rapport with them.

The inclusion criteria were Gujarati speaking Indian women with LEP, over the age of 18, diagnosed with breast cancer (at least six months post diagnosis) and have completed their main treatments (surgical, chemotherapy and/or radiotherapy). Reasons for this inclusion criteria have been justified in chapter 3 (see 3.1.2). South Asian women with LEP and who spoke a language other than Gujarati were excluded due to previous problems experienced by the researcher in including such women and using interpreters. This issue has been briefly highlighted in chapter 3 (section 3.1.3) and is discussed in more detail in part 2 of this chapter (section 5.9).

5.2.3 Participants

Five Gujarati speaking Indian women took part in this study. Two women were recruited via the Asian Women's Breast Cancer Group (AWBCG) and 3 were introduced to the researcher via community group members. Participants' demographic and cancer information are summarised in table 5.1.

Age: The age of the participants ranged from 55 – 76 years (mean age – 66 years).

Ethnicity: All the women were Indian and described themselves as Hindus. They were all first generation immigrants and had been living in the UK for an average of 36 years. Three were from India and two from Kenya.

Marital status: The majority of women described themselves as widows (n = 4) and one woman was married. Four women had one or more children. During the time of diagnosis, three were married and two were widows.

Employment status: Four women were retired and one described herself as a housewife.

Breast cancer diagnosis and treatment¹: The women's age at initial diagnosis ranged from 29 – 69 years (mean age – 51 years) and time since initial diagnosis ranged from 4 – 32 years (mean time – 15 years). All the women had primary breast cancer. Four of the women's cancer was found via breast self-examination and one woman's cancer was detected through breast screening. With regards to surgical treatment, 3 had undergone a mastectomy and 2 a lumpectomy. All the mastectomy patients chose to wear a breast prosthesis. The majority of women had undergone adjuvant therapy (n = 4) in the form of chemotherapy (n = 1), radiotherapy (n = 3), Tamoxifen (n = 2) and Arimidex (n = 1).

5.2.4 Interpreters

Two professional female interpreters were used for this study. The first interpreter was employed through a council and assisted in the interviews that were conducted in London. She has a total of 22 years of experience as an interpreter (15 years in India and 7 years in the UK) and is fluent in Gujarati, Hindi, Urdu and Marathi. Some women did not want the interpreter to belong to their community or social group, due to worry that the information would not remain confidential or because they would not feel comfortable sharing their personal experiences in the presence of a known community member. Therefore, it was ensured that the interpreter was a stranger to these participants. However, the interpreter was known to one of the participants as she had acted as an interpreter for her previously. The participant was asked if this would cause any problems but she was happy to use this interpreter. The second interpreter was a freelance interpreter and assisted with the interview that took place in Cardiff. This interpreter has over 10 years of experience and is fluent in the Gujarati language. The Cardiff participant and interpreter were part of the same community. However, both interpreter and participant were comfortable to participate. Both interpreters have undertaken work within the NHS.

5.2.5 Interview schedule

The interview schedule prepared for study 1 was used for this study (appendix 5).

5.2.6 Semi-structured interviews

Semi-structured interviews were adopted as it allows the researcher to encourage participants to share their experiences in an open-ended and non-directive format; thus generating data that is

¹ Some participants had more than one treatment.

suitable for phenomenological analysis (Willig, 2001). It is important that the focus is on the participants to share their experiences and be encouraged to elaborate on these, which can be achieved using a semi-structured approach.

5.2.7 Procedure

Ethical approval was obtained from the School of Life Sciences Research Ethics Committee at the University of the West of England, Bristol.

Participants' contact details were passed onto the researcher by support group or community group leaders/facilitators. The researcher then contacted each potential participant to explain the study in more detail and to arrange a suitable time and place to conduct the interview. All but one interview took place in the participant's home.

As the first two women who showed an interest in the research lived in North London, their local council was contacted to seek out a professional interpreter. It was specified that an interpreter who is fluent in Gujarati and its various dialects, has an understanding of health terminology and is experienced in dealing with sensitive issues was needed. Due to the private nature of cancer, some women did not want the interpreter to be part of their community, thus this requirement was also met by the interpreter.

The interviews were conducted by the researcher in Gujarati. Once appropriate interpreters were selected, the researcher met with them (before the interviews) to discuss the aims of the research and explain the researcher's expectations of the role that the interpreter would be playing in the interview process. The importance of meeting with the interpreter to discuss the interview format has been documented in the literature (Baker, Hussain & Saunders, 1991; Murray & Wynne, 2001). Interpreters were told only to intervene when asked and that their involvement would be quite minimal due to the researcher's understanding of the Gujarati language. Thus they were mainly needed to translate the questions. When their assistance was needed, the interpreters were instructed to convey an accurate account intended by the participant rather than give a literal translation. This was important as some words may not be easily translated or even exist in the Gujarati language (Werner, Heinik, Lin & Bleich, 1999). The interpreters were informed that the interviews would be of a sensitive nature and asked to study the interview schedule in detail and follow it during the interview.

Once a convenient time and place was arranged with the participant, the researcher made contact with the interpreters to ensure they were able to attend the interview. Before each interview, the researcher and interpreter met up and the interpreter was briefly told about the participant's caste and spoken dialect of Gujarati. This was important when greeting and conversing with the participant.

A one-to-one semi-structured interview was conducted with each participant. At the beginning of each interview, the participant was given an information sheet, which was prepared in English (appendix 15). This sheet outlined the purpose of the research and nature of participation in detail.

Table 5.1: Study 3: Demographic and breast cancer information (n = 5)

Pseudonym	Age (years)	Marital status	Children	Occupation	Ethnicity	Country of Birth	Time in the UK (years)	Age at Diagnosis (years)	Time since diagnosis (years)	Treatment (in order)	Primary/Secondary cancer
Hansa	60	Widow	0	Retired	Indian	India	34	56	4	M, C	Primary
Alpa	55	Widow	2	Retired	Indian	India	36	29	26	M, R	Primary
Manjula	76	Married	2	Housewife	Indian	Kenya	32	44	32	M	Primary
Raksha	76	Widow	2	Retired	Indian	Kenya	38	69	7	L, R, T, A	Primary
Deepa	61	Widow	3	Retired	Indian	India	40	55	6	L, R, T	Primary

Treatment: M = Mastectomy; L = Lumpectomy; C = Chemotherapy; R = Radiotherapy; T = Tamoxifen; A = Arimidex

As many of the women were unable to read in English or Gujarati, the interpreter verbally went through the information sheet with them. It was for this reason, that the information sheet was not translated into Gujarati (and also due to the variation in dialects). On understanding the information sheet, participants were given the opportunity to ask any questions. Once happy with the information, the participant signed the consent form (appendix 16). The interpreter was required to sign a confidentiality agreement form in the researcher and participant's presence (appendix 17). This form states that the interpreter will not divulge any information to third parties and respect the confidentiality of the study at all times. Three forms were completed; one copy for the participant, one for the researcher and one for the interpreter. This acted as further assurance for the participant that their responses would remain confidential throughout the research.

On completion of the interview, participants were thanked for their time and given a £20 Marks and Spencer gift card as a way of thanking them for sharing their experiences. The interviews lasted between 55 and 75 minutes (average time, 67 minutes). All the interviews were audio recorded. It was also noted if participants were interested in receiving a summary of the findings. The interpreters were also thanked for their assistance and paid for their time.

5.2.8 Analysis

The interviews were translated into English (known as forward translation) and transcribed verbatim by the researcher. The translated data were checked for accuracy by another independent translator, who has a fluent understanding of the Gujarati language. The independent translator was required to listen to the Gujarati interviews and check that the translated English accounts represented a clear account of the original Gujarati accounts. Any discrepancies in the translations were discussed and amended accordingly (Bullinger et al, 1998). The process of forward translation is an accurate way of checking the precision of the translations (Baker et al, 1991; Dunckley et al, 2003). This provided confidence that the translated English transcripts accurately captured the true meaning of the participants' experiences. This was especially important as meanings can be lost in translation when transcribing verbatim, particularly when some words do not exist in the Gujarati language or are difficult to translate (e.g. when cultural idioms are used) (Wallin & Ahlstrom, 2006). Two of the five women were interested in receiving a summary of the findings. These women were unable to read in English and Gujarati. However, these women were recruited through a support group and therefore summary of the findings (appendix 9) were sent to the support group facilitators (with their permission) who provided a verbal Gujarati translation of the findings to the women at their next meeting.

5.2.9 Interpretative Phenomenological Analysis

An idiographic, inductive approach using Interpretative Phenomenological Analysis (IPA) was used to analyse the data. IPA is "concerned with the detailed examination of individual lived experience and how individuals make sense of that experience" (Eatough & Smith (2008) p179). IPA is phenomenological in that the focus is on exploring the participant's personal experiences and it is interpretative in that the researcher is trying to make sense of the participant's experiences. This is

known as a two stage process or double hermeneutic, whereby the participant is trying to make sense of their world and the researcher is trying to make sense of the participant trying to make sense of their world (insider's perspective), whilst trying to make sense of these experiences in relation to the research question as an 'outsider' (Smith & Osborn, 2003). This method of analysis allows the researcher to gain a deeper understanding of the participant's experiences than traditional analytic methods (Reid et al, 2005), and has become an established analytic method within the realms of health psychology (Smith, 2004). This method was also deemed suitable due to the small sample size used, which has been recommended as a reasonable sample size to conduct IPA (Smith & Osborn, 2003). IPA studies tend to be conducted on small sample sizes due to its commitment to provide a detailed interpretative account of the individual transcripts (Smith & Osborn, 2003).

It has been argued that IPA is not appropriate to conduct on data that has been obtained in another language and then translated for analysis (Larkin, Dierckx de Casterle & Schotsmans, 2007; Raval & Smith, 2003; Temple, 2002). This is because phenomenological studies place great emphasis on the way in which participants use language to describe their experiences. The process of translation has the potential to alter or inadequately capture the participant's meanings and the way in which they use their language to communicate their experiences (Squires, 2009). There is also a risk that interpreters may not always provide accurate interpretations or translations and possibly even put words in the participant's mouth (Raval & Smith, 2003). For this reason, Squires (2009) recommends that IPA can only take place in the participant's language and avoid the use of interpreters or translators during the data collection and analysis process. Although I needed the assistance of an interpreter for the present study, I had great control of the process as I was able to pick up on the interpreter's errors, whose translations were excluded during the transcription process. The participant's accounts were transcribed as verbatim as possible whilst staying very close to the meanings that were implied. The translated datasets also underwent a thorough accuracy and reliability check through forward translation (carried out by an independent translator). Therefore conducting IPA on the present datasets is justified and deemed appropriate.

Smith and Osborn's (2003) step by step approach to analyse the data using IPA was used. The first step was to familiarise myself with the transcripts by reading and re-reading the transcript in detail. Interesting points and ideas were annotated in the left-hand margin. Once the entire transcript had been annotated, the right hand margin was used to document emergent theme titles throughout the transcript. The next stage involved studying the list of themes and looking for connections between the emergent themes. Here, the list of themes were organised into a cluster of themes whilst identifying super-ordinate themes. The software package NVivo was used to help organise and manage the themes. To ensure the themes reflected a true account of the participant's experiences, relevant extracts were placed under each theme. Throughout this process, the list of themes were modified and further developed until a master list of themes was created. This process was completed for each transcript, making note of repeating patterns and identifying new issues, thus looking for similarities and differences across and within the datasets. Once this had been done for all five transcripts, a final table consisting of super-ordinate themes with sub-themes emerging within each super-ordinate theme was constructed. Even at this stage, themes were being modified and developed in order to ensure that the generated themes accurately captured the participants' experiences. The final stage involved transferring the themes into a narrative account, which is listed below. See appendix 8 for a worked example. The themes were verified by an independent

researcher who is familiar with IPA to ensure the validity of the data (Reid et al, 2005). At this stage, the independent researcher was randomly presented with three of the five transcripts to study and check that the themes provide a clear and accurate account of the participants' experiences. Any concerns were discussed but on the whole, the independent researcher was in full agreement of the researcher's interpretations.

In order to ensure awareness of the researcher's role whilst conducting IPA, it is important for researchers to reflect upon their role whilst conducting the interviews and analysing the data (Reid et al, 2005). The researcher kept a reflexive journal and reflected after conducting each interview, and during and after the analysis process.

5.3 Findings

IPA of the datasets captured the women's breast cancer experiences through five main themes with three sub-themes emerging within each main theme. The five main themes are: 'Making sense of the cancer', 'A shared experience', 'Replacing the negative with the positive', 'Healthcare experiences' and 'Accepting an altered appearance'.

Each theme is described in detail below. Italicised sub-headings represent the sub-themes that emerged. Participant quotations are used to verify the identified themes. All names quoted in text are pseudonyms.

Before summarising each theme, it is important to note that all the women were rather descriptive in explaining treatment procedures and most aspects of their experiences, yet they were often unable to clearly express the emotional aspects. Consequently, it required considerable probing to encourage the women to open up and share their feelings. The word 'something' was very popular when the women attempted to express their emotional thoughts and feelings. This is illustrated in the examples below.

Extract 1:

Researcher: Has undergoing treatment changed the way you feel about your appearance or body?

Manjula: You feel something.

Researcher: In what way, can you tell me more?

Manjula: Um it's like you've lost a breast so it's ruined the shape and it's not like I used to be.

Extract 2:

Researcher: So did you blame God as to why you got it?

Alpa: At the beginning I did, when I found out. I thought why me? Why did God choose me? But then...

Researcher: And how did you feel then?

Alpa: I did feel then. I thought, I don't know, why me. Because I hadn't ever heard of it either. Now if anyone mentions it you have heard the name [cancer] often enough but then I hadn't even heard the word so that's why I felt something. But then I was okay.

Researcher: You just said you felt something. Would you mind telling me what kind of feelings?

Alpa: As in hurt, upset. I thought oh God, why did I have to get this.

Researcher: So sadness, upset.

Alpa: Yes, I was sad. I cried; things like that.

5.3.1 Making sense of the cancer

The women's breast cancer experiences were very difficult and distressing. For some, this was the first time they had even heard of the word cancer. This left the women in a confused and perplexed state. It was important for them to be able to understand the concept of cancer and make sense of it and their surroundings in order to accept and manage their experiences.

'I knew nothing about it'

Some women had very limited knowledge and little awareness of breast cancer. The majority of women were unaware that a lump can be something serious and potentially related to cancer. There was also a limited understanding that cancer signs can also be asymptomatic. For some women the lack of awareness or seriousness of detecting a lump resulted in a delayed diagnosis. Some also stated that they were unaware that an illness such as cancer even exists and can occur on various parts of the body. Consequently, the unexpected diagnosis combined with the lack of knowledge of cancer was found to be a highly shocking and distressing experience for them all.

"This [points below her armpit] became very hard and would hurt. And then it started hurting from here [points to her back] but I just thought it's nothing so I didn't do anything about it."

Raksha, aged 76

"I found a lump. I just ignored it thinking it happens you know."

Deepa, aged 61

"At that time I didn't know you get different types of cancer. Then it was just cancer is cancer."

Manjula, aged 76

This limited knowledge and awareness of cancer was also the result of the taboos and stigma associated with it. Therefore, it was not openly talked about and consequently some women had very little awareness of its existence. As a result, some women felt alone and isolated and felt they were the only ones going through this illness. It was only during their treatments that women met others in similar circumstances. This helped to increase their knowledge of varying types of cancers and enabled them to gain a better understanding and acceptance. Women were also able to talk to other cancer patients and share their experiences and seek information. However, this was very limited due to their limited understanding or ability to communicate in English.

“When I went for my treatment at *** [city], that’s when I saw that SOOO MANY people get cancer. You see that some don’t have a right [breast], some don’t have a left [breast] and then... you can get cancer anywhere can’t you? And there was purple marks on a man there. So I asked someone there. I said “why does he have purple marks there”, and she said “because he has cancer there”. I was shocked seeing that, that day. Before that I thought I was the only one.”**

Alpa, aged 55

“There was one Gujarati woman there. She also had this operation [mastectomy] and she um she had a White friend who she was very close to. And that White woman and Gujarati woman spoke to me and she told me she had it so we shared our experiences.”

Manjula, aged 76

The fact that all the women were not literate in the English language also hindered their ability to gain a full awareness and understanding of the cancer. Even if they wanted to, some felt they were unable to ask questions or gain a better understanding because of their limited ability in communicating in English. However, women who wanted to know more about the cancer, tried to do so by asking questions or reading more about it, if the information was available in Gujarati.

“At times you do want to know more but because you don’t know how to and can’t speak so you just sit there quietly. But at times you do want to know more.”

Alpa, aged 55

“If I see books on cancer in Gujarati at the hospital or elsewhere I would read them.”

Raksha, aged 76

Nonetheless, the women were satisfied with the basic understanding of the treatments they underwent and why they were necessary (*through the help of interpreters – discussed in more detail in the next theme*). Although the women were unable to use medical terms, they were able to clearly describe the procedures that they underwent.

“You know where they pull from here [points to her underarms, raises her arm to explain], well they take things out from here [referring to lymph nodes]. So they didn’t think it necessary to give me chemotherapy. The doctor said that they took out 2

things [2 lymph nodes] and they test it. So one was clean and one had a lump. Because of the one that had the lump... they gave me chemotherapy."

Hansa, aged 60

'What, why, how?'

Due to the shock of the cancer diagnosis and limited knowledge of the disease, women wanted to gain some perspective and understand why they had developed it. They did this by looking for explanations. For example, Deepa did not think she would be at risk of cancer as she believed that breastfeeding reduces one's chances and she had breastfed all of her children and therefore was confused as to why she still got it. She then went on to attribute her cancer to stress.

"I felt like why has it happened. I don't know. I have breastfed all my children and I still got it so I don't know...it may happen more to White women because they breastfeed less and we [Asians] always breastfeed more. And if anything has happened to us it's because there's a reason for it, something with the cells in the body. Like with me, my mind was always troubled. One who doesn't talk openly and keeps things bottled up."

Deepa, aged 61

Others did not want to understand the causes of their cancer and just accepted that these things happen. For these women, a fatalistic attitude was evident whereby they accepted their diagnosis as being God's will. It was not in these women's tendency to blame God for getting the cancer and accepted it as part of their fate. Some women also felt that it was related to karma and they were to endure this illness to make up for bad deeds from their past lives.

"I just thought it was written for me, it was my fate."

Manjula, aged 76

"It can't be a punishment from God. If's it written for us, what we have done in our past life will happen to us. It's not God's fault, it's our doing."

Deepa, aged 61

However, there were times when the treatments would get too much to bear, leaving some women temporarily feeling sorry for themselves. Such feelings would often be accompanied by momentary thoughts that the cancer was an act of punishment from their God.

"At the beginning I did, when I found out. I thought why me? Why did God choose me?"

Alpa, aged 55

'Now there is more, before there was nothing'

The women also explained that it was not just them who had little knowledge of the disease, but culturally, the Indian community had very little understanding and awareness of cancer. Due to the

taboos of cancer, it was not openly talked about and misconceptions about breast cancer were internalised by the community and the individuals themselves. For example, beliefs that cancer is an automatic death sentence, it can be contagious and can only happen to White women were expressed by some of these women. They talked about how such beliefs and taboos were more prominent during the time the women had received their diagnosis but acknowledged that, over time, taboos have reduced. This has resulted in people being more open to talk about cancer related issues and more willing to learn about the illness. Interestingly, Raksha only took her symptoms seriously after she had been to a talk aimed at increasing breast cancer awareness.

“They [Indian community] think that as soon as you got cancer it’s such a bad dangerous disease and people die from this. So there’s a fear associated with it. And people also used to think that cancer, like TB [tuberculosis], they will catch it. Now people know that you can’t catch it.”

Manjula, aged 76

“Now the *** hall [community function] takes place, and so if anyone asks, people will talk about it there. Just recently a woman had bowel cancer and people are occasionally talking about these things. But before...you wouldn’t hear about such programmes [talks]. Now more takes place, there was one at ***** [community centre] and at the ***** [leisure centre]. But before I don’t recall ever attending such programmes. They didn’t exist.”**

Alpa, aged 55

“There was a talk on cancer and I went to it. I had been meaning to get it checked by the doctor for the last few days. One time I called the surgery was closed and the other day it was engaged so I didn’t call back. And on the third day there was a talk on cancer. And there they were talking about how to get it checked and everything... And then after I went to the doctor the next day. I saw the nurse and she checked it and said there is a lump.”

Raksha, aged 76

During the time that most of these women underwent their diagnosis and treatments, support groups were rare and culturally specific support groups were non-existent. Rasksha (along with other breast cancer survivors who took part in studies 1 and 2) acknowledged this limitation and proactively helped to set up a cultural specific support group for Asian women. The women also spoke of the importance of support groups in helping to minimise taboos, raise awareness, act as a source of informational support and a place where they can talk to other breast cancer survivors in their own language. Raksha and Manjula mentioned that they regularly attend support groups and this helps them because being around other cancer patients allows them to share information and gain emotional support. The other three women were unable to attend any support groups due to personal commitments and because there was not a cultural specific support group within their area. Nonetheless, they also acknowledged the importance of support groups in increasing women’s understanding of cancer.

“It’s very helpful and that’s how you learn about others’ experiences and then if you need anything like information then talks can be arranged too.”

Raksha, aged 76

Some women also found that there was no or very little availability of written cancer information in their own language. However, they recognised that over time this has become available prompting women to understand and learn more about different types of cancers. This is something some women felt they would have liked to have had at the time of their diagnosis in order to gain a better understanding.

“At that time I didn’t know you can get information on paper.”

Manjula, aged 76

5.3.2 A shared experience

As the women shared their stories, it became evident that their cancer experience was not just confined to the individual but affected other people too. This was mainly family members, who played a significant role in the women’s lives.

‘It affected them a lot’

All the women explained that their diagnosis had a negative impact on their family members who were described as showing feelings of shock, distress, worry and sadness.

“The family did feel something because at that time cancer was a big thing because not many people got cancer then so for a few days everyone did feel something. My mum was the most affected.”

Alpa, aged 55

A few women’s experiences were further exacerbated as they had other issues to deal with alongside their cancer, often making it harder for them to focus solely on dealing with the cancer and working on getting better. For example, Deepa and Alpa had younger children to care for. These women did not want their illness to add to their family’s worry and therefore tried to stay strong and determined to beat the disease to avoid putting their family through additional worries and stress. Undergoing the diagnosis and treatment of cancer was particularly challenging for Deepa who was also acting as a full time carer to her ill husband, and therefore, her main priority was to care for him. Consequently, her illness became secondary as she was more concerned in caring for her husband and bringing up her three young daughters. For this reason she did not have time to focus on recovering from her treatments or to seek support as her husband’s illness took precedence. This can be seen in the quotes below.

“They [healthcare professionals] tried very hard to make me understand that if I look after myself then I will be able to look after him but if I focus on him then we will both be ill.”

Deepa, aged 61

“They [healthcare professionals] did tell me about one [breast cancer support group] but I didn’t have time to go. Do I attend to my husband or go there.”

Deepa, aged 61

‘They were very supportive’

All the women stated how support was very important in helping them get through their cancer experience. Family members, particularly immediate family, played a major role in providing these women with this support. They were described as offering a lot of practical support such as taking them to hospital appointments, helping with house work such as shopping, cleaning and cooking, and assisting with tasks that the women found difficult to do due to their surgical treatments such as bathing or brushing their hair. This allowed women to focus on getting better without having to take on additional worries or responsibilities. For example, Alpa’s husband was described as being great in supporting her, from an emotional and practical perspective.

“My cancer experience was scary. It’s a scary experience but if you have a lot of support, encouragement and help then it really helps. And if you get the right treatment then you’re okay. So you need good family and healthcare support. If you don’t get good family or healthcare support then a person can break down.”

Manjula, aged 76

“He [husband] would do all the house work. And when I had my operation, my son had an operation on the tonsils. So he was in hospital, I was in hospital and my eldest son would go to school. And my husband would go work, drop him to school, then to come see me and to see the other son so my husband was very supportive. Cooking-wise he can cook everything so he would cook for me too.”

Alpa, aged 55

Although great emphasis was placed on family members, some women also mentioned friends, other relatives, community members and work colleagues in providing practical and emotional support. Being open about their cancer allowed these women to gain support from extended family members and other sources. This was especially important for women who were limited in receiving adequate support from immediate family as they did not live near them or because some family members were not prepared to support them.

“*** [niece] used to come with me but one day when we went hospital for the chemotherapy, we were there until 7pm in ***** [Hospital] and ***** [nephew] got annoyed. And then a few days later we went back to get the pink line inserted [another part of the chemo treatment] and when we came back they gave us**

another appointment and *** [niece] uttered “Great, I have to take you again in the morning”, she said “Great I have to take you again in the morning”. So ***** [friend] said “forget her, **** [another friend] will take you”. So **** [friend] has been taking me from then on. So ***** [niece] is not so interested.”**

Hansa, aged 60

While this was very upsetting for Hansa, her close friends and community members stepped in and provided her with enough support to help her to get through her illness.

“I didn’t feel alone. *** [friend] was always with me. She used to visit me every day.”**

Hansa, aged 60

The women also explained how faith in their God was also an important source of support and engaging in religious activities (such as praying, attending religious meetings) helped them. Some also stated that their faith in God had increased. As mentioned in ‘making sense of the cancer’ theme, some women accepted their illness as God’s will. They also believed that God will give them strength and help them get through it.

“Even though God gave me this cancer but along with that he sent me very good treatment and support and gave me strength that I needed to get over it.”

Manjula, aged 76

‘She would come with me everywhere’

All of the women had very limited ability to understand and communicate in the English language. For this reason, they needed information about their breast cancer diagnosis and treatment to be translated and they relied heavily on family members to accompany them to hospital appointments and act as translators. This often meant that healthcare professionals would communicate with the family members instead of talking directly to the patient, expecting the family member to relay the information back to them. Despite this, some women felt included during the consultations and felt informed at each stage.

“They would explain everything to *** [niece], not me. But they did explain things to her.”**

Hansa, aged 60

“The nurse who was there, she did tell me about radiotherapy and so did the doctor and they said that I will feel tiredness and things.”

Raksha, aged 76

The women acknowledged that this meant they may not get a detailed understanding and information may go amiss. Despite this, some expressed that they would rather have someone they know translate for them as they felt comfortable in the presence of their family members or close friends. However, Deepa expressed her preference for a professional interpreter as they are more

accurate than family members in relaying information. Yet some women were unaware that professional interpreters existed and could be requested.

“I can’t understand English well or read it and when you ask them [children], they read it once and tell you the main things but the kids don’t explain everything in detail do they? [laughs].”

Deepa, aged 61

Although the women had to rely on others to help them in overcoming language barriers, some voiced their concerns about burdening others with their problems as it often meant family members would need to take time off from work in order to be present.

“If I knew English, then I could go to the doctor by myself.”

Hansa, aged 60

“Someone would always be with me but I did think that it would be nice if I knew it [English] then its better but I can’t communicate everything... and then you wouldn’t have to waste her [daughter-in-law] time.”

Raksha, aged 76

While some women felt they had no choice but to rely on their family members to support them, others tried to avoid inconveniencing them by attending hospital appointments by themselves and attempting to get by with their limited understanding of English. This would limit the accuracy of understanding and information that the women could receive and also prohibited them in asking for further advice and information. For example, when asking Deepa if the hospital staff had given her information about the type of financial support that she can receive, she replied by saying: **“They may have but I don’t understand English too well.”**

“I would just guess what they are saying. Even now I go to the hospital on my own and some things I don’t understand but I make assumptions as to what they may be saying.”

Deepa, aged 61

Relying on family members and other people to act as interpreters also meant that treatment decisions were often made as a family, where they would help the patient or often decide the best treatment for them. In many cases, the women were satisfied with this format as they felt they had been informed and involved in the decision making process and ultimately placed greater trust in literate and educated family members.

“They [daughter] would still understand that little bit more than me as they have grown up here. So she said to me “Mummy what’s the point in taking it all out”. They [consultant] did say that it will take a couple of years for it to fill but ... after that it will be normal whereas if you do the other [mastectomy], then you could get an artificial one [reconstruction]. So my daughter said rather than do the artificial thing, it’s better to have some of your breast. So I said okay we’ll do it that way.”

Deepa, aged 61

However, Alpa explained that she did not feel involved in the decision making process and this conversation took place mainly between the consultant and her husband. Alpa felt rather hurt and excluded by this, but later understood that they had her best interests at heart.

“The doctor was good. He said “it’s good for you that we have taken it out”. I did say I was hurt that no one told me but then he gave me advice and told me it was for the best and because of the way it was, it was better to remove it so that it wouldn’t affect me later in life. So they told me about it later.”

Alpa, aged 55

5.3.3 Replacing the negative with the positive

The unexpected cancer diagnosis was very shocking and upsetting for all the women. Along with coming to terms with the diagnosis, many found their treatment regimens difficult to tolerate resulting in frustration with adjusting to a new identity as a cancer patient. The cancer as a whole had an adverse impact. However, all the women were strong and determined to get through it, and did so by embracing a positive attitude to manage and adjust to their new, somewhat altered lifestyle.

‘I did what I could’

The associated side effects whilst undergoing treatments had a negative physical and emotional impact on all of the women. Side effects included tiredness, joint pain, nausea, loss of appetite and hot flushes. Some found these side effects highly challenging. Furthermore some aspects of the treatment continued to have a negative impact on some women’s quality of life once their treatment had ended. This left some feeling that they were limited in what they could and could not do in comparison to the way their lifestyle was before the cancer. For example, Deepa mentioned how the surgical treatment led to complications, resulting in loss of some arm mobility. She now struggles to lift heavy objects or open jars. Some women felt they had to depend on others to carry out small and often trivial tasks that they were capable of doing before the cancer. This loss of independence left them feeling very frustrated and angry at the whole situation.

“It’s true that I have found it very difficult with my arm because I couldn’t wash my hair, do my brush or open the door, so that was hard.”

Deepa, aged 61

“My arm used to hurt so it was very difficult to do work and I couldn’t do things like I used to be able to [before the operation]. So that was hard to manage.”

Manjula, aged 76

Women spoke of how they managed this by trying to maintain as much normality as possible and do as much as they could that was within their capacity to do so. Realising they were no longer as able as before helped them to accept their new identity as a cancer patient and not let such negative thoughts and feelings be a constant reminder of being a cancer patient. Instead of continuing to feel

low, they picked themselves up by trying to do things that were in their power to do so in order to maintain as much normality in their life as possible. For young women this meant returning to work.

“My doctor said from before to leave work but I said I want to work while I can. So I did what I could.”

Alpa, aged 55

“I would go to bathe him [husband], 2 people would come with me because I couldn’t bathe him alone. They would bathe him but I would be there. So I had 2 people for that. And then if I was to cut his hair, or cut his nails, I would do all that.”

Deepa, aged 61

‘I was open but she hid it’

Being open helped some women accept, understand and manage their situations in a positive manner. A few women explained that one of the advantages of being open meant that they were not limited in the amount of support that they received and could attend support groups and gain appropriate support as they felt they had nothing to hide.

“I told anyone who asked me. I didn’t feel I had to hide it.”

Raksha, aged 76

“When these things happen, they happen. But there’s no point in hiding it. I don’t like hiding it.”

Hansa, aged 60

However, not all women were open and some kept their diagnosis hidden or restricted to immediate family members. There were some reasons for this, but ultimately this decision helped women to manage their experiences positively and avoid any negative responses. For example, the limited understanding of cancer, within the women’s community, often led some community members to gossip and make insensitive comments. Therefore, to avoid these negative remarks, some women chose to keep their diagnosis hidden.

“They [community members] want to see it all too. That’s very bad isn’t it? They [community members] say show me. Why do they [community members] need to see what’s in your body. It hurts you know. These people...even in that position, they ask show me and I say no, I don’t want to do anything like that. Firstly, I have a bottle hanging off me, my stitches are hurting me and then why should I show them and take my clothes off? They don’t have sense like that. And from time to time they ask did they chop it all off? Did they chop it all off? Um how did they cut it off? They don’t need to know all that. They do that a lot in ours [community].”

Deepa, aged 61

“At that time it was embarrassing. At that time, if you have cancer then everyone says “oh you’ve got cancer, oh you’ve got cancer”. And then people keep phoning and keep asking and then you’re constantly reminded of it.”

Manjula, aged 76

Some women became more open as time went on and as people became more aware about cancer related illnesses and less emphasis was placed on the taboos and stigma attached to cancer. However, these women were aware that cancer is still not very openly talked about in their community and thus other people continue to hide their illness.

“I didn’t tell anyone. But now... it happens so it’s talked about a little but even now some people keep it quiet and hide it.”

Manjula, aged 76

‘Why worry, just live’

Positive thinking was very important to all the women. They all explained that undergoing such a life threatening illness made them reassess their life as a whole and spoke of living life to its fullest and trivial matters were no longer important. A few women also talked about attending spiritual courses which enabled them to appreciate a profound way of living and connecting with their inner selves, which in turn helped them to get rid of any negative thoughts and adopt a positive and healthy way of living. This also enabled women to overcome thoughts of recurrence, which was always at the back of their minds. On reflecting on their experience, a few women also commented on how, in hindsight, it was easier to focus on the positive aspects of their experience than the negative.

“I’m grateful that it was found straightaway and I was given the treatment straightaway.”

Manjula, aged 76

“Whether you live more or less, as long as you have lived that life, that is important. So while we are alive we should just live it well.”

Deepa, aged 61

“I do sometimes worry about that [recurrence] but then I think oh everyone else is living.”

Alpa, aged 55

5.3.4 Healthcare experiences

The women’s breast cancer experiences were also shaped by the type of healthcare they received. In overcoming the language barrier and feeling well supported by their family members and others around them, healthcare providers also played a role by providing them with appropriate care and support.

'I got a lot of help from them'

All the women found healthcare professionals to be highly supportive. They felt that the majority of the information was clearly communicated and their breast care nurses were very caring and helpful. The nurses were described as providing them with emotional support, reassurance and encouragement throughout their cancer journey.

"I was shattered and my husband called the nurse and they came and gave me encouragement and consoled me."

Manjula, aged 76

"They [healthcare professionals] looked after me very nicely. They did, so I can't fault them."

Deepa, aged 61

Whilst the majority of the women's experiences were highly positive, a few mentioned that at times appointments would often get delayed, resulting in waiting around. This often left them feeling anxious and frustrated.

"When I would go to the hospital and they would make you remove your clothes and make you sit there for 10 hours; that I didn't like."

Alpa, aged 55

(Note: Alpa's response of "10 hours" was exaggerated to portray that she was left sitting for a longer period than expected).

'They knew what they were doing'

As well as relying on educated family members for advice and in helping to make treatment decisions, all the women had great trust in the healthcare professionals in providing the best care. This was even more important for those who did not have other sources from which to gain informational support. However, Deepa's trust in healthcare professionals resulted in a delayed diagnosis as they assured her she had nothing to worry about and, believing that they know best, she left it, only to find that she had breast cancer a few months later. Deepa was disappointed with the healthcare team as she felt she had placed a great level of trust in them and was let down by the care that she was initially given.

"I was told its breast cancer. And that they will have to operate within 2 weeks. So I said "it's been all this time, and I've been telling you and you kept saying its nothing, third time you said its nothing" so I was relaxed you know that it's nothing and I had been also saying that where you took the tissue from, it's hurting more yet you still didn't do [anything]."

Deepa, aged 61

'It's because of the way we are, culturally'

As well as language barriers, some women voiced their concerns from a cultural perspective. A few stated that their diet is culturally specific and were therefore unable to eat hospital food. Alpa explained how the hospital staff tried to be accommodating and meet her needs but it was not the same because she was not used to eating westernised foods. This resulted in her being discharged from hospital as the staff felt she would be better cared for in her own environment, where she would be able to eat properly. This added more strain to her recovery time as she had to travel long distances for radiotherapy treatment, which became very tiring. Similarly, Hansa was not accustomed to eating cooked food from environments other than her own and did not eat onion and garlic due to religious reasons. She managed this by having food prepared at home and brought in for her whilst she was recovering in hospital.

"I stayed there [hospital] for a week but I didn't like their food. And they [healthcare professionals] said "tell me and we'll make it for you" but I said "you don't have the right things [ingredients]" so how can they cook for me. And then they gave me nuts and the nuts here are different and I didn't like that either so then they told my husband, you'll have to take her home, she can't stay here."

Alpa, aged 55

******* [friend] would come to the hospital to give me food. ***** [friend] and ***** [niece] would come to give me food at the hospital. ***** [friend] would do the cooking because ***** [niece] uses garlic so she wouldn't bring the food and ***** [friend] cooks without garlic so she would bring the food from home. And I gave ***** [member of the community] £50 towards petrol for dropping the food to the hospital for me."**

Hansa, aged 60

Some of the women also spoke about their concerns of being treated by male healthcare professionals, due to feelings of embarrassment. They explained that, culturally, it is not appropriate to be examined by male healthcare professionals or to even have a relationship with a man other than their husband. The women expressed strong initial concerns about exposing themselves to male healthcare professionals but did go on to explain that as time went on they accepted that only male healthcare professionals are available to treat them so they got used to it and became less bothered by it, although they would prefer to be treated by and feel comfortable amongst a female healthcare professional.

Alpa: Before when I would have to see a man I would feel something.

Researcher: In what way?

Alpa: As in ... because of the way we are [culturally], so we feel like we shouldn't associate with men, I don't even like talking to men too much. I don't like talking to men much so for a few days I didn't like it. And after the operation, they would check me and there so many doctors there, around 7 or 8. And when they check everything,

you feel funny because they look and touch. For a few days I really felt it. *(When Alpa was further probed to find out how she felt, she expressed feelings of embarrassment).*

Alpa, aged 55

5.3.5 Accepting an altered appearance

Body image concerns (or the lack of) became an evolving theme that emerged amongst discussions with all the women. Issues around the type of treatment, clothing and the amount of importance placed on appearance are described below.

'Mastectomy Vs Lumpectomy'

Body image concerns were very much dependent on the type of treatments that women underwent and the severity of the side effects. Three had undergone a mastectomy and for some of them, losing a breast seemed to have had a greater impact on their body and self-esteem than for those who had a lump removed. For example, Manjula felt that she had lost an important part of her body, and no longer felt balanced or 'whole'. This instigated femininity issues in some women who described initial feelings of not feeling feminine enough.

"Initially I did feel like less of a woman but now it's all forgotten, it's in the past."

Manjula, aged 76

Some women also expressed feeling body conscious, especially when going out in public which often resulted in limiting their social activities and avoiding public places such as swimming pools. Women felt that wearing a breast prosthesis helped them to overcome their body image concerns and helped them to regain their body shape. Although initially some of the women found it hard to get used to wearing a prosthesis (due to the physical effects of it being heavy and uncomfortable to wear) and would worry about it falling out in public. There was also a worry that other people would be able to tell that they were missing a breast. This was especially worrying for those who wanted to keep their breast cancer private and avoid community members from finding out.

"You look better when you go outside so nobody knows when you go outside."

Manjula, aged 76

Alpa and Manjula also spoke of how they could not go out without their prosthesis. However, as they learnt to accept their new cancer identity and became used to wearing their prosthesis, they became more confident in going out in public. Feeling body conscious became less of an issue, resulting in Alpa feeling comfortable going out without her breast prosthesis.

"At the beginning it was all new but now I go swimming and everywhere, sauna. I don't even put a pad in either. I don't feel like I will be embarrassed or anything like that."

Alpa, aged 55

Of the five women, only one (Hansa) received chemotherapy treatment. For Hansa, concerns about losing her hair and the impact on her body and self-esteem were evident as she took precautionary measures to avoid losing her hair (by wearing a cold cap) and preparing scarves as a way to conceal the hair loss. She also dealt with this issue positively by reassuring herself that the hair loss would be temporary.

“There’s no use in worrying. If they [hair] go they go, if they stay they stay (laughs).”

Hansa, aged 60

‘You can’t tell too much in loose clothes.’

Some of the women who wore a breast prosthesis commented on the impact it had on their choice of clothing. Some of them often wore traditional Asian clothing typically in the form of a sari. They felt that wearing a prosthesis was less obvious in Asian clothing as the blouses worn with their saris are often a loose fit and can also be tailored to their body shape. Additionally, draping the sari and covering the chest area made the women feel that the loss of a breast was less obvious than when wearing English clothes. For this reason some women stated that they would feel less conscious about their prosthesis when they were traditionally dressed.

“I feel it’s less obvious in saris as opposed to wearing dresses.”

Manjula, aged 76

Hansa described how it was not so easy to know if someone was wearing a prosthesis in a sari and therefore rarely wore her prosthesis. This was also dependent on whether the women were large-chested or not.

For women who wore their prosthesis regularly, shopping for specific bras was often challenging. For example, Alpa spoke of how she would have to shop for specific bras that gave her better support and could hold a prosthesis in place. This often meant having to shop for expensive underwear which was often frustrating.

“The bras are no good. They [breast prosthesis] all fall out. I can only wear Marks [and Spencer] bras. The £16 one. I bought a £12 one once but that was no good. So this £16 one is more supportive. The pad doesn’t come out in it. But the other bras are no good.”

Alpa, aged 55

‘I’m still alive’

All the women in some form or another underwent appearance changes, whether it was a result of having a lumpectomy, mastectomy, radiotherapy or chemotherapy. However, Deepa, Raksha and Hansa were not so concerned by the changes and it did not affect their body and self-esteem too greatly as they were not particularly invested in their appearance and the changes that followed after their treatment. Instead, they placed greater emphasis on their health and being alive.

“I'm not ...into my body...yeah I am into my body as in it should work properly, or walk or get you to places.”

Deepa, aged 61

Some women also felt that due to their age, appearance issues were a trivial matter and they were not bothered by the changes as much as younger women, who some women felt would be more invested in their appearance.

“I know this is permanent so I'm not too bothered. Younger people feel more (laughs a little).

Raksha, aged 76

(This comment was made in reference to Raksha's chest which had become discoloured from the radiotherapy and she mentioned a change in the shape of her nipple).

5.4 Conclusion

This is the first UK based study that has explored breast cancer experiences of Gujarati speaking Indian women with LEP. Interestingly, findings of this study present very similar findings to those found in studies 1 and 2 (for example, issues centred around the impact of the illness on family members, body image concerns, healthcare experiences, social support, cultural taboos of cancer, religious beliefs, cultural values, and the ways in which the women managed their experiences through positive thoughts and behaviours), with the exception of the emphasis on limited knowledge of cancer and the impact of language barriers on the women's experiences. These findings will be discussed collectively in chapter 6.

Another interesting and unanticipated issue that arose whilst conducting this study was the role that interpreters play in healthcare and research settings. Using an interpreter in the current study raised several issues, where the accuracy of their interpretation process was questioned. This is discussed in detail in the next section; drawing on my own experiences of working with interpreters for this research.

Part 2: Working with interpreters

5.5 Introduction

Within the UK, people who speak little or no English (Limited English Proficiency; LEP) are accessing healthcare within a predominantly English speaking setting. Individuals with LEP face many problems; whereby language is seen to act as a communication barrier and can have an adverse impact on their psychological, social and physical well-being. This has been highlighted in a substantial number of papers (e.g. Moore & Butow, 2005; Butow et al, 2011; Gerrish, 2001; Owens & Randhawa, 2004; Cortis 2004; Weinick & Krauss, 2000). The inability to fully understand a diagnosis and its associated treatments can have a negative impact on the quality of care and support that the patient receives, especially if the patient does not feel confident in asking questions. The utilisation of interpreters and translators during consultations can help to reduce language barriers and help to effectively communicate instructions to patients, thus promoting a clear understanding of their illness and reducing anxieties (Karliner et al, 2007).

“Interpreters translate the meaning and function of messages exchanged between service user and service provider” (Gill et al (2004) p322). The terms interpreter and translator are often used interchangeably. While both perform similar tasks of translating words from one language to another, the difference lies in the context in which the translation takes place. A translator converts written material (i.e. interview transcripts or primary and secondary sources) from one language to another, whereas an interpreter provides verbal translation between a minimum of two people who do not speak the same language (i.e. during a consultation or to conduct a qualitative research study) (Hole, 2007).

Hospitals and healthcare professionals are now expected to meet patients’ language and communication needs by providing them with translated materials or professional interpreters (NHS, 2010). A report comprising of 247 NHS Trusts found that 23.3 million pounds was spent on translation and interpreting services in 2011 (Gan, 2012). The appropriateness of this amount has been debated, particularly in a climate where the NHS is striving to cut costs. Therefore, due to practical constraints of time and money, utilisation of professional translation and interpreter services, within the NHS, is very much ad hoc (Gan, 2012; Hilfinger Messias, McDowell & Estrada, 2009; Jones, 2007). This has resulted in relying on untrained interpreters, bilingual staff and family and friends to act as interpreters, which can compromise effective communication (Trevatt & Kelly, 2006). The challenge of using untrained interpreters is discussed below. While interpreters are key in bridging the communication gap, they may not always be the most accurate. Despite the patient and interpreter sharing a common language, it can still hinder effective communication between the patient and healthcare professional (Elderkin-Thompson, Silver & Waitzkin, 2001; Flores, 2005). Before discussing the problems of working with interpreters in the healthcare and research field, it is important to describe the different styles and types of interpreters that are utilised.

5.6 Styles of interpreting

The role of the interpreter ranges from adopting a passive to more of an active role. Traditionally, interpreters have been seen to take on an invisible, passive role as conduits who are required to provide verbatim translations in a “neutral, faithful, and machine-like manner” (Hsieh (2006) p721). This is known as the linguistic model (Cushing, 2003, Tribe, 1999), where the interpreter is trained to give literal translations without making any additions, omissions or polishing the translated language, and thus minimising their presence as much as possible. However, it is without a doubt that the presence of an interpreter will affect the dyadic relationship between both parties. It is often difficult for interpreters to take on such a passive role (Bolden, 2000). One reason for this is because interpreters can often share the same cultural background as the individual with LEP and as a result, they are not only aware of the cultural differences but also the linguistic differences such as cultural idioms – where a verbatim translation would change the meaning of the speech. For example, a verbatim translation of the Hindi expression ‘ parching of blood’ would be meaningless when translated into English (‘dry blood’). Yet a South Asian interpreter familiar with the phrase can translate it in a way that would make sense (‘to become afraid’). It is for this reason that interpreters may sometimes feel that they need to play an active role and put what is being said into context so that the interviewer/interviewee can make sense of the language and respond appropriately. This is pertinent in situations where certain words (e.g. ‘cancer’ or ‘depression’) do not exist in a particular language, and therefore it is necessary to use contextual concepts and explanations to convey accurate meaning. Furthermore, due to the shared cultural background, an individual with LEP can often feel that they can relate to the interpreter and may attempt to seek empathy from them (particularly in health care settings). In this case it would be hard for the interpreter to act in a robotic manner, especially if the health matter is a serious and sensitive one.

Tribe and Morrissey (2004) outline 4 basic styles of interpreting and state that the different styles are dependent on the type and situation in which the interpreting is required: Linguistic interpreter (outlined above, linguistic model – best used in legal settings where purely factual information is required), constructionist interpreter, advocate interpreter and bicultural interpreter. In the constructionist mode, the interpreter works within the context of meaning and is therefore more concerned about getting across the meaning and feelings conveyed by the client rather than providing a verbatim translation (Raval, 2003). This form of interpreting is best used in psychotherapeutic/counselling domains or when conducting qualitative research. The advocate interpreter provides a service beyond interpreting by offering help, advice and ensuring that appropriate healthcare needs of the client are met (Razban, 2003). Similar to the constructionist interpreter, the bicultural interpreter, places greater emphasis on understanding the client’s emotional world within their cultural context. This style is also useful when working within mental health and psychological research and recommended when there is time to develop a sense of trust and understanding between the interviewer, interviewee and interpreter.

5.7 Accuracy of interpreters

Researchers looking at the role of the interpreter have consistently found that interpreters refrain from playing the conduit role for reasons stated above (Angelelli, 2004; Hsieh, 2006; Davidson,

2000). On the other hand, many researchers have questioned the accuracy of the interpretations provided and documented the various errors that are made; often due to lack of training (Farooq, Fear & Oyebode, 1997; Cambridge, 1999; Davidson, 2000; Elderkin-Thompson et al, 2001). For example, on evaluating responses during a clinical interview of 10 English speaking and 10 non-English speaking South Asian patients with mental health problems, Farooq et al (1997) detected many errors during the interpretation process. Errors included partially or completely omitting the message, simplifying a detailed response and rewording the interviewer's questions which would generate a different response. Similarly, Flores (2005) conducted a systematic review to examine the impact of interpreter services on quality of care. On reviewing 36 papers, Flores discussed how many of the studies showed that having no interpreter or an untrained ad hoc interpreter can hinder communication and quality of health care for patients with LEP. He went on to conclude that patients with LEP need, but are not always provided with adequate interpreters.

Common errors made during interpretations have been outlined in several papers (Farooq et al, 1997; Farooq & Fear, 2003; Flores et al, 2003) and are briefly described below:

- Omission: The message is completely or partially deleted.
- Substitution: The content of the message is replaced to mean something other than what was said.
- Addition: The interpreter includes information that the client did not state.
- Condensation: The tendency to simplify a long and lengthy response.
- Role exchange: The interpreter takes over the interview and adds/replaces the interviewer's questions.
- False Fluency: The interpreter uses an incorrect word/phrase, or uses a word/phrase that does not exist in that particular language.
- Editorialisation: The interpreter provides an interpretation based on his or her own personal views.

It is important to note that the amount and type of errors made during consultations is dependent on the type of interpreter that is used, considered below.

5.8 Types of interpreters

There are two main types of interpreters: professional and untrained, ad hoc. Professional interpreters are skilled and trained to deliver accurate translations whilst maintaining a strict code of conduct. Ad hoc interpreters tend to be family members, friends or bilingual staff (untrained medical staff and non-medical staff). Professional interpreters are the best type to utilise and are less likely to commit erroneous translations compared to untrained, ad hoc interpreters (Flores et al, 2003). Ad hoc interpreters lack the knowledge of specialist terminology (i.e. medical terminology; Gerrish, 2001) and due to their untrained language skills, it can result in them committing mistakes such as

those outlined above. However, problems of delivering accurate translation and interpreting services can also be apparent in professional interpreters, particularly if they are not specialised in a specific area (i.e. within a medical setting).

Many studies have reported that the quality of interpretations are compromised when using ad hoc compared to professional interpreters (Flores et al, 2003; Diamond et al, 2009; Bischoff & Hudelson, 2010). For example, Elderkin-Thompson et al (2001) examined the accuracy of interpretations when using untrained nurse interpreters. Errors observed during the video-taped consultations included omission, editorialisation, substitution and false fluency. Consequently, incorrect symptoms were communicated back to the consultant, resulting in them not having a clear understanding of the patient's situation. However, accurate interpretations were also observed. This was most successful when consultants and interpreters spoke slowly, clearly and constructed simple sentences; which enabled understanding in patients who have a basic or slight understanding of the English language. Similarly, Flores et al (2003) stated that ad hoc interpreters are more likely to make erroneous translations than professional interpreters. Errors observed included omission, false fluency, substitution, editing information and addition (see above). This can have serious clinical consequences for the patient such as misdiagnosis, prescribing wrong medications and hindering the patient's opportunity to ask further questions (Baker et al, 1996).

Despite the errors outlined above, there is a greater prevalence of using ad hoc interpreters, mainly family members or friends (Flores et al, 2003; Diamond et al, 2009; Rose et al, 2010). Rose et al (2010) examined the use of interpreters between consultants and breast cancer patients with LEP. On examining which healthcare professionals used interpreters during their consultations, 41% reported using a trained medical interpreter, 21% reported using telephone language interpretation services, 76% reported using bilingual staff not specifically trained in medical interpretation, and 86% reported using patients' friends or family members for assistance in communicating with patients with LEP. Using family members (particularly young children) as interpreters can be highly problematic as they may choose to censor information to protect the patient or answer for the patient without asking them questions. Family members have also been known to ignore questions and do not always repeat information back to the patient when it's regarding sensitive or embarrassing topics such as menstruation, contraception and bowel movement (Barron et al, 2010; Flores, 2005).

While some studies have found that patients prefer to use family or friends as interpreters because they are easily accessible and greater trust is placed on them than a stranger (Alexander et al, 2004), other studies have reported that patients prefer to have bilingual staff act as interpreters rather than their family or friends. This is because many patients do not like to inconvenience their family members, who may need to take time off work to attend hospital appointments. Also, the presence of a bilingual staff member reassures the patient that their personal issues will remain private and confidential and they need not worry about personal information being spread to extended family or community members (Bischoff & Hudelson, 2010). Just as family members may not feel comfortable being present when private medical matters are being discussed, patients may also find it embarrassing discussing sensitive issues in front of a family member that they want to protect, especially children, as they may not want to appear vulnerable in front of them (Barron et al, 2010).

Most of the literature on interpreters' roles has been documented within mental health research (e.g. Raval, 2003; Tribe & Morrisey, 2004) or general medical consultations (David & Rhee, 1998; Kuo & Fagan, 1999). Also, a lot of the existing research has examined the interpreter's role through the Spanish language (Flores et al, 2003; Seijo, Gomez & Freidenberg, 1995; Elderkin-Thompson et al, 2001). Nonetheless, similar issues apply across languages and health settings. Very little is known about how healthcare professionals communicate within the oncology field (Rose et al, 2010). As with any health issues, language barriers within cancer settings can constrain communication between the patient and the healthcare professional, hindering the patient's ability to understand their cancer diagnosis, the treatments involved (and its accompanying side effects), the impact this has on their quality of life and seeking further information (Sepucha, Belkora, Mutchnick & Esserman, 2002; Epstein & Street, 2007). Seeking further information can be especially problematic if written information is not available in the patient's language. For example, some languages, such as Sylheti, do not have a written form (Temple & Young, 2004). Furthermore, some people may not be literate in their mother tongue language (Szczepura, et al, 2005); thereby raising additional problems for healthcare professionals and researchers with regards to relaying information back to individuals with LEP.

5.9 Working with interpreters in qualitative research

It is clear that while interpreters are key in bridging the language barrier, many difficulties and challenges in the quality of the interpreting service provided have been extensively documented in the literature. However, research looking at the experiences of working with interpreters from a researcher's perspective is limited (Alexander et al, 2004; Hsieh, 2006). While there is a vast scope of literature looking at the problems of translating scales for cross-cultural use, very little work has looked into conducting qualitative research in another language with the aid of an interpreter (Kapborg & Bertero, 2002; Birbili, 2000; Temple & Edwards, 2002). The next section will highlight qualitative researchers' perspectives of working with interpreters, including my reflections of working with an interpreter whilst interviewing Gujarati speaking women (study 3). Although my mother-tongue language is Gujarati, my understanding of the language is more proficient than my oral skills. It is for this reason that I felt it was best to use an interpreter to help me communicate the questions, understand the varying Gujarati dialects and translate the odd phrases or cultural idioms that I may not be familiar with.

When using an interpreter in qualitative research, the research becomes known as a cross-language qualitative study; which comes with additional language challenges (Temple & Young, 2004). When an interviewer is unable to understand the participant and has to rely on an interpreter, the researcher loses some element of control over the interview. The researcher is unaware of the accuracy of information being translated and if in fact the responses are being translated verbatim, summarised or modified.

Where researchers require an interpreter they could adopt one of two models: a passive or active interpreter model (Pitchforth & van Teijlingen, 2005). The passive model requires the researcher to ask the participant questions through the interpreter, who would then relay the participant's response back to the researcher. This method allows the researcher to have control over the

interview by being able to follow what is being said and having the opportunity to ask further questions. However, this approach can be very time consuming for all parties involved and becomes a rather structured question and answer session; inhibiting a conversation to flow naturally. The active interpreter model allows the interpreter to carry out the majority of the interview. The researcher is present throughout the interview process and the interpreter summarises the key points during certain aspects of the interview to allow the researcher to ask additional questions. This model is less time consuming and allows the interpreter to build a better rapport with the participant which in turn allows the interview to flow more like a conversation. However, this means that the researcher has less control over the interview process. For this model to be successful, it is also important that the interpreter is highly familiar and skilled with the research aims and methodological approach so that he or she can execute this productively in order to gather rich data.

Other factors to consider when working with an interpreter include the type of interpreter used, the interpreter's role and cultural factors (Freed, 1988). The literature presents mixed views as to which type of interpreter is best to use during an interview process. Some researchers state that participants prefer to have an interpreter who is a well-established, respected community or family member due to trusting that what they say will be kept confidential (Hennings, Williams & Haque, 1996; Phelan & Parkman, 1995). However, confidentiality cannot always be ensured (Pernice, 1994). Similar issues exist when using interpreters within the research and healthcare setting (as previously discussed). For example, interpreters can be selective in what they translate back to the researcher as they may feel the need to protect the participant (Murray & Wynne, 2001). In some cases a community or family member can hinder the participant's responses. For example, if the topic in discussion was regarding their family experience, then the participant may not feel comfortable giving honest responses. Many researchers recommend using an unknown professional interpreter who is able to practice ethical issues of confidentiality and does not feel the need to play an advocate role (Jentsch, 1998).

Whilst conducting this research, participants were given a choice of which language (English or mother-tongue) they preferred to be interviewed in and the type of interpreter they wished to have present (professional or unprofessional interpreter, i.e. community member). During study 1, the first 2 participants with LEP stated their preferences of wanting a known individual (family member or community member) to act as their interpreter. Although using a non-professional interpreter known to the participants can help to establish trust and a rapport with the participant (Thompson & Woolf, 2004), this was found to be highly problematic. Due to the shared language, I was able to detect how both interpreters attempted to take over the interview process by rewording my questions, answering for the participants, and paraphrasing the participant's responses. The interpreters would also engage in role exchange where they would go into a conversation of their own and ask additional questions. These interviews did not represent an accurate account of the women's responses and were therefore omitted from analysis. One of the interviews took place with a Muslim woman who spoke Urdu. Although not a language that I am fluent in, I was still able to detect the major errors that occurred. In this case, the participant would give one word responses which I understood to mean 'okay', yet the interpreter would give a detailed response which appeared to be her opinion rather than the participant's account (Editorialisation).

The remainder of the interviews (study 3) were conducted by 2 professional interpreters who were highly experienced and familiar with interpreting in health settings, although not specifically in

breast cancer. Although these interviews worked well for all involved and facilitated translations that were relatively accurate, some difficulties (already documented in the literature i.e. Farooq & Fear, 2003) were still experienced. For example, it was observed that on some occasions the interpreter gave inaccurate translations, paraphrased responses, gave additional responses and reworded questions. Examples of such errors are given in the following extracts:

Extract 1

Researcher: How did you feel about the care and information that you received from your GP and the consultants?

Manjula: The GP didn't give much information. He sent me to the hospital and the consultants did everything. The consultants would call me every month for check-ups and then every 3 months and then every 6 months. They would check and just tell me that everything is okay so it's just reassuring for me that nothing has spread or come back.

Interpreter 1: It was just for my satisfaction. But anyway whenever they called me for my check up, monthly check up, it may be fortnightly or monthly or once in two months. Depending on my check-up I used to go and well I was happy.

The above extract is an example of an inaccurate translation (containing elements of omission and addition). The interpreter not only paraphrased the response, but was inaccurate on the times the check-ups occurred; claiming it was "monthly check up, it may be me fortnightly or monthly or once in two months", whereas the participant stated the check-ups were every month, then every 3 months and then every 6 months.

Extract 2

Researcher: Did you ever blame God as to why you got the cancer?

Manjula: At that time.

Interpreter 1: I did blame him but apart from the blame God gave me everything I needed to support myself.

The above extract is an example of the interpreter adding her own interpretations to what the participant said (editorialisation). Funnily enough the participant actually replied to this particular question in English, thus no translation was required. The participant then paused so as to reflect on her answer and may have wanted to say more on this subject but the interpreter did not give her this opportunity and abruptly interrupted her, adding more than what was said.

Extract 3

Researcher: So how were you told?

Interpreter 1: How were you told, how did they tell you, did they tell you straightaway?

Raksha: Yes they told me straightaway.

The above extract is an example of how the interpreter reworded my original question, which resulted in the participant replying to the latter question (role exchange). The interpreter had not given the participant the opportunity to respond but asked the same questions in 3 different ways one after another. During the debrief session, the interpreter stated that the participant may not have understood the question so she felt it appropriate to add exemplar questions. I felt that this resulted in the interpreter putting words in the participant's mouth. Furthermore, the interpreter took it upon herself to probe further which in essence was for the researcher to do.

The above errors occurred during the first two interviews which took place one after the other. During the debrief session, these errors were discussed with the interpreter. Her role in the research process and my ability to understand the language was reiterated to her. Fortunately everything that was discussed was taken on board and resulted in the rest of the interviews running smoothly. It is possible that using different interpreters may (or may not) have yielded similar mistakes during each interview and further producing inconsistent translations. Using the same interpreter for all the interviews allows the researcher to build a rapport with the interpreter, for the interpreter and researcher to understand each other's working relationship, and shape the interpreter accordingly; thus avoiding same errors being made all the time (Twinn, 1997). However, using the same interpreter can result in the interpreter getting bored in repeating the same questions and hearing similar responses (Kapborg & Berterö, 2002). This occurred during the second interview (with the professional interpreter), where the interpreter was not paying attention to what the participant was saying and was scribbling on a piece of paper. During this time, I needed the interpreter to intervene, and when I asked her, she had to ask the participant to repeat herself. I felt that this was very unprofessional of her, especially as the participant was sharing her personal experiences on a sensitive topic and may have found this behaviour to be rather offensive.

Despite the problems experienced, the interpreter's skills improved and she quickly learnt of my questioning style. She adhered to the ethical guidelines of the research in respecting the confidentiality of the responses and did a great job in verbally translating the participant information sheet and helping to gain written consent from the participant. This was especially useful as some of the women were unable to read in Gujarati.

It is highly recommended to set up a meeting with the interpreter before conducting the interviews in order to clarify role expectations, the research process (particularly if the interpreter is not familiar conducting qualitative research) and aims of the interview (Phelan & Parkman, 1995; Murray & Wynne, 2001). It is also important to have a debrief session at the end of the interview; especially if the interview contains sensitive and emotive issues (Baker, Hussain & Saunders, 1991). Having studied the guidelines of how best to work with an interpreter (Tribe & Thompson, 2008), I sent the interview schedule to the interpreters to study prior to the interviews and arranged to meet up with them to explain the purpose of the research and their role during the interview process. Despite both the interpreters assuring me that they understood the requirements and their role in the interviews, they would often take on a more proactive role and take control of the situation. This was particularly frustrating when working with one of the interpreters as the frequent pauses interfered with the flow of the conversation whilst the participant was telling her story. An advantage of qualitative interviews is that they facilitate responses to flow like a conversation. When

an interpreter needs to constantly interrupt to translate the dialogue between the researcher and the participant, this flow-like conversation becomes disjointed (Teijlingen van & Ireland, 2003). This adds to the disadvantage of working with an interpreter, as well as making the interviews more time consuming. In my case, the frequent interruptions were unnecessary due to my fluent understanding of the language (which had been highlighted to the interpreter).

Working with the second interpreter (based in Cardiff) was more positive. Very little errors were made by her. The only issue that occurred, which to an extent was out of the interpreter's control, was that the interpreter was known to the participant. The participant was made aware of this and was happy to share her experience in the interpreter's presence. However, on some occasions, this resulted in the participant speaking directly to the interpreter and mentioning people, knowing that the interpreter would know who she is talking about. This resulted in me needing explanations of how the people being mentioned were related to the participant in order to understand her experiences and probe her further. The other issue observed was that of role exchange. When the interpreter knew the question was not answered clearly (or the participant digressed from the topic), she would often take it on herself to probe further.

My experiences are concurrent with other qualitative researchers who have reported similar challenges whilst working with interpreters. For example, Pitchforth and van Teijlingen (2005) found that working with the interpreter created some tension as on occasions the interpreter would not ask questions or interpret answers as she felt the response was obvious, despite the researchers stressing the importance of this when analysing data. Pitchforth and van Teijlingen found that there were occasions where the interpreter would do more than just translate back what had been said such as adding her own interpretations or omitting information that she did not deem relevant.

From a research perspective, interpreters can fail to understand the importance of detailed responses needed for the analysis. However this is very much dependent on the level of analysis that the researcher wants to undertake and the level of detailed transcription and translations that are required. If for example the aim is to understand a group of women's responses, subtle changes in the translation process may not be such a big deal to the researcher or impact on their analysis (Pitchforth & van Teijlingen, 2005) as opposed to focussing on the individuals' experience on a detailed level, where the emphasis is on words and the language used (in-depth analysis). Here it is important to get very accurate translations in order to analyse the data appropriately (Squires, 2009).

From a cultural perspective, both the interpreter's background and previous cultural experiences enabled them to relate to the participants and in turn establish a good rapport with them which helped to facilitate detailed and open responses (Jentsch, 1998). The participants varied in their origins from India, which meant they differed in the caste that they belong to. This results in varying Gujarati dialects and religious beliefs. Before meeting with each participant, I explained the caste of the participant to the interpreters. Due to the interpreters' familiarity of the varying Gujarati cultures, they greeted each participant accordingly, establishing a positive rapport from the onset. This was particularly helpful as being born in the UK and accustomed to the western ways of living, I have a limited knowledge of different cultural backgrounds and had not considered the importance of greeting others in their own language in a particular way. This is a problem when one is too close to the research as small yet significant issues can be overlooked.

5.10 Conclusion

The above studies show how healthcare professionals are none the wiser in the accuracy of the interpretation process. Similarly, a researcher who is unable to understand any part of the participant's language is also entirely dependent on the interpreter to provide accurate information, without adding, deleting or altering any meanings. Fortunately my understanding of the language and cultural background enabled me to follow the interviews very closely. However, researchers working with interpreters need to be aware of potential challenges that they can face. Even though roles are determined from the onset, it does not mean that the interviews will always run smoothly. Whichever 'interpreter approach' the researcher chooses to adopt (passive or active), they are both flawed. In an ideal world the perfect interpreter would be one who is able to translate as accurately as possible, whilst taking into account the cultural perspective of the role of language (i.e. appropriately translate cultural idioms rather than verbatim). Better yet (and although highly rare; Temple & Young, 2004), a bilingual qualitative researcher who has the potential to conduct the interviews without the help of an interpreter would be the best option. Researchers or healthcare professionals working with an interpreter for the first time may find this very demanding. It should be noted that both healthcare professionals and qualitative researchers would undergo very similar experiences whilst working with an interpreter; whether it's to enhance the patient's quality of care or to explore a certain phenomenon. Therefore, some of the difficulties experienced from a researcher's perspective can also be applied to healthcare professionals who have to work with interpreters. A few guidelines have been produced on how to best work with an interpreter, in both the NHS and research context, that can help to overcome initial anxieties and should be encouraged to follow (e.g. Phelan & Parkman, 1995; Tribe & Morrisey, 2004; Tribe & Thompson, 2008; Willison, 2010).

5.11 Overall Conclusion

This chapter has provided a detailed account of conducting research with participants with LEP. The third study of this thesis was presented, exploring the psychosocial impact of breast cancer in a sample of Indian women with LEP, with the help of 2 professional interpreters. Whilst conducting this study, the researcher became aware of the dynamics of working with an interpreter. The challenges experienced were discussed in the second part of this chapter, along with the utilisation and accuracy of different types of interpreters experienced by healthcare professionals when treating patients with LEP.

This was the final qualitative study in this thesis. All 3 qualitative studies produced very similar findings which are discussed collectively in the next chapter. These findings informed the development of a quantitative study (chapter 7).

6 Qualitative findings: Discussion

6.1 Introduction

The findings from the qualitative studies provide an in-depth and insightful understanding of the psychosocial impact of breast cancer in Black and South Asian women. All the women who took part in these studies were grateful to have been given the opportunity to share their emotional and often challenging experiences, as expressed by Kaveeta (aged 53 [study 1]): *“I’d like to thank you for creating the space for me to talk about it and be able to help”*. This also allowed the researcher to obtain a range of diverse concerns. More specifically, the 3 qualitative studies captured:

- A detailed understanding of Black and South Asian women’s breast cancer experiences,
- The way in which breast cancer experiences are managed and
- How breast cancer is experienced in South Asian, specifically Gujarati-speaking women with LEP.

The women’s experiences and ways in which they managed them were embedded across all 3 studies, and many similar findings emerged as a result. The themes were often reframed to capture the essence of the women’s experiences in a given study. These include support (especially in relation to religion/spirituality, family members and support groups), cultural influences (beliefs and attitudes towards cancer), understanding and living with the illness, and appearance concerns (as a result of treatment). For this reason, the findings of all 3 qualitative studies will be discussed collectively. Figure 6.1 provides a summary of the themes and sub-themes from each study. The sub-themes are colour coded to show the similarities across the studies. The red sub-themes represent issues around support. As family were described as one of the main sources of support, the impact on family members is also briefly discussed under this section. The orange sub-themes represent body image concerns, pink captures how some aspects, often challenging ones, were managed and perceived in a positive light and blue represents cultural influences (including cultural beliefs and values). Finally, the green sub-themes are aspects of the experiences that were unique to women with LEP and will be discussed separately.

The findings raise important implications for research and practice. These issues will be discussed in the final chapter of this thesis (chapter 8).

Figure 6.1: Summary of themes and sub-themes

Study 1 Black and South Asian women's experiences of breast cancer	Study 2 Black and South Asian women's experiences of managing the psychosocial and cultural impact of breast cancer	Study 3 Exploring the lived experience of breast cancer in Gujarati-speaking Indian women
Familial concerns <ul style="list-style-type: none"> • <i>'Impact on family members'</i> • <i>'Staying strong for the family's sake'</i> • <i>'Being a burden'</i> 	Social support needs <ul style="list-style-type: none"> • <i>'Getting the right balance'</i> • <i>'Having information is important'</i> • <i>'Once I found the group, I have not looked back'</i> • <i>'God was with me'</i> 	Making sense of the cancer <ul style="list-style-type: none"> • <i>'I knew nothing about it'</i> • <i>'What, why, how?'</i> • <i>'Now there is more, before there was nothing'</i>
Social support <ul style="list-style-type: none"> • <i>'Unlimited support'</i> • <i>'Support from similar others'</i> 	Loss of control <ul style="list-style-type: none"> • <i>'Why me?'</i> • <i>'I'm taking control now'</i> • <i>'I found that loss of control was very, very difficult for me'</i> 	'A shared experience' <ul style="list-style-type: none"> • <i>'It affected them a lot'</i> • <i>'They were very supportive'</i> • <i>'She would come with me everywhere'</i>
Spirituality <ul style="list-style-type: none"> • <i>'Spiritual faith and beliefs'</i> • <i>'Fatalistic beliefs'</i> • <i>'Punishment'</i> 	Cultural taboos and expectations <ul style="list-style-type: none"> • <i>'She's got the big C'</i> • <i>'She must have done something wrong in life'</i> 	'Replacing the negative with the positive' <ul style="list-style-type: none"> • <i>'I did what I could'</i> • <i>'I was open but she hid it'</i> • <i>'Why worry, just live'</i>
Body image concerns <ul style="list-style-type: none"> • <i>'Altered appearance'</i> • <i>'Use of appearance-related products'</i> • <i>'Clothing issues'</i> • <i>'Health Vs Appearance'</i> • <i>'Femininity issues'</i> 		'Healthcare experiences <ul style="list-style-type: none"> • <i>'I got a lot of help from them'</i> • <i>'They knew what they were doing'</i> • <i>'It's because of the way we are, culturally'</i>
Healthcare experiences <ul style="list-style-type: none"> • <i>'Satisfaction with healthcare'</i> • <i>'Type of Care: Private Vs NHS'</i> • <i>'Gender of the healthcare professionals'</i> 		'Accepting an altered appearance' <ul style="list-style-type: none"> • <i>'Mastectomy Vs Lumpectomy'</i> • <i>'You can't tell too much in loose clothes.'</i> • <i>'I'm still alive'</i>
Life post cancer: What next? <ul style="list-style-type: none"> • <i>'Fear of recurrence'</i> • <i>'Changes to quality of life'</i> • <i>'Thankful to be alive'</i> • <i>'Altruistic tendencies'</i> 		

6.2 Key sources of support

Support played a highly influential role in the women's experiences and the way in which these were managed. Support sought from family members, support groups, healthcare professionals and through religion/spirituality was described as valuable in meeting their needs. This was evident in all 3 studies. Social support has been identified as an important resource in equipping patients to adequately deal with their cancer experience, regardless of ethnicity (Knobf, 2007; Stevens & Duttlinger, 1998; Sullivan, 1997).

6.2.1 Family

Women in all 3 studies explained the negative impact that their diagnosis and treatment had on family members. Despite this being a distressing time for family members, they were perceived to be a strong source of support for women who were fortunate enough to receive it. This is concurrent with other BME and breast cancer studies, whereby family members (i.e. partners, children and other female relatives) are often reported as the main source of support and described as offering practical and emotional support (Balneaves et al, 2007; Banning et al, 2009; Blows et al, 2009; Gurm et al, 2008; Henderson et al, 2003b; Howard et al, 2007; Lackey et al, 2001).

Within BME communities, the family is characterised by strong ties and a wide kinship network; which is often made up of immediate and extended family members (Guidry et al, 2003; Shams, 1994). Therefore, this source of support occurs as a natural process, due to the traditional expectations of caring and supporting elderly members and those who are ill. Holding multi-generational ties within and beyond one's household is especially true in South Asian communities, where family members are not only a major source of support but also play a significant role in women's health-related experiences (Grewal et al, 2005; Mann, 2009).

While the majority of women in the studies were well supported, a few reported receiving limited or very little support (studies 1 and 2). Variations in the amount and quality of support sought and received have also been reported; where family and friends do not want, or are unable, to offer their support (e.g. relationships become fragmented due to family living too far away (e.g. abroad) or marital breakdown) (Blows et al, 2009; Henderson et al, 2003b). Also, due to the taboos and stigma that are associated with cancer, some women rely on their family for emotional support which is not necessarily provided since they may avoid discussing such issues (Henderson et al, 2003b; Wilmoth & Sander, 2001). Alternatively, some individuals may not find it easy to communicate their feelings to family members because of these cultural taboos, and are therefore unable to receive adequate social support (Henderson et al 2003b; Ashing-Giwa & Ganz, 1997). Some women's support network was limited due to cultural expectations on South Asian women to adhere to traditional roles of looking after and prioritising their family (Grewal et al, 2005). The latter was reported by a handful of the South Asian women in the current qualitative studies.

6.2.2 Support groups

Previous research has found the importance of gaining support from other cancer patients, often via support groups (Russell et al, 2008; Moore, 2001; Henderson et al, 2003a). Support groups have been known to enhance feelings of altruism, belonging, reduce isolation, increase psychological well-being, provide an opportunity to share personal cancer experiences, receive information and improve quality of life. Consequently, support groups have been reported as a useful resource for breast cancer survivors (Coreil, Wilke & Pintado, 2004; Lydon, 2009; Knobf, 2007). The support groups that women in the present studies attended were made up of other Black or South Asian women. It was important to the women (especially in study 3) to be around other breast cancer patients who they could relate to from a cultural perspective. This included understanding each other's cultural background, communicating with others in their own language (especially important for women with LEP) and talking about the availability of products such as wigs. A few women who mentioned attending breast cancer support groups that consisted mainly of White women did not find these helpful because of the cultural barriers.

Traditionally, breast cancer support groups have been made up of White, English speaking middle class women (Fobair, 1997) and ethnic minority women tend to be highly under-represented in support group settings (Avis et al, 2008). This is because ethnic minority women prefer to attend groups that are made up of other women with whom they can relate to on a cultural level (Ashing et al, 2003; Barg & Gullatte, 2001; Blows et al, 2009; Henderson et al, 2003b; Knobf, 2007). For example, BME women would find it easier talking with other BME women or seek appropriate information about accessing wigs that would meet their cultural needs. This is something that breast cancer groups of mainly White women may not be able to offer.

Another reason support groups, specifically cultural-specific groups, are deemed important to ethnic minority women is because of the cultural taboos associated with cancer. As mentioned above, family members may avoid discussing issues related to cancer, so cultural specific cancer support groups are proactive in abolishing cultural taboos and aim to educate and allow women to openly express their concerns and receive emotional support (Knobf et al, 2003).

The women in the qualitative studies perceived receiving support or being around other breast cancer survivors to be very useful as it allowed them to compare their experiences with others. It has been widely documented that individuals, when confronted with serious health problems such as cancer, engage in comparative behaviours with other people who are in a similar situation, and use this as a coping mechanism (Bogart & Helgeson, 2000; Buunk & Gibbons, 2007; Carmack Taylor et al, 2007; Van der Zee et al, 2000). This coincides with the findings of the qualitative studies.

Traditionally it has been assumed that individuals engage in two types of comparisons: downward comparisons (comparisons to someone who is in a worse state in order to feel better about one's situation) and upward comparisons (comparisons to someone who is doing better, resulting in the individual feeling worse about their situation) (Festinger, 1954). However, Buunk and Ybema (1997) have proposed that upward and downward comparisons can be interpreted in both a positive and negative way (identification-contrast model). This depends on whether the individual identifies or contrasts themselves to the target. Hence, social comparison behaviours can be broken down into four types: upward contrast (feeling worse when comparing to a target in a better situation), upward

identification (feeling better when comparing to a target in a better situation, on the realisation that it is possible to improve), downward identification (feeling worse when comparing to a target in a worse situation, on the realisation that it is possible to decline) and downward contrast (feeling better when comparing to a target in a worse situation). The tendency to engage in downward contrast or upward identification comparisons was evident amongst women in the qualitative studies. Both these comparative styles helped women to manage their experience in a positive manner (Bennenbroek, Buunk, van der Zee & Grol, 2003; Bogart & Helgeson, 2000; Ven der Zee et al, 2000).

It is also possible for people to engage in lateral comparisons (comparing to similar others who are in similar circumstances) in order to reduce anxiety and feelings of isolation through reassurance that the person is not alone in their experience (Dibb & Yardley, 2006). This was evident within the qualitative studies (particularly in studies two and three), which consequently enabled the women to deal with their experiences in a positive way (Bogart & Helgeson, 2000). This was especially true for women who felt isolated because of their limited knowledge of cancer and/or due to the cultural taboos which prohibit such issues being openly talked about (this will be explained later in this chapter).

It is also important to note that support groups are not suitable for everyone. While hearing positive cancer stories can be inspirational, hearing negative accounts can be discouraging for some women, particularly if they learn that a group member has passed away. This can result in women engaging in downward identification or upward contrast and therefore avoid attending support groups (Coreil et al, 2004). Some women avoid support groups because they do not want to be reminded of their cancer identity or feel worse about their situation (Buunk & Gibbons, 2007). Alternatively, a woman may perceive her situation to be the worst in the group which can make her feel worse (Coreil et al, 2004).

6.2.3 Healthcare professionals

All the women in the present studies spoke very highly of the emotional and informational support that they received from healthcare professionals (mainly breast care nurses and/or oncology consultants). This made the women feel well cared for and helped them understand and manage their illness in a positive manner. This finding is consistent with the breast cancer literature, where studies have reported that healthcare professionals play an important role in supporting patients, both emotionally and by acting as information providers (Arora et al, 2007; Kristiansen, Tijornhoj-Thomsen & Krasnik, 2010; Rees & Bath, 2000).

Healthcare professionals are portrayed as having expert knowledge, ability to maintain professional relationships with patients and experienced in helping patients cope as well as having the ability to cope with patients' distress (Finfgeld-Connett, 2007). For this reason, they are valued as a source of support. The professional relationship between the patient and healthcare professional is one that requires little interpersonal commitment. Furthermore, the lack of reciprocity within this relationship allows the healthcare professional to provide the patient with what Campbell (1984) termed as "moderated love" (healthcare professional's ability to provide a subtle balance between involvement and detachment, and concern and hope for their patient). This can be explained using Simmel's (1971) "stranger" concept. A stranger is someone who has no strong attachments to a

person and is therefore not bound through ties of kinship (Simmel, 1971). Thus a stranger's relationship with an individual is characterised by social distance and objectivity. Healthcare professionals' position as a "stranger" allows them to embrace patients' emotional reactions in a way that family or friends may not be able to (Kristiansen et al, 2010).

However, a small number of women in studies 1 and 2 felt that their support needs were not adequately met by their healthcare professionals. This resulted in them having to find other sources of support, such as support groups. While support from healthcare professionals is important, this is often only available within a limited time and space (i.e. clinical context) and can also vary in the type of support that is offered (Kristiansen et al, 2010). This has also been reported in other studies, whereby increased workloads and time pressures have been found to impede healthcare professionals' ability to provide appropriate support (Botti et al, 2006; Manning & Dickens, 2007).

6.2.4 Religion and spirituality

Religion and/or spirituality were very important aspects of the women's breast cancer experiences. Research has shown that BME women are more likely to rely on God for support than family or friends (Henderson et al, 2003a). The role of religion and spirituality has been discussed in detail in part 2 of chapter 1 and the present findings support the BME breast cancer literature (e.g. Banning et al, 2009; Howard et al, 2007; Knobf, 2007).

The way in which support is sought through religion and spirituality can be divided into intrapersonal and interpersonal resources (Fischer et al, 2010). Intrapersonal coping strategies emphasise individualism such as seeking strength and support within a divine being, whilst the interpersonal aspect places emphasis on external resources such as support from church-based community members or pastors (Krause et al, 2001). Women in the present studies engaged in both inter- and intra-personal coping strategies. This was evident in their discussions of having faith in their God to get them through the illness; engaging in religious activities such as praying and reading holy books to feel closer to God, and attending places of worship such as church and receiving support from the church members or spiritual meditative type courses. As well as family members, BME groups have a tendency to hold fictive kinships (regarding people as family without being related by blood or through marriage) with friends and church members, with whom they rely on for support (Alexander et al, 2004). This was particularly true for the Black Caribbean women in study 2, who talked about receiving practical, emotional and moral support from their church members.

A small number of women in studies 1 and 2 expressed their anger and blame towards God for getting the cancer. This shows that religion may not always act as a positive source of support as it has the potential to elicit negative feelings of helplessness and hopelessness (Levine et al 2007; Shaw, Joseph & Linley, 2005).

6.3 Body image concerns

Body image concerns emerged in the qualitative studies (studies 1 and 3) due to the negative effects of their treatment, which not only altered women's appearance but also triggered femininity issues, and affected their psychological and social well-being. The use of appearance-related products such

as wigs and breast prosthesis acted as a tool for managing the adverse changes. This was very important to the women as it helped boost their self-confidence and carry on with their daily lifestyle. It is also worth noting that many of the women expressed that their partner's support influenced the extent of their body image concerns. Many women were re-assured by their partners that appearance was not important in relation to survival. This helped the women accept and manage their altered appearance positively.

The profound psychosocial impact of treatment on body image is well known in the breast cancer literature. This has been documented in White and BME groups (Ashing-Giwa et al 2004; Baxter et al, 2006; Helms et al, 2008; Russell et al, 2008; Taleghani, Yekta & Nasrabadi, 2005; Watts et al, 2004). The findings from the present studies and current literature show that similar body image concerns are experienced in breast cancer survivors, regardless of ethnicity. However, from a cultural perspective, many women in the qualitative studies felt their needs were not met due to the limited availability of appearance-related products that were culturally suitable. This is an additional issue that ethnic minority women have to deal with which can exacerbate their experiences. The lack of appropriate coloured prosthesis, wigs and lymphoedema sleeves is commonly reported in the BME breast cancer literature (Blows et al, 2009; Nelson & Macias 2008; Wilmoth & Sanders, 2001).

The dissatisfaction with appearance-related products was not shared amongst all the women, particularly amongst the South Asian women who were more concerned about the function of the products and survival than the appearance of the products. While body image concerns were expressed, they were not the most prominent aspect of their experience; greater emphasis was placed on social support, and religion and spirituality (especially in study 3). In a similar manner, Howard et al's (2007) study of South Asian breast cancer survivors also did not discuss body image concerns at great lengths. It is possible that South Asian women may avoid attaching significance to their appearance because they hold conservative attitudes towards their body which are shaped by the cultural values of modesty and respecting the body (Bottorff et al, 1998).

Along with body image, issues pertaining to sexuality have been reported in some BME breast cancer studies (e.g. Ashing et al, 2003; Ashing-Giwa et al, 2007; Farmer & Smith, 2002; Im et al, 2002; Wilmoth & Sanders, 2001). In many BME cultures, any topics related to the female body are not considered appropriate to openly discuss, including menarche, sexual intercourse, infertility and menopause (Culley et al, 2007; Kim, 1993). Even when probed, intimate relationships and sexuality was not discussed, and often avoided, in any of the present qualitative studies. It is possible that the women did not have any concerns in this area or were not comfortable talking about personal issues around intimacy due to the taboos of talking about sexuality and private body parts (Bottorff et al, 1998; Watts et al, 2004; Wilmoth & Sanders, 2001).

6.4 Positive aspects of the experience

Despite the negative impact of breast cancer, positive aspects were also described by the women in all 3 studies, specifically in relation to a newfound outlook and appreciation of life. This attitude and re-assessment of one's life allows women to manage their experiences in a positive manner, which can improve their quality of life. This is also a common finding in other cancer research (Chen & Chang, 2011; Farmer & Smith, 2002; Jim, Richardson, Golden-Kreutz & Anderson, 2006). The concept

of taking control of the illness also helped many of the women accept and manage their situation in a positive light. This is discussed in more detail in the next section (end of section 6.5).

6.5 Cultural beliefs

The qualitative studies have shown how culture plays an influential role in shaping women's experiences of breast cancer. Support through religion and spirituality, and support groups from a cultural perspective have been discussed above. Additional to this, cultural beliefs and attitudes amongst the women and within their communities were also embedded in their experiences. These issues were centred on cultural taboos of cancer, modesty, and beliefs about the causes of cancer; based around religious explanations of fatalism and punishment from God. These cultural beliefs, values and explanations have been consistently reported in the BME breast cancer literature (Ashing-Giwa et al, 2004; Banning, 2011; Banning et al, 2009; Baron-Epel et al, 2004; Deepak, 2004; Gurm et al, 2008; Howard et al, 2007; Im et al, 2002; Watts et al, 2004). It is important to note that cultural influences are not just present in Black and South Asian communities but exist in other ethnic groups too, such as East Asian (e.g. Korean) and Middle Eastern Asian (e.g. Israeli) cultures (Ashing-Giwa et al, 2004; Baron-Epel et al, 2004; Im et al, 2002; Harandy et al, 2010; Taleghani, Yekta & Nasrabadi, 2006). These beliefs are particularly fixed in uneducated, first generation immigrants (Gurm et al, 2008) who despite living in the UK for most of their lives, continue to maintain their strong cultural beliefs and practices from their country of origin (Meneses & Yarbrow, 2007).

Within the western society, cancer as an illness is feared and is almost always associated with negative connotations such as grim, killer and death, especially if the illness is not well understood (Chapple, Ziebland & McPherson, 2004). Additional cultural taboos and stigma related to cancer exist in BME communities. For example, modesty and honour are highly valued in these cultures and a great emphasis is placed on the woman (particularly in the South Asian communities) to maintain the family's honour and reputation (Banning et al, 2009; Botorff et al, 1998). Therefore, it is not considered appropriate to openly talk about an illness which can compromise the family's status and honour and bring shame upon them. It is also not considered appropriate for women to talk about or show private body parts to others, especially males (Bottorff et al, 1998; Howard et al, 2007). This was evident with many of the South Asian participants who did not feel very comfortable when treated by male healthcare professionals.

In all 3 qualitative studies, the concept of control (or the loss of) determined the women's experiences and the way in which they managed this. This was defined by beliefs about the control they had over the cancer. The concept of locus of control has been identified as a crucial factor in determining how illnesses are viewed and managed (Bourjolly, 1999). When looking for causes of the cancer, majority of women held the belief that the cancer was predetermined by external forces such as God or chance (fatalistic attitude). High levels of external locus of control are prevalent in Black and South Asian cultures (Fischer et al, 2010; Gurm et al, 2008; Harandy et al, 2010). It has been suggested that fatalism is often associated with passive behaviours due to the belief that action will not influence the outcome (Sheppard, Adams, Lamdan & Taylor, 2011). This type of coping can have a negative emotional affect on the experience, especially if an attitude is based on the underpinnings of Karma and the cancer is seen as a form of punishment from God (Gurm et al,

2008). The belief that cancer is a form of punishment for bad deeds is common in ethnic minority cultures (Ashing-Giwa et al, 2004; Balneaves et al, 2007; Moore, 2001). Even if women do not believe, they are often subjected to negative comments from community members who insinuate they must have done something bad to deserve the cancer. This is another way that cancer is stigmatised in BME cultures, resulting in women covering up their illness. The women in the qualitative studies managed this by avoiding people who gossip and make negative and insensitive comments, and keeping the cancer private; a strategy found to be common in other BME and breast cancer studies (Gurm et al, 2008; Henderson et al, 2003b).

However, it is also possible that such beliefs (external locus of control and cultural beliefs) provide women with the opportunity to understand and accept the cancer and take control of the situation where possible (Chen & Chang, 2011; Deimling et al, 2006). This can involve making an adjustment to their lifestyle (i.e. diet, self re-interpretation – reflection and adopting of a positive outlook of life,) or through preparation (information seeking), resulting in positive and active ways of dealing with the illness (Chen & Chang, 2011; Royak-Schaler et al, 2008). It is also not surprising that external beliefs are prominent in ethnic minority women, given the importance placed on religion. This can also be actively managed in the form of prayers or meditation (from a spiritual perspective) in order to seek comfort and control of the situation (Gurm et al, 2008). Adopting adaptive behaviours while holding an external locus of control implies that individuals perceive that cancer can be controlled by external and internal sources, known as a vicarious control (Taylor, Lichtman & Wood, 1984). This was evident in the qualitative studies, where women came to realise that the cancer could not have been prevented but managed this loss of control in a positive manner. These findings concur with Chen and Chang (2011), who found that their Chinese cancer patients took control of the disease by changing their lifestyle and personal beliefs, which resulted in greater acceptance of the cancer.

6.6 Experiences unique to Indian women with LEP

In addition to the similar qualitative findings across the 3 studies, Indian women's (with LEP) experiences (study 3) were further influenced by their cultural barriers, which had an impact on their cancer knowledge and inability to communicate in English (discussed below). Firstly, the findings show that the women were not very expressive when sharing the emotional impact of their cancer experience, assuming a rather stoic role. Culturally, South Asian women should be seen to be modest, strong, tolerant, independent, and not show any signs of weakness that can harm their family's honour (Lipson, Dibble & Minarik, 1996). Therefore, there is a tendency for women to internalise their pain and grief and keep their emotions intact (Niaz & Hassan, 2006). This could explain why so many women found it hard to be emotionally expressive (see extracts in chapter 5; 5.3.3). Furthermore, stoicism is a common characteristic in many BME cultures (Feher & Maly, 1999; Howard et al, 2007). For example, Howard et al (2007) observed that their South Asian breast cancer participants often described their experiences in a stoic, 'just another illness' manner.

6.6.1 Limited cancer knowledge

The women in study 3 stated that before their breast cancer, they had very little knowledge and awareness about cancer. Research in this area has consistently found that South Asian immigrant

women lack adequate knowledge about cancer, and often internalise myths and inaccurate beliefs about cancer; particularly those who are not English literate, uneducated and less acculturated to the western ways of living (Ahmad, Gupta, Rawlins & Stewart, 2002; Ashing-Giwa et al, 2004; Bottorff et al, 2007; Howard et al, 2007; Meneses & Yarbrow, 2007; Sadler et al, 2001). Lack of knowledge in relation to other health conditions (such as cardiovascular disease and diabetes) has also been reported amongst South Asian populations (Darr, Astin & Atkin, 2008; Kandula et al, 2010; Rankin & Bhopal, 2001).

One of the reasons for this lack of understanding can be attributed to the cultural taboos and stigma associated with cancer (mentioned above), which result in such issues being covered up and not openly talked about (Bailey, Erwin & Belin, 2000; Scanlon & Wood, 2005). Another explanation can be due to the limited or non-availability of informational and educational material on breast health and cancer in one's mother-tongue language (Watts et al, 2004). The limited knowledge and understanding of breast cancer is conveyed in this study through some of the women who did not perceive a lump or ache in the breast area to be potentially serious. Whilst this shows their lack of awareness of breast cancer and symptoms, an alternative explanation can be that in the first instance their symptoms were not taken seriously as they may have attributed it to other factors such as muscle strain, and therefore waited before acting in the hope that the symptom will resolve itself (Bottorff et al, 2007).

6.6.2 Language barrier

Language barriers played a role in shaping the women's experiences. Firstly they contribute to the women's lack of understanding of breast cancer due to their inability or lack of confidence to communicate in English. This also resulted in the women being unable to gain full informational and emotional support from healthcare professionals, despite being satisfied by the care and support they received by them.

As well as receiving support from other cancer patients, the women in study 3 also voiced their concerns of not being able to ask questions or get further information from healthcare professionals because of the language barrier; resulting in the women taking a passive role. This finding has also been reported in the literature where patients with LEP have been found to value the importance of shared language in communicating with healthcare professionals and also in receiving printed information in their own language to aid their understanding of the illness (Ashing-Giwa et al, 2004; Blows et al, 2009; Gurm et al, 2008; Kumar et al, 2004). This can potentially explain why some of the women placed great trust in healthcare professionals to know what treatments are best for them, due to their own limited understanding of cancer.

Study 3 also reiterates the importance of family as a source of support. Family have been seen to be vital in breast cancer survivors' experiences due to the various types of support they provide. As well as support, family members were especially pertinent in the women's experiences as they were key in helping them overcome language barriers by acting as interpreters/translators during health consultations. It is interesting to note that only one woman was aware that professional interpreters can be requested, and that was after her cancer experience. It could be that professional interpreter services were less common and not as readily available during the time the women underwent their

experiences or healthcare professionals were not acutely aware of or knew how to access such services (Gerrish, 2001).

While family members are the preferred choice of interpreters (Grewal et al, 2005), it appears that healthcare professionals too rely on family members to act as translators (Gerrish, Chau, Sobowale & Birks, 2004). Using family members as interpreters may not always be the best thing for the patient as family members may not be very accurate when relaying the information between both parties. This is especially true for family members who were not highly fluent in English themselves yet were the only ones available to translate the information, and were more literate than the women. The accuracy of interpreters' translations has been discussed in part 2 of chapter 5.

Family members were also heavily involved in discussing treatment options and in the final decision making process. This involvement in the decision making process, whether it's a joint decision or the decision has been made solely by a family member, is common in ethnic minority communities as health issues are often seen as a family concern and therefore issues are dealt with together rather than treated as an individual matter (Howard et al, 2007). This may be especially true for patients with LEP as they place greater trust on those who are more educated and literate.

The importance of family members in communicating health information and their involvement in the treatment decision making process has been acknowledged in research with BME groups, particularly where patients with LEP are concerned (Bhakta, Katbamna & Parke 2000; Bottorff et al. 1998; Gerrish, 2001; Grewal et al, 2005; Gurm et al, 2008; Howard et al, 2007).

6.7 Conclusion

The qualitative studies provide meaningful insights into the psychosocial impact of breast cancer in Black and South Asian women, specifically from a cultural perspective. They add to the existing BME and breast cancer literature and offer valuable contributions and implications within the field of research and for healthcare professionals (discussed in chapter 8).

In summary, psychological, social and cultural influences were found to be important in shaping women's experiences. These included emotional impact throughout the cancer journey, role of family, religion and spirituality, support groups and various other sources of support, cultural beliefs and values, body image concerns, language barriers and knowledge/understanding of illnesses such as breast cancer. The aim of the qualitative findings was to inform the development of a questionnaire study. Therefore, aspects that were recurring findings in each of the qualitative studies (and also supported by the breast cancer literature) are further examined in study 4 on a larger BME and White population.

7 Study 4: Breast cancer experiences in White, Black and South Asian women

7.1 Introduction

This chapter presents the final study of this thesis.

While there is limited, albeit growing body of research exploring the psychosocial impact of breast cancer in BME women, quantitative research, particularly amongst South Asian breast cancer survivors in the UK is sparse (Paskett et al 2008; Roy et al, 2005; Russell et al, 2008). Existing studies have examined the relationship of ethnicity in relation to factors that impact breast cancer experiences (e.g. coping styles) and predominantly include American-based populations such as Black, White and/or Hispanics (Bourjolly & Hirschman, 2001; Bourjolly, 1998; Culver et al, 2002, 2004; Fogel et al, 2003; Schlebush & van Oers, 1999; Paskett et al, 2008; Pickler & Winterowd, 2003; Reynolds et al, 2000). For example, Culver et al (2004) compared coping patterns between Black, White and Hispanic breast cancer survivors, and found that religion was a commonly used coping strategy amongst Black and Hispanic women compared to White women. To date, the only known study that has included South Asian participants in their study was that of Roy et al (2005), who examined coping and adaptation to various types of cancers (including breast cancer) in South Asian and White patients and found that South Asian women held greater fatalistic attitudes and reported higher levels of depression than White women.

In order to gain a better understanding of Black and South Asian women's breast cancer experiences, it is important to explore the ways in which psychosocial and cultural factors affect quality of life. While there is no one agreed definition of quality of life (Fallowfield, 2009), it is generally described as a multidimensional concept that encompasses physical, emotional, social, psychological, spiritual and financial well-being (Paskett et al, 2008). Findings from the qualitative phase of this thesis highlighted important psychological, social and cultural factors that influenced women's experiences of breast cancer. These include psychosocial functioning, social support, body image concerns, social comparison tendencies, beliefs about cancer, healthcare experiences and cultural issues, all of which can affect quality of life. These issues were used to develop a questionnaire that can be measured with a larger sample so that appropriate comparisons (within and across groups) and generalisations can be made. The use of qualitative findings is thought to be a useful strategy in developing high quality survey questions (Morgan, 1998). Therefore, the final part of this thesis took on a quantitative research approach in order to gain a comprehensive understanding of the psychosocial impact of breast cancer in BME women, via triangulation, complementarity and development of the findings from the previous studies (as detailed in chapter 2). As well as examining differences within the ethnic minority group, differences between ethnic minority and White breast cancer survivors, who comprise the majority (87.9%) of the UK population (Office for National Statistics, 2011b), will also be examined. Comparing experiences with the White population can help to see where the differences exist and how this can be improved in order to ensure all cancer patients are provided with appropriate care and support.

The objectives of this study were to:

- Determine predictors of quality of life (*including demographic, breast cancer and psychosocial variables*).
- Examine similarities and differences in breast cancer experiences amongst Black, South Asian and White breast cancer survivors.

7.2 Method

7.2.1 Design

This study took on a cross-sectional, mixed method design via a questionnaire that utilised both open and closed ended questions; placing greater emphasis on the quantitative aspect (QUAN + qual). This design was adopted as it is the quickest and most convenient method to collect data when conducting research with a large sample size. Furthermore, it is hoped that this research will influence stakeholders such as policy makers, funding bodies and practitioners to improve patients' healthcare experiences, and therefore, this design is more likely to be perceived as credible as they prefer to deal with large data, based on statistical facts. Open ended questions were used to expand understanding of issues relating to language barriers and appearance related products (such as wigs, scarves and prosthesis), in a way that can be easily quantified. The use of open ended questions as an adjunct to the closed ended questions was chosen to give participants the opportunity to elaborate on their responses (Reja, Manfreda, Hlebee & Vehovar, 2003).

7.2.2 Designing the questionnaire

The design of the questionnaire was based on findings from the previous qualitative studies and the previous literature. It was evident from the findings of studies 1, 2 and 3 that the diagnosis and treatment of breast cancer was a distressing time for everyone (psychological impact). The themes within these studies revealed the importance of support (through family, friends, healthcare professionals, support groups and religion/spirituality) and the negative affect that treatment had on women's body image (social impact). Cultural beliefs and values, and language barriers also influenced women's experiences (cultural impact). These aspects were therefore deemed important to further investigate through a questionnaire. Table 7.1 illustrates how the findings from the qualitative phase of this research informed the development of the questionnaire (QUAL → quan). Relevant standardised measures were selected for the majority of the questionnaire, while other aspects included self-constructed items if suitable standardised measures were not available. Advice was sought from various breast cancer support group members/facilitators during the development of the questionnaire to assess its feasibility. The choice of measures is justified in section 7.2.3.

Table 7.1: Qualitative findings informing design of the questionnaire (QUAL → quan)

Key findings from qualitative studies		Quantitative measures
Psychological impact	Psychological distress	Hospital Anxiety and Depression Scale
Social impact	Support: Sources	Self-constructed items
	Social comparison	Identification-Contrast Scale
	Body image Appearance-related products	Body Image after Breast Cancer Questionnaire Self-constructed items
Cultural impact	Beliefs about cancer	Multidimensional Health Locus of Control God Health Locus of Control
	Healthcare experience (e.g. language barriers, gender of healthcare professional)	Self-constructed items
Outcome variable	Quality of life	Functional Assessment of Cancer Therapy-General

The questionnaire (appendix 18) was available to complete on paper or online. An online option was included to increase participation (Sax, Gilmartin & Bryant, 2003). It was designed using the software Qualtrics and a simplified web address was provided to access the questionnaire online: tinyurl.com/breastcancerstudy.

The questionnaire comprised nine sections and took approximately 30-45 minutes to complete. As a number of psychosocial factors were being examined, keeping the questionnaire as short as possible was a priority to ensure that potential participants would not be deterred by the length of the questionnaire. However, it was also important to cover the topics in as much as detail as possible. Therefore, a lot of thought was put into choosing appropriate measures. These are listed below, along with a rationale for the selection of each measure.

7.2.3 Measures

7.2.3.1 Demographic information

The following demographic information was collected: age, city/town of residence, employment status, marital status, education background, ethnic identity (as defined by the 2011 UK census), religious beliefs, languages spoken and generation status (whether they were first generation immigrants or second generation Britons (information on generation status was collected for the Black and South Asian women only).

7.2.3.2 Breast cancer Information

The following breast cancer information was collected: type of breast cancer, time since diagnosis, types of surgical and adjuvant treatment(s), family history of breast cancer, way in which the cancer was found and information about lymphoedema.

7.2.3.3 Quality of Life

Quality of life was assessed via the Functional Assessment of Cancer Therapy - General (Version 4; FACT-G; Cella et al, 1993) measure. This measure consists of 27 items, based on a 5-point likert scale ranging from 0 (not at all) to 4 (very much). Participants are asked to base their answers on how they have felt over the last 7 days. There are 4 sub-scales: physical well-being (7 items), social/family well-being (7 items), emotional well-being (6 items) and functional well-being (7 items). Each sub-scale can be summed to give an overall quality of life score; the higher the score, the better the quality of life. Internal consistency (as measured by Cronbach's alpha; Chronbach, 1951) of the sub-scales is as follows: Physical well-being ($\alpha = 0.88$), social/family well-being ($\alpha = 0.87$), emotional well-being ($\alpha = 0.76$) and functional well-being ($\alpha = 0.90$).

The European Organization for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ-C30; Aaronson et al, 1993) and its breast cancer specific questionnaire (EORTC QLQ-BR23; Sprangers et al, 1996), and the FACT-G are the most common, well developed and widely used instruments to measure quality of life in breast cancer patients (Montazeri, 2008). The FACT-B includes an additional breast cancer sub-scale (10 items). Items on this sub-scale are mostly based around appearance. This is an important aspect and has been explored in detail in another section of the questionnaire (appearance concerns). Therefore to avoid repetition of similar items, FACT-G was chosen. While the FACT-G and EORTC QLQ-30 include similar items to assess quality of life, the FACT-G was shorter, especially if the EORTC QLQ BR23 was to be included (comprising of 53 items compared to 27 or 37 items with the FACT-G or FACT-B, respectively).

An additional question was included to assess overall quality of life on a scale ranging from 1 (very poor) to 10 (excellent).

7.2.3.4 Social support

Instruments such as the short form Supportive Care Needs Survey (SCNS-SF34; Boyes, Girgis & Lecathelinais, 2009) and the Sources of Social Support Scale (SSSS; Carver, 2000), have both been used with cancer patients (Carver, 2000; Kinsinger et al, 2011; Siegel et al, 2007; Smith et al, 2007) and were considered for this study. However, the SCNS-SF34 assesses support needs on a range of domains such as psychological, health, informational, physical, sexuality, patient care and support needs and has many items ($n=34$), whereas the present study wanted to simply assess the different sources of support that are available for various aspects of support. While the SSSS measures support in this manner, the items and sub-scales were not deemed appropriate for the present study. For example, the SSSS measures emotional, informational, practical and negative support, and

more emphasis is placed on emotional support from 5 different sources (husband/partner, adult women in the family, other family members, friends and healthcare professionals). It does not consider other sources such as work colleagues, community groups or support groups.

Therefore, based on previous support measures, social support for the present study was measured using self-constructed, non-validated items. This was divided into 2 sections: support from support groups and different types of support from various sources.

Support groups

This section comprised of 3 questions. The first asked whether support via groups/networks such as Breast Cancer Care were sought. There was the option to list up to 3 support networks. For each group/network accessed, participants were asked to a) rate how helpful this was, on a scale ranging from 1 (not at all helpful) to 10 (very helpful), and b) state how they heard about them. Those who did not access any networks/groups were asked to select reasons for not doing so, from a list of 6 items (including an 'other' option – where additional reasons could be listed).

Sources of support

Participants were asked to select all the sources of support that had provided them with overall support and to rank these sources in order of supportiveness, whereby 1 was the most important (9 sources were listed: family, husband/partner, friends, work colleagues, religion/spirituality, cancer support networks/support groups, community groups, healthcare professionals and an 'other' option was provided). These sources were derived from the findings of the qualitative studies.

The next section included 5 different types of support (practical, emotional, informational, financial and moral) with 10 options (family, husband/partner, friends, work colleagues, cancer support networks, community groups, healthcare professionals, nobody, support not needed, other). Participants were required to select as many sources that provided them with each type of support.

Finally, a question to assess overall support during the breast cancer experience was measured via a scale ranging from 1 (not at all supported) to 10 (very well supported) was included.

7.2.3.5 Psychological functioning

Psychological measures such as the Beck Depression Inventory (BDI; Beck, 1961), Center for Epidemiologic Studies Depression Scale (CES-D; Radloff, 1977) and Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983) have been widely used and validated in cancer patients (Alexander, Palmer & Stone, 2010; Carroll, Kathol, Noyes & Wald, 1993; Carver & Antoni, 2004; Land et al, 2006; Love et al, 2001; Mitchell, Meader & Symonds, 2010; Montazeri, 2008; Moorey et al, 1990). Other instruments that have commonly assessed psychological functioning in cancer patients include the Profile of Mood States (POMS; McNair, Lorr & Droppleman, 1971) and the Mental Adjustment to Cancer scale (MAC; Watson et al, 1988).

All of these measures were considered for the present study. However, the measure felt to be most appropriate was the HADS. This was because a) the HADS has fewer items than the other measures

(14 items compared to BDI – 21 items, CES-D – 20 items, POMS short form – 37 items and MAC short form – 29 items), and b) the HADS covers 2 important areas of psychological functioning: depression and anxiety, whereas the BDI and CES-D scales measure depression only and it was felt that the MAC scale was more a measure of coping with cancer than psychological functioning.

The HADS consists of 14 items with 2 sub-scales (anxiety and depression, 7 items each). Participants are asked to base their answers on how they have felt over the last 7 days. Each item is rated on a 4-point likert-type scale ranging from 0 to 3. Each item of the sub-scales can be summed to give an overall score (scores range from 0-21 for each sub-scale). Internal consistency of the sub-scales is as follows: Anxiety ($\alpha = 0.84$) and Depression ($\alpha = 0.83$). Cut off values, determined by Zigmond and Snaith (1983), were used to indicate clinical levels of depression and anxiety. Scores between 0-7 are regarded as being in the normal range (not clinically significant), 8-10 as 'borderline' distress and 11+ as 'case' level, indicating severe levels of distress.

7.2.3.6 Social comparison tendencies

This was measured via the Identification-Contrast Scale (ICS; Van der Zee et al, 2000), a scale developed to measure four social comparison processes (upward identification, upward contrast, downward identification and downward contrast). This scale was used because social comparison is more complex than individuals simply engaging in upward or downward comparisons. Buunk and Ybema's (1997) identification model proposes that the types of comparison that individuals engage in are dependent on whether or not they identify with the comparison target, which in turn can determine whether the comparison is positively or negatively interpreted. Therefore, it was important to understand the type of comparisons that participants engaged in. The measure has been validated within various contexts, including cancer (Van der Zee et al, 2000; Van der Zee et al, 1999, Brakel, Dijkstra & Buunk, 2012), burnout amongst teachers (Carmona et al, 2006), students (Chayer & Bouffard, 2010) and in patients with spinal cord injury (Buunk, Zurriaga & González, 2006).

The measure consists of 12 items with 4 sub-scales: upward identification, upward contrast, downward identification and downward contrast – and there are 3 items in each sub-scale. Although a generic measure, the scale can be easily adapted, thus participants were asked to base their comparisons with other cancer patients. Each item is rated on a 5 point likert-type scale, ranging from 1 (strongly disagree) to 5 (strongly agree). Each item of the sub-scales can be summed to give an overall score (scores range from 0-15 for each sub-scale). Higher scores indicate greater levels of engaging in a social comparison behaviour pertaining to each sub-scale. Internal consistency of the sub-scales is as follows: upward identification ($\alpha = 0.92$), upward contrast ($\alpha = 0.88$), downward identification ($\alpha = 0.93$) and downward contrast ($\alpha = 0.83$).

7.2.3.7 Beliefs about cancer

Beliefs (including religious beliefs) and attitudes towards how much control one feels they have over their cancer was determined by measuring Locus of Control (LOC). This was assessed via the widely used Multidimensional Health Locus of Control (MHLC-Form C (a condition specific measure of LOC;

Wallston, Stein, & Smith, 1994) and the God Health Locus of Control (GHLOC – an adjunct to the MHLC; Wallston et al, 1999) scales. The MHLC-Form C consists of 18 items with 4 sub-scales: internal (ILOC; 6 items), chance (CLOC; 6 items), doctors (DLOC; 3 items), and other people (OPLOC; 3 items). Each item is rated on a 6 point likert-type scale, ranging from 1 (strongly disagree) to 6 (strongly agree). The items can be summed to give an overall score for each sub-scale. The higher the score, the greater the beliefs pertaining to each sub-scale. Internal consistency of the sub-scales is as follows: internal ($\alpha = 0.67$), chance ($\alpha = 0.76$), doctor ($\alpha = 0.45$) and other people ($\alpha = 0.69$). As the alpha coefficient for the DLOC sub-scale was below 0.60 and therefore an unacceptable value (DeVellis, 1991), it was not used in subsequent analysis.

It has been recognised that control beliefs attributed to chance and other people are not the only concepts that can determine external LOC. Spirituality is another factor that can be attributed to an external LOC, particularly in populations where the role of religion is embedded in their health concerns and experiences (Banning et al, 2009; Gurm et al, 2008; Henderson et al 2003b; Howard et al, 2007; Holt, Clark, Kreuter & Rubio, 2003). Religion was a recurring theme in all the qualitative studies of this thesis, therefore it was deemed important to include this additional scale. The GHLOC consists of 6 items, which were interspersed with the MHLC items. Thus, the response rating and scoring system was the same as the MHLC. The internal consistency was $\alpha = 0.94$.

The validity of both these scales has been evidenced within various contexts and health conditions such as cancer (including breast cancer), diabetes, arthritis and pain (Bourjolly, 1999; Chaplin et al, 2001; Naus, Price & Peter, 2005; Wallston et al, 1994; Wallston, 2005).

7.2.3.8 Appearance concerns

This aspect was divided into 2 areas: assessment of body image concerns (assessed via a validated measure) and concerns regarding the appearance and cultural suitability of products such as wigs (assessed via self-constructed items).

Body image concerns

There are 2 well known validated measures used to assess body image in breast cancer patients: Body Image Scale (BIS; Hopwood, Fletcher, Lee & Al Ghazal, 2001) and the Body Image after Breast Cancer Questionnaire (BIBCQ; Baxter, 1998). Both measures are highly reliable and have been widely used (Baxter et al 2006; Chen et al, 2010; Metcalfe, Esplen, Goel & Narod, 2004; Moreira, Silva, Marques & Canavarro, 2009; Zhang, Liu & Jin, 2011). For this study, body image concerns were assessed via the BIBCQ, a tool designed to specifically measure the long term impact of breast cancer on body image.

Despite the BIS being a brief (10 items) and robust measure that is applicable to all cancer patients in both clinical and research settings (Moreira et al, 2009), the BIBCQ was chosen because of its comprehensiveness and thoroughness in assessing important and multidimensional components of body image in breast cancer patients (Baxter et al, 2006). The BIBCQ consists of 53 items, which are based on a 5 point likert scale. Participants are asked to base their answers on how they have felt over the last month. The measure is broken down into 2 response categories: ranging from 1

(strongly disagree) to 5 (strongly agree) and 1 (never/almost never) to 5 (always/almost always). The questionnaire has 6 sub-scales: vulnerability (feelings of susceptibility of the body to the cancer), body stigma (feelings of wanting to keep the body hidden and to avoid physical intimacy), limitations (feelings about competence and ability of the body), body concerns (feelings of satisfaction with their body shape and appearance), transparency (obviousness of cancer-related changes on the appearance) and arm concerns (symptoms and concerns about the appearance of the arm). The sum of the items on each sub-scale can be used to determine an overall score of body image concerns. The higher the score, the greater the level of body image concerns. The flexibility of this measure means that not all the sub-scales need to be administered at the same time. For this study 3 sub-scales were used: body stigma (11 items), transparency (5) and arm concerns (4 items). These 3 sub-scales were used because the items pertain to the relevant body image concerns that were pertinent to the breast cancer survivors who participated in the qualitative studies. Furthermore, the arm concerns sub-scale is a unique component to measure body image in breast cancer patients, particularly for those who experience lymphoedema as a result of their treatment. Internal consistency of the sub-scales is as follows: body stigma ($\alpha = 0.89$), transparency ($\alpha = 0.78$) and arm concerns ($\alpha = 0.77$).

Appearance-related products

This section was self-constructed by the researcher, based on the comments made by breast cancer survivors in the qualitative studies and feedback from support group facilitators. Seven products that women may have used as a result of their breast cancer treatment were listed. These included: wigs, scarves, breast prosthesis, lymphoedema sleeve, make-up, lingerie/swimwear and an 'other' option. The questions included open and closed ended responses. Participants were asked to select as many of the products that they used/are using and answer 3 questions: where they got the product from (close ended: NHS/Self-bought/other), satisfaction with the product (closed ended: on a scale ranging from 1, very dissatisfied to 10, very satisfied), and to state their overall opinion of the product in relation to meeting their cultural needs (open ended).

7.2.3.9 Healthcare experience

Healthcare experiences in relation to support and cultural issues were measured via self-constructed, non-validated items. This was in the form of 8 questions and was divided into 3 sections: healthcare support, gender of healthcare professionals and healthcare issues in relation to language barriers.

Healthcare support

Participants were asked:

1. About the type of health care they received (NHS care, private care or both).
2. About the type of support received; via 5 self-constructed items, which were assessed on a 5 point likert scale, ranging from 1 (strongly disagree) to 5 (strongly agree).

3. To select a healthcare professional whom they were mainly in contact with (breast care nurse, consultant or both) and describe how supportive this person was from a range of 18 positive and negative adjectives such as caring, sympathetic, distant and rude (there was an option to include additional words). The adjectives were derived from the comments made by women in the qualitative studies (studies 1-3; chapters 3-5).
4. To report their overall satisfaction with the health care that they received, on a scale ranging from 1 (very dissatisfied) to 10 (very satisfied).

Gender of healthcare professional

5. Whether they were treated mostly by male staff, female staff or both (equally).
6. Whether they had a preference in whom they were treated by, and if so the gender of the healthcare professional by whom they would have preferred to be treated by.
7. To explain their reasons for having a preference or not, in an open ended question.

Language (*this section was for women whose first language was not English*).

8. Whether breast cancer information was provided in their mother-tongue language. If 'yes' was selected, participants were asked to rate the usefulness of this information on a scale ranging from 1 (not at all helpful/useful) to 10 (very helpful/useful), and to explain their reasons with an open ended response. If 'no' was selected, participants were asked if they would have liked to receive information in their mother tongue language.

7.2.4 Recruitment strategy

A range of strategies were undertaken to maximise recruitment. As the BME population can be hard to reach, it was important to maximise sampling strategies and gain a diversity of participants (Ashing-Giwa et al, 2004).

Firstly, a method of snowball and chain referral sampling were adopted. This included approaching participants and support groups who had participated and helped with recruitment for the qualitative studies. After interviewing participants in the first 2 qualitative studies, they were asked if the researcher could keep their details and contact them to participate in future studies. Those who had given permission were contacted to see if they would be interested in taking part in the present study and if they knew other breast cancer survivors who might also be interested in participating. Support group gatekeepers were either contacted by telephone to discuss recruitment or sent a letter outlining the objective and their role if they supported this study. The latter was followed up by a telephone call.

Support groups in cities with a high ethnic minority population were approached: Asian Women's Breast Cancer Group (AWBCG; London), Cancer Black Care (CBC; London), Paul D'auria Cancer support (London), Cancer You Are Not Alone (CYANA; London), White House – Cancer support centre (Dudley), Haven (London, Leeds and Hereford), Coping with Cancer (Leicester), Breast Cancer Care (London) and Asian Cancer support group (London). All the support groups agreed to help with

recruitment. 10 questionnaire packs were sent to each support group, except Breast Cancer Care and Haven. Haven agreed to display posters (appendix 19) advertising the study in their 3 centres and Breast Cancer Care (after gaining approval) allowed the researcher to gain access to their service users via Breast Cancer Voices. Breast Cancer Voices comprises of a group of breast cancer survivors. Thus the study was advertised calling for eligible breast cancer survivors to take part via their website and monthly newsletter.

Secondly, NHS sites across England, in cities with a high ethnic minority population were approached. Researchers/healthcare professionals who have an interest in researching ethnic minority communities were approached to act as gatekeepers to access a main consultant who would be interested in supporting this project. Key gatekeepers such as consultants were then emailed a letter requesting their assistance in helping to identify potential patients to take part in the study, and an information sheet which outlined the details of the study and their role in the research process. This method resulted in 5 sites agreeing to support the study, namely: Frenchay Hospital, Bristol (North Bristol Trust); Avon Primary Care Research Collaboration (NHS Bristol); University Hospital, Coventry (University Hospital Coventry and Warwickshire); Ealing Hospital, Middlesex (Ealing Trust) and Northwick Park Hospital, London (North West London Hospitals trust).

The study was also eligible to be included in the National Institute for Health Research (NIHR) portfolio and therefore the study was advertised on the National Cancer Research Network (UKNCRN). This resulted in a number of research nurses contacting the researcher, thus recruitment took place at an additional 5 sites: Hillingdon Hospital, London (Hillingdon trust), Good Hope Hospital, Sutton Coldfield (Heart of England Foundation trust; HEFT), Birmingham Heartland Hospital, Birmingham (HEFT), City Hospital, Birmingham (Sandwell & West Birmingham trust) and Bradford Royal Infirmary, Bradford (Bradford Teaching Hospitals NHS Foundation trust). Information about the number of questionnaire packs that were sent to each trust, distributed by the research nurses and the number of returned questionnaires is presented in table 7.2.

Table 7.2: Distribution of the questionnaire packs through NHS sites

NHS Site	Questionnaires			
	Sent (n)	Distributed (n)	Returned (n)	Response rate (%)
Frenchay Hospital, Bristol	50	50	17	34
Avon Primary Care, Bristol	1	1	1	100
University Hospital, Coventry	180	129	60	47
Ealing Hospital, Middlesex	81	81	5	6
Northwick Park Hospital, London	140	98	29	30
Hillingdon Hospital, London	30	10	1	10
Good Hope Hospital, Sutton Coldfield	60	Unknown	7	-
Birmingham Heartland Hospital, Birmingham	30	22	3	14
City Hospital, Birmingham	55	39	9	23
Bradford Royal Infirmary, Bradford	30	21	3	14
Total	657	451	135	
Mean response rate				28

Recruitment via the media was also sought, where local and national press releases of the study were distributed and featured in papers such as the Bristol Evening Post. The press releases were also picked up and further promoted on a number of local radio stations, including BBC radio (Asian hour) and Jack FM. This method generated some interest, with 6 (4 White, 1 Black and 1 South Asian) women contacting the researcher for further information. Posters advertising the study were also disseminated at various cancer and ethnicity and health related conferences and workshops. Information about the study was also posted online on the Minority Ethnic Health Jiscmail forum.

Other measures were taken to increase response rates. For example, letters were personalised, a stamped addressed envelope was provided and the questionnaire was available to complete on-line or on paper (Edwards et al, 2002).

7.2.5 Participants

7.2.5.1 Eligibility criteria

The eligibility criteria to participate in this study are outlined below.

Inclusion criteria:

- English speaking/literate women, aged 18 and above,
- Of White, Black or South Asian ethnicity and
- Diagnosed with primary breast cancer and between 6 months and 5 years, post diagnosis.

Exclusion criteria:

- Women with secondary breast cancer: A local recurrence (in the treated breast or near the mastectomy scar) or distant metastasis (somewhere else in the body).
- Women who are less than 6 months post diagnosis and still undergoing treatment (i.e. chemo or radio-therapy).
- Women who are unable to read and speak in fluent English.

Women who do not adequately speak, read or write in English were excluded in this study as it was not possible to translate the questionnaire in the variety of South Asian languages that exist. Also, translating the questionnaire from one language to another may effect the psychometric properties of some of the standardised measures; particularly when certain words such as 'cancer' do not exist in many South Asian languages (Bottorff et al, 1998).

Women needed to be more than 6 months post diagnosis as this time frame would give women time to come to terms with their cancer diagnosis. Women still undergoing treatment and women with secondary cancer were excluded as this would have an impact on the way they complete the questionnaire. A maximum time frame of 5 years post diagnosis was determined as 5 years is the commonly reported survival rate (Cancer Research UK, 2011) and thus women's experiences of breast cancer beyond 5 years may differ as they may believe they are free from the disease.

Furthermore, care and treatment provided may change over time. This will be consistent amongst women who were diagnosed within the last 5 years and therefore appropriate comparisons within the breast cancer population can be made.

7.2.5.2 Sample size

A minimum of 120 participants (40 in each group) were needed in order to run appropriate statistical tests. This number is based on Cohen's (1988) values of alpha (0.05), power (0.80) and a medium effect size (0.25), which are deemed appropriate when multiple variables are involved. This was calculated on the software program GPower.

185 women completed the questionnaire. However, 12 of these responses were omitted as they did not meet the eligibility criteria (2 women did not report their ethnic identity, 4 women described their ethnic identity as East Asian (namely Filipino and Chinese), 3 women reported having breast cancer which exceeded the 5 year time frame, and 3 women reported having secondary breast cancer). Therefore, a total of 173 eligible breast cancer survivors took part in the study. 159 (92%) women completed the paper version and 14 (8%) women completed the online version of the questionnaire. Participants' demographic information is presented in greater detail in the results section.

78% of the women were recruited through the NHS, 13% via support groups (mainly CBC, AWBCG and White house) and 9% were recruited via other means (mentioned in 7.2.4). The majority of the women recruited via support groups were South Asian (19%) and Black (15%) compared to 9% of White women. 81%, 76% and 73% of the White, South Asian and Black (respectively) women were recruited via the NHS.

Participant response rates cannot be determined as other people (i.e. support group facilitators) were involved in the recruitment process. Therefore, it was difficult to keep an account of how many questionnaires were distributed via support groups and how many of these were returned. Whereas a record of the number of questionnaires distributed and returned via the NHS were recorded. Given the information provided by the healthcare professionals, an approximate average response rate between the 10 Trusts can be inferred to be 28%.

7.2.6 Ethics approvals

Ethical approval was obtained from the South West Research Ethics Committee, Bristol (via the Integrated Research Approval System; IRAS) and School of Life Sciences Research Ethics Committee at the University of the West of England, Bristol. Approval from Research and Design (R&D) for each participating NHS site was sought. Relevant paperwork specific to individual R&D guidelines, such as data protection and honorary contracts were also obtained. Through the IRAS system to gain NHS ethical approval, the study was also submitted to the NIHR system and granted approval to be included in their portfolio. Approval was also sought from individual organisations such as Breast Cancer Care.

7.2.7 Data collection

Data was collected for one year, from September 2010 to September 2011.

The questionnaire pack included: a letter inviting the participant to take part (depending on how the participant was recruited, the letter was either from the researcher, support group gatekeepers or a healthcare professional, such as the patient's consultant or breast care nurse), participant information sheet, the questionnaire booklet, a form to provide name and contact details if they were interested in hearing about the findings of the study and a stamped addressed envelope for which the completed questionnaire could be returned (appendix 18, 20-23).

Eligible participants were sent a questionnaire pack directly from the researcher or the support group gatekeepers, who agreed to help with recruitment.

Participants who were interested in taking part and had heard about the study via radio shows, newspaper articles or newsletters contacted the researcher. The researcher explained the study in more detail, ensured they were eligible to participate and sent out a questionnaire pack.

7.2.7.1 NHS Trusts

For the majority of the sites (8/10), a team of research and Macmillan nurses identified potential and eligible patients from their patient records (via their names, as ethnicity is not routinely recorded) and either sent them a questionnaire pack by post or personally distributed the questionnaire packs during outpatient clinics. For 2 of the sites, hospital staff were too busy to help with recruitment. Therefore, the researcher attended the hospitals and identified potential participants (via their names). Permission was sought to access patient records. The list of names were then approved by the research nurse and consultants to ensure patients were eligible (i.e. English speaking, free from recurrence and to ensure there was no other reason that patients should not be contacted). Eligible patients were then sent the questionnaire packs from the hospital grounds. As the responses needed to be entered on the NIHR portfolio, a label stating the name of the trust was placed on the back of each questionnaire to make it easier to record the number of responses from each trust.

All the questionnaire responses were anonymous. Data was then entered and analysed on the statistical program, SPSS (version 19).

7.3 Results

Participants who wanted to know about the results of this study (and expressed so by providing their contact details; appendix 23) were sent a summary of the key findings (appendix 24).

7.3.1 Data analysis

7.3.1.1 Quantitative data

Interval and nominal numerical data was collected, thus appropriate statistical tests were performed accordingly. To ensure parametric tests can be conducted, assumptions were explored by checking the distribution of the variables, using the Kolmogorov-Smirnov test and by examining histograms for each group. The test and graphs showed that the majority of the variables were not normally distributed ($p < 0.05$). However, parametric tests are often robust and therefore unaffected by violations of assumptions (Norman, 2010). This is further supported by the central limit theorem which states that with large enough samples of $n > 30$, the rate at which the sampling distribution approaches normal increases (Field, 2009). Furthermore, the data was checked for outliers by examining boxplots. No large numbers of outliers were detected; however, the few that were observed were tested using z-scores. All the variable scores were between -3.29 and 3.29, giving confidence that the data was free from any major outliers. Therefore use of parametric tests are justified.

7.3.1.2 Qualitative data

Responses to the open ended questions were analysed via content analysis, using a deductive approach at a manifest level (a less interpretive approach, staying close to the surface of the text). Content analysis is a common method used to analyse qualitative data in health research (Elo & Kyngas 2007). This type of analysis allows researchers to examine large volumes of data in a systematic and objective way by identifying concepts or categories which can be quantified and analysed using statistics (Hsieh & Shannon, 2005; Shields & Twycross, 2008). Deductive content analysis is used when the coding of the data is based on previous knowledge or research, with the goal to extend and support existing research (Hsieh & Shannon, 2005). In this case the coding of the data was initially guided by the findings from the previous qualitative studies. It is for this reason that deductive content analysis was believed to be an appropriate method of analysis.

The open-ended responses were studied in detail and key concepts were identified as initial codes. Similar responses were coded and then quantified by counting the frequency of the codes. This was further organised by ethnicity.

To avoid researcher bias, the coded data was checked by a second independent researcher, familiar in using content analysis, and discussed until both researchers were in agreement of the codes (Woods, Priest & Roberts, 2002).

7.3.2 Descriptive data

Participant demographic and breast cancer information are summarised in tables 7.3 and 7.4.

Table 7.3: Study 4: Demographic information (n = 173)

n (%)	Whole group 173 (100)	White 80 (46)	Black 40 (23)		South Asian 53 (31)	
Age						
Mean (range) in years	58 (32 – 81)	61 (41-78)	57 (32-81)		55 (36-71)	
Ethnic identity n (%)						
White	80 (46)	80 (100)	Caribbean	39 (98)	Indian	42 (79)
Black	40 (23)		African	1 (2)	Pakistani	10 (19)
South Asian	53 (31)				Bangladeshi	1 (2)
Residence n (%)						
Bristol	21 (12)	15 (71)	3 (14)		3 (14)	
London	50 (29)	1 (2)	17 (34)		32 (64)	
West Midlands	33 (19)	11 (33)	16 (48)		6 (18)	
Warwickshire	60 (35)	48 (80)	4 (7)		8 (13)	
Other	9 (5)	5 (56)	0 (0)		4 (44)	
Employment status n (%)						
Full time	42 (24)	20 (48)	10 (24)		12 (29)	
Part time	29 (17)	14 (48)	3 (10)		12 (41)	
Self-employed	7 (4)	3 (43)	2 (29)		2 (29)	
Student	2 (2)	0 (0)	2 (100)		0 (0)	
Retired	67 (39)	39 (58)	15 (22)		13 (19)	
Unemployed	14 (8)	1 (7)	6 (43)		7 (50)	
Other	11 (6)	3 (27)	2 (18)		6 (55)	
Marital status n (%)						
Single	19 (11)	2 (11)	13 (68)		4 (21)	
In a relationship	8 (5)	5 (63)	3 (38)		0 (0)	
Married	102 (60)	54 (53)	10 (10)		38 (37)	
Separated	5 (3)	0 (0)	4 (80)		1 (20)	
Divorced	14 (8)	6 (43)	3 (21)		5 (36)	
Widowed	22 (13)	12 (55)	6 (27)		4 (18)	

NB: Total percentages will not always equal 100 because figures have been rounded up to the nearest whole number.

Table 7.3 continued

	n (%)	Whole group 173 (100)	White 80 (46)	Black 40 (23)	South Asian 53 (31)
Education level	n (%)				
GCSE		44 (26)	27 (61)	6 (14)	11 (25)
A-Level		11 (6)	9 (82)	1 (9)	1 (9)
Diploma		36 (21)	10 (28)	14 (39)	12 (33)
Undergraduate		29 (17)	11 (38)	9 (31)	9 (31)
Postgraduate		12 (7)	6 (50)	1 (8)	5 (42)
No qualification		38 (22)	16 (42)	9 (24)	13 (34)
Religious belief	n (%)				
Christian		94 (55)	63 (67)	28 (30)	3 (3)
Buddhist		2 (1)	0 (0)	1 (50)	1 (50)
Jewish		2 (1)	2 (100)	0 (0)	0 (0)
Hindu		27 (16)	0 (0)	0 (0)	27 (100)
Sikh		9 (5)	0 (0)	0 (0)	9 (100)
Muslim		11 (6)	0 (0)	0 (0)	11 (100)
No religious belief		14 (8)	11 (79)	3 (21)	0 (0)
Other beliefs		12 (7)	4 (33)	7 (58)	1 (8)
Mother-tongue language	n (%)				
English		129 (75)	80 (62)	40 (31)	9 (7)
Gujarati		22 (13)	0 (0)	0 (0)	22 (100)
Punjabi		10 (6)	0 (0)	0 (0)	10 (100)
Urdu		8 (5)	0 (0)	0 (0)	8 (100)
Bengali		3 (2)	0 (0)	0 (0)	3 (100)
Tamil		1 (1)	0 (0)	0 (0)	1 (100)
Generation status	n (%)				
1 st generation immigrants		72 (79)	0 (0)	28 (39)	45 (63)
2 nd generation Britons		19 (21)	0 (0)	12 (63)	7 (37)
Time in the UK					
Mean (range) in years		36 (8-56)	-	39 (8-56)	34 (10-50)
Country of origin	n (%)				
South Asia (India, Pakistan & Sri Lanka)		22 (31)	0 (0)	0 (0)	22 (100)
East Africa (Kenya, Uganda, Malawi & Tanzania)		21 (30)	0 (0)	0 (0)	21 (100)
Caribbean Islands (Jamaica, Barbados, Trinidad & West Indies)		25 (35)	0 (0)	25 (100)	0 (0)
West Africa (Nigeria & Ghana)		3 (4)	0 (0)	3 (100)	0 (0)

NB: Total percentages will not always equal 100 because figures have been rounded up to the nearest whole number.

Table 7.4: Study 4: Breast cancer information (n = 173)

	Whole group 173 (100)	White 80 (46)	Black 40 (23)	South Asian 53 (31)
Time since diagnosis mean (range) in months	29 (6 – 60)	29 (6 – 60)	29 (6 – 60)	29 (6 – 60)
Family history of breast cancer n (%)	43 (25)	20 (47)	14 (33)	9 (21)
Cancer detection n (%)				
Screening	67 (39)	40 (60)	9 (13)	18 (27)
BSE	96 (56)	36 (38)	27 (28)	33 (34)
GP	4 (2)	3 (75)	0 (0)	1 (25)
Partner	1 (1)	0 (0)	0 (0)	1 (100)
other	4 (2)	1 (25)	3 (75)	0 (0)
Type of cancer n (%)				
Invasive	87 (54)	45 (52)	18 (21)	24 (28)
Non-invasive	29 (18)	11 (38)	8 (28)	10 (34)
Not sure	44 (27)	19 (43)	12 (27)	13 (30)
Other	2 (1)	1 (50)	1 (50)	0 (0)
Treatment n (%)				
Surgical				
Mastectomy	43 (25)	15 (35)	13 (30)	15 (35)
MIR	10 (6)	5 (50)	1 (10)	4 (40)
MDR	14 (8)	6 (43)	6 (43)	2 (14)
Lumpectomy	97 (56)	54 (56)	18 (19)	25 (26)
No treatment	3 (2)	0 (0)	1 (33)	2 (67)
Not sure	5 (3)	0 (0)	1 (20)	4 (80)
Adjuvant therapy*				
Chemotherapy	108 (62)	47 (41)	27 (25)	34 (31)
Radiotherapy	157 (91)	73 (46)	35 (22)	49 (31)
Neither	7 (4)	3 (43)	3 (43)	1 (14)
Hormone therapy*				
Tamoxifen	93 (54)	49 (53)	13 (14)	31 (33)
Aromatase inhibitors	50 (29)	24 (48)	12 (24)	14 (28)
Other	3 (2)	3 (100)	0 (0)	0 (0)
None	32 (18)	11 (34)	15 (47)	6 (19)
Not sure	7 (4)	0 (0)	3 (43)	4 (57)
Lymphoedema n (%)	39 (23)	2 (5)	13 (33)	24 (62)

NB: Total percentages will not always equal 100 because figures have been rounded up to the nearest whole number.

* Participants had more than one treatment.

7.3.3 Inferential

7.3.3.1 Pearson's correlations

Pearson correlations tests were carried out to examine the relationship between the predictor variables (age, time since diagnosis, type of treatment, lymphoedema, psychological functioning, social comparison tendencies, beliefs about cancer, body image, support and healthcare experience) and the outcome variable (overall quality of life) on the whole group and for each group, based on their ethnicity. This is summarised in tables 7.5 and 7.6.

Demographic and cancer variables

For the whole group, there was a positive correlation between quality of life (as measured by the FACT-G) and age (older women reported better quality of life; $p < 0.05$). With regards to treatment, quality of life was positively correlated to the type of surgery and chemotherapy. Women who had a lumpectomy reported a better quality of life than mastectomy patients, and those who did not undergo chemotherapy treatment reported a better quality of life ($p < 0.05$, $p < 0.01$, respectively). Women suffering with lymphoedema reported poorer levels of quality of life ($p < 0.01$). With regards to ethnicity, quality of life was correlated with chemotherapy treatment for White and Black women only, both groups who received chemotherapy reported a poorer overall quality of life.

Table 7.5: Pearson correlations: Demographic/breast cancer variables and quality of life

Quality of Life	Pearson Correlation			
	Whole sample	White	Black	South Asian
Age	0.172*	0.138	0.154	-0.007
Time since diagnosis	-0.066	-0.059	-0.056	-0.110
Surgical treatment	0.199*	0.206	0.206	0.087
Chemotherapy	0.249**	0.271*	0.318*	0.167
Radiotherapy	-0.001	-0.075	0.135	-0.048
Tamoxifen	0.024	0.112	-0.051	-0.015
Arimidex	0.074	0.055	0.155	0.066
Lymphoedema	0.267**	0.171	0.169	0.142

**Correlation is significant at the 0.01 level; * Correlation is significant at the 0.05 level

Psychosocial variables

For the whole group, there was a negative correlation between quality and life and the following variables: anxiety, depression, upward contrast, downward identification, God health locus of control and body image ($p < 0.01$), and a positive correlation with downward contrast, support and healthcare experience ($p < 0.05$; $p < 0.01$). The relationship between the variables was also examined for the ethnic groups. Anxiety, depression, upward contrast and body image were negatively correlated with quality of life for the White, South Asian and Black women, and positively

correlated with support. This was significant at the $p < 0.01$ level. A positive correlation between quality of life with chance locus of control ($p < 0.05$) and upward identification ($p < 0.01$) was evident in the South Asian women only, while there was a positive correlation between quality of life and internal locus of control for the White women only ($p < 0.05$). There was also a negative correlation between quality of life and downward identification for the White and South Asian women ($p < 0.01$).

Table 7.6: Pearson correlations: Psychosocial variables and quality of life

Quality of Life	Pearson Correlation			
	Whole sample	White	Black	South Asian
Anxiety	-0.669**	-0.625**	-0.636**	-0.708**
Depression	-0.792**	-0.796**	-0.796**	-0.722**
Upward identification	0.088	0.016	-0.037	0.409**
Upward contrast	-0.529**	-0.480**	-0.468**	-0.618**
Downward identification	-0.415**	-0.519**	-0.241	-0.386**
Downward contrast	0.163*	0.012	0.161	0.165
Internal locus of control	0.071	0.239*	0.062	0.103
Chance locus of control	0.067	0.211	-0.106	0.285*
Other people locus of control	0.049	0.026	0.075	0.135
God health locus of control	-0.205**	-0.076	-0.177	0.052
Body image	-0.533**	-0.286*	-0.547**	-0.625**
Support	0.613**	0.449**	0.732**	0.691**
Healthcare experience	0.209**	0.079	0.169	0.263

**Correlation is significant at the 0.01 level; * Correlation is significant at the 0.05 level

7.3.3.2 Hierarchical multiple regression

Hierarchical multiple regression was used to assess the extent to which psychosocial factors (anxiety, depression, social comparison tendencies, control beliefs, body image, support and healthcare experience) predicted quality of life, after controlling for demographic (age and ethnicity) and breast cancer variables (time since diagnosis, type of treatment: mastectomy, lumpectomy, chemotherapy and radiotherapy). Preliminary analyses were conducted to ensure no violation of the assumption of normality, linearity, multicollinearity and homoscedasticity. The demographic and breast cancer variables were entered in step 1, explaining 15.9% of the variance in quality of life. Ethnic identity (South Asian; $\beta = -.31$, $p < 0.001$) and undergoing chemotherapy treatment ($\beta = .22$, $p < 0.05$) were the strongest factors in explaining quality of life. After entering the psychosocial variables in step 2, the total variance explained by the model as a whole was 77.1% ($F(20, 135) = 22.67$, $p < 0.001$). The psychosocial variables explained an additional 61.2% of the variance in quality of life after controlling for the demographic and breast cancer variables ($F(13, 135) = 27.68$, $p < 0.001$). A closer look at the model shows that the following variables significantly contributed to explaining quality of life (in order of importance as determined by the *beta* (β) value): depression ($\beta = -.42$, $p < 0.001$), support ($\beta = .28$, $p < 0.001$), anxiety ($\beta = -.22$, $p < 0.001$), and receiving chemotherapy treatment ($\beta = .13$, $p < 0.05$).

7.3.3.3 ANOVA: Standardised measures

Mean scores for each variable for the whole group and for each group, based on their ethnicity are presented in table 7.7. A cut off point based on the median value was used to determine the levels for each variable. For example, those who scored higher than 85.67 (median) on the quality of life scale indicated a better quality of life. This was applied to all the measures except for the HADS, whereby cut off scores were based on clinical values (as stated in 7.2.3.5).

Table 7.7: Mean scores for each psychosocial variable

	Whole sample	White	Black	South Asian
Quality of life	81.76 (18.65)	87.39 (15.03)	80.21 (21.32)	74.42 (19.00)
Anxiety	7.83 (3.33)	7.25 (3.06)	7.51 (3.33)	8.95 (3.20)
Depression	4.62 (3.93)	3.31 (3.10)	4.98 (4.25)	6.32 (4.15)
Upward identification	11.46 (2.51)	11.21 (2.52)	11.75 (2.77)	11.62 (2.31)
Upward contrast	7.09 (2.88)	6.76 (2.85)	6.77 (2.96)	7.79 (2.78)
Downward identification	8.10 (3.11)	7.75 (2.94)	7.59 (2.90)	9.00 (3.36)
Downward contrast	11.77(2.55)	12.30 (2.16)	11.50 (2.57)	11.21 (2.94)
Internal locus of control	19.01 (5.72)	17.95 (5.41)	18.96 (6.55)	20.69 (5.19)
Chance locus of control	22.86 (6.94)	22.10 (6.69)	20.84 (7.25)	25.68 (6.29)
Other people locus of control	10.44 (3.98)	10.37 (3.95)	9.58 (4.41)	11.18 (3.63)
God health locus of control	17.69 (10.42)	11.60 (7.98)	22.36 (9.65)	23.54 (9.16)
Body image	45.40 (16.75)	39.87 (13.76)	47.78 (17.25)	52.26 (17.96)
Social support	8.38 (2.01)	8.73 (1.98)	8.08 (1.97)	8.08 (2.19)
Healthcare experience	8.56 (2.01)	9.00 (1.96)	8.20 (2.08)	8.17 (1.94)

Standard deviation in parenthesis

One-way between-group ANOVAs were performed to explore the impact of ethnicity on the following variables: age at diagnosis, quality of life, anxiety, depression, social comparison tendencies, cancer beliefs, body image, support and healthcare experience. This is summarised in table 7.8.

Table 7.8: ANOVA results for demographic and psychosocial variables

Variables	Significant level
Age at diagnosis	$p < 0.05$
Quality of life	$p < 0.001$
Anxiety	$p < 0.05$
Depression	$p < 0.001$
Upward identification	$p > 0.05$ (ns)
Upward contrast	$p > 0.05$ (ns)
Downward identification	$p < 0.05$
Downward contrast	$p < 0.05$
Internal locus of control	$p < 0.05$
Chance locus of control	$p < 0.05$
Other people locus of control	$p > 0.05$ (ns)
God health locus of control	$p < 0.001$
Body Image	$P < 0.001$
Support	$p > 0.05$ (ns)
Healthcare experience	$p < 0.05$

ns = non-significant

Age at diagnosis

An approximate age at diagnosis was calculated by subtracting time since diagnosis from participant's age. The mean age for participants at diagnosis was 56 years ($sd = 10.12$). A one-way ANOVA showed a statistical significant difference on age at diagnosis between ethnic identity ($F(2, 82.41) = 6.16$, $MSE = 96.47$, $p < 0.05$). Further examination of this via Tukey's showed that White women were diagnosed at an older age ($\bar{x} = 58$, $sd = 8.51$) than South Asian women ($\bar{x} = 52$, $sd = 9.22$).

Quality of Life

The mean score for overall quality of life for the whole group was 81.76 ($sd = 18.65$), indicating a poor quality of life (median = 85.67). This was higher than the mean scores for a non-clinical adult US sample ($n = 1,075$, $\bar{x} = 80.1$, $sd = 17$) and sample of US adult patients with cancer ($n = 2,236$, $\bar{x} = 80.9$, $sd = 17$) (Brucker et al, 2005). One-way ANOVA showed a significant difference on quality of life between the ethnic groups ($F(2, 84.93) = 8.59$, $MSE = 319.74$, $p < 0.001$). Further examination of this via Tukey's showed that White women reported a better quality of life ($\bar{x} = 87.39$, $sd = 15.03$) than South Asian women ($\bar{x} = 74.42$, $sd = 19.00$).

Psychological functioning

Anxiety

Anxiety levels for the whole group indicate normal levels of anxiety ($\bar{x} = 7.83$, $sd = 3.33$, possible range 0-21, higher scores indicate greater levels of anxiety). 86 (49.7%) women reported normal levels of anxiety, 48 (27.7%) with borderline levels and 39 (22.5%) with severe levels of anxiety. The mean score reported for this study was slightly higher than normative data for a non-clinical adult UK population ($n = 1,792$, $\bar{x} = 6.14$, $sd = 3.76$) (Crawford, Henry, Crombie & Taylor, 2001). However, it was very similar to normative data for a female cancer population ($n = 367$, $\bar{x} = 7.13$, $sd = 4.09$) (Schwarz et al, 2008). One-way ANOVA showed a significant difference on anxiety between the ethnic groups ($F(2, 170) = 4.57$, $MSE = 10.64$, $p < 0.05$). Further examination of this via Tukey's showed that South Asian women reported greater levels of anxiety ($\bar{x} = 8.95$, $sd = 3.20$) than White women ($\bar{x} = 7.25$, $sd = 3.06$).

Depression

Depression levels for the whole group was low, indicating normal levels of depression ($\bar{x} = 4.62$, $sd = 3.93$, possible range 0-21, higher scores indicate greater levels of depression). 131 (75.7%) women reported normal levels of depression, 23 (13.3%) borderline levels and 19 (11%) severe levels of depression. The mean score reported in this study was slightly higher than normative data for a non-clinical adult UK population ($n = 1,792$, $\bar{x} = 3.68$, $sd = 3.07$) (Crawford, Henry, Crombie & Taylor, 2001), but lower in comparison to a female cancer population ($n = 367$, $\bar{x} = 5.93$, $sd = 4.33$) (Schwarz et al, 2008). One-way ANOVA showed a significant difference on depression between the ethnic groups ($F(2, 84.87) = 10.65$, $MSE = 13.86$, $p < 0.001$). Further examination of this via Tukey's showed that South Asian women reported greater levels of depression ($\bar{x} = 6.32$, $sd = 4.15$) than White women ($\bar{x} = 3.31$, $sd = 3.10$).

Social comparison

Overall the sample engaged in greater levels of positive social comparison behaviours (upward identification ($\bar{x} = 11.46$, $sd = 2.51$, median = 12) and downward contrast ($\bar{x} = 11.77$, $sd = 2.55$, median = 12)) than negative comparisons (upward contrast ($\bar{x} = 7.09$, $sd = 2.88$, median = 7) and downward identification ($\bar{x} = 8.10$, $sd = 3.11$, median = 8)). This shows that women felt better about their own situation when comparing themselves to other cancer patients regardless of whether other patients were in a better or worse state. This finding is similar (although the mean score for each sub-scale was higher in the present study) to a sample of patients with spinal cord injury ($n = 70$, upward identification: $\bar{x} = 9.55$, $sd = 3.57$, downward contrast: $\bar{x} = 9.73$, $sd = 3.43$, upward contrast: $\bar{x} = 6.40$, $sd = 3.25$ and downward identification: $\bar{x} = 6.64$, $sd = 3.14$) (Buunk Zurriaga & Gonzalez, 2006). However, the mean scores were considerably lower for each sub-scale when compared to the mean scores of cancer patients in Van der Zee et al's (2000) study ($n = 112$, upward identification: $\bar{x} = 3.14$, $sd = 1.32$, downward contrast: $\bar{x} = 2.81$, $sd = 1.24$, upward contrast: $\bar{x} = 2.79$, $sd = 1.26$ and downward identification: $\bar{x} = 3.01$, $sd = 1.22$).

One-way ANOVAs only showed a significant difference on downward identification and downward contrast between the ethnic groups ($F(2, 167) = 3.33$, $MSE = 9.41$, $p < 0.05$ and $F(2, 88.23) = 3.25$,

MSE = 6.35, $p < 0.05$, respectively). Further examination via Tukey's showed that White women ($\bar{x} = 12.30$, $sd = 2.16$) reported engaging in downward contrast comparisons more than South Asian women ($\bar{x} = 11.21$, $sd = 2.94$). While the ANOVA provides some evidence of an effect on downward identification between the ethnic groups, the Tukey's post hoc test does not show any significances when the sample is broken down into smaller ethnic groups ($p > 0.05$). However, a simple comparison using the independent sample t-test shows that South Asian women ($\bar{x} = 9.00$, $sd = 3.36$) reported higher levels of engaging in downward identification comparisons than Black ($\bar{x} = 7.59$, $sd = 2.90$) and White women ($\bar{x} = 7.75$, $sd = 2.94$).

There was no significant difference on upward identification and upward contrast between the ethnic groups ($p > 0.05$).

Beliefs about cancer

The mean scores from this study were compared with the mean scores of a sample of 109 breast cancer survivors (Naus et al, 2005).

Internal locus of control

There was a high belief that the women were in control of their cancer ($\bar{x} = 19.01$, $sd = 5.72$, median = 19). This mean score was higher than the mean reported in Naus et al's study ($\bar{x} = 18.69$, $sd = 4.69$). One-way ANOVA showed a significant difference on internal locus of control between the ethnic groups ($F(2, 164) = 3.62$, $MSE = 31.73$, $p < 0.05$). Further examination of this via Tukey's showed that South Asian women reported having a higher level of internal locus of control ($\bar{x} = 20.69$, $sd = 5.19$) compared to the White women ($\bar{x} = 17.95$, $sd = 5.41$).

Chance locus of control

The belief that the cancer was due to an external cause such as chance was low amongst this group ($\bar{x} = 22.86$, $sd = 6.94$, median = 24). The mean score in this study was higher than the mean reported in Naus et al's study ($\bar{x} = 15.52$, $sd = 5.87$). One-way ANOVA showed a significant difference on chance locus of control between the ethnic groups ($F(2, 163) = 6.58$, $MSE = 45.05$, $p < 0.05$). Further examination of this via Tukey's showed that South Asian women ($\bar{x} = 25.68$, $sd = 6.29$) reported a higher level of chance locus of control compared to the White ($\bar{x} = 22.10$, $sd = 6.70$) and Black women ($\bar{x} = 20.84$, $sd = 7.25$).

Other people locus of control

The belief that the cancer was due to an external cause such as other people was on the low side amongst this group ($\bar{x} = 10.44$, $sd = 3.98$, median = 11). This was higher than the mean reported in Naus et al's study ($\bar{x} = 8.94$, $sd = 2.84$). One-way ANOVA showed a non-significant difference on other people locus of control between the ethnic groups ($p > 0.05$).

God health locus of control

The belief that God was in control of the cancer was slightly towards the higher end amongst this group ($\bar{x} = 17.69$, $sd = 10.42$, median = 17). This was very similar to the mean score reported in Naus

et al's study ($\bar{x} = 17.66$, $sd = 8.90$). One-way ANOVA showed a significant difference on God health locus of control between the ethnic groups ($F(2, 164) = 35.64$, $MSE = 76.55$, $p < 0.001$). Further examination of this via Tukey's showed that the South Asian ($\bar{x} = 23.54$, $sd = 9.16$) and Black women ($\bar{x} = 22.36$, $sd = 9.65$) reported having a higher level of God health locus of control compared to the White women ($\bar{x} = 11.60$, $sd = 7.98$).

Body image

High levels of body image concerns were evident in the group ($\bar{x} = 45.40$, $sd = 16.75$, median = 42). This was higher than the mean from a sample of 164 breast cancer survivors ($\bar{x} = 38.3$, $sd = 14.4$) (Baxter et al, 2006). One-way ANOVA showed a significant difference on body image between the ethnic groups ($F(2, 165) = 9.84$, $MSE = 253.76$, $p < 0.001$). Further examination of this via Tukey's showed that Black ($\bar{x} = 47.78$, $sd = 17.25$) and South Asian women ($\bar{x} = 52.26$, $sd = 17.96$) reported greater levels of body image concerns than the White women ($\bar{x} = 39.87$, $sd = 13.76$).

Body image concerns were further examined based on the type of treatment; specifically those who had a mastectomy (without breast reconstruction), lumpectomy, chemotherapy and radiotherapy treatment as the impact of these treatments have the potential to affect body image concerns.

Surgical treatment

Mastectomy without breast reconstruction: All the women who had undergone a mastectomy without breast reconstruction ($n = 43$) reported high levels of body image concerns ($\bar{x} = 51.95$, $sd = 14.72$, median = 50). This was higher than that of a breast cancer population who received a mastectomy ($\bar{x} = 43.4$, $sd = 14.4$) (Baxter et al, 2006). There was no significant difference on body image between the ethnic groups ($p > 0.05$).

Lumpectomy: Women who had a lumpectomy ($n = 94$) also reported high levels of body image concerns ($\bar{x} = 39.03$, $sd = 14.52$, median = 36.45). This was higher than that of a breast cancer population who received a lumpectomy ($\bar{x} = 36.8$, $sd = 13.6$) (Baxter et al, 2006), but lower than a sample of 538 Chinese breast cancer patients ($\bar{x} = 40.44$, $sd = 11.2$) (Zhang et al, 2011). One-way ANOVA showed a significant difference on body image between the ethnic groups ($F(2, 33.25) = 6.84$, $MSE = 187.24$, $p < 0.05$). Further examination of this via Tukey's showed that South Asian women ($\bar{x} = 47.05$, $sd = 17.71$) reported greater levels of body image concerns than the White women ($\bar{x} = 34.73$, $sd = 11.00$).

Adjuvant treatment

Chemotherapy: Women who received chemotherapy treatment ($n = 106$) reported high levels of body image concerns ($\bar{x} = 47.90$, $sd = 16.66$, median = 45). One-way ANOVA showed a significant difference on body image between the ethnic groups ($F(2, 103) = 7.90$, $MSE = 245.21$, $p < 0.05$). Further examination of this via Tukey's showed that South Asian women ($\bar{x} = 55.59$; $sd = 18.49$) reported greater levels of body image concerns than the White women ($\bar{x} = 41.57$; $sd = 13.01$).

Radiotherapy: Women who received radiotherapy ($n = 152$) reported high levels of body image concerns ($\bar{x} = 44.59$, $sd = 16.68$, median = 41.72). One-way ANOVA showed a significant difference

on body image between the ethnic groups ($F(2, 149) = 10.77$, $MSE = 246.37$, $p < 0.001$). Further examination of this via Tukey's showed that South Asian ($\bar{x} = 51.94$; $sd = 18.30$) and Black women ($\bar{x} = 47.28$, $sd = 16.68$) reported greater levels of body image concerns than the White women ($\bar{x} = 38.61$, $sd = 13.25$).

Note: There was no normative data available for which comparisons can be based with regards to patients undergoing adjuvant treatment.

7.3.3.4 ANOVA, Chi square and content analysis: Self-constructed items

Social Support

Overall the women reported being very satisfied by the support they received during their breast cancer experience ($\bar{x} = 8.4$, $sd = 2.01$). This was similar across the three groups. One-way ANOVA showed that there was no statistical significant difference on overall support between the groups ($p > 0.05$).

Support: Sources and types

Table 7.9 shows a list of sources that provided women with support during their breast cancer experience. Family (95%), husband/partner (95%), friends (87%) and healthcare professionals (86%) were reported to be the women's main sources of support. Other sources listed included religion/spirituality (42%), work colleagues (40%), support groups (29%) and community groups (21%).

Table 7.9: Sources of support

Sources of support	Whole sample n (%)	White n (%)	South Asian n (%)	Black n (%)
Family	161 (95)	76 (95)	51 (96)	34 (94)
Husband/partner ^a	103 (95)	56 (95)	36 (95)	11 (92)
Friends	147 (87)	70 (88)	45 (85)	32 (89)
Healthcare Professional	146 (86)	69 (86)	43 (81)	34 (94)
Religion/spirituality	71 (42)	17 (21)	34 (64)	20 (56)
Work colleagues ^b	52 (69)	31 (84)	11 (44)	10 (77)
Support groups	49 (29)	18 (23)	19 (36)	12 (33)
Community groups	35 (21)	11 (14)	11 (21)	13 (36)

a = examined for women with partners/husbands; b = examined for women who were in employment

A Chi-square test was performed to see if there was an association between ethnic identity and source of support. This test showed no significant associations between the support sought from

family, husband/partner¹, friends, support groups² and healthcare professionals and ethnic identity ($p > 0.05$). However, there was a statistically significant difference in support sought through religion/spirituality ($\chi^2 (2, n = 169) = 27.53, p < 0.001, phi = 0.40$), community groups ($\chi^2 (2, n = 169) = 7.56, p < 0.05, phi = 0.02$), and work colleagues³ ($\chi^2 (2, n = 75) = 11.53, p < 0.05, phi = 0.39$). An examination of the ethnic identity*support source cross-tabulation show the following: a greater number of South Asian (64%) and Black (56%) women turned to religion/spirituality for support compared to the White women (21%), Black (36%) and South Asian (21%) women sought/received support from their community groups more than White women (14%), and White (84%) and Black (77%) women received support from work colleagues more than the South Asian women (44%).

Types of support

Table 7.10 shows the type of support received by each source. As can be seen, women received majority of their practical, emotional and moral support from family members (73%, 75% and 60, respectively) and husbands/partners (86%, 81% and 79%, respectively). Friends and healthcare professionals also played a role in providing the women with emotional support (67% and 46%). Support groups (68%) and healthcare professionals (82%) were reported to provide the most informational support.

Table 7.10: Types of support received from different sources

Type of support →	Practical	Emotional	Informational	Financial	Moral
Source ↓	n (%)	n (%)	n (%)	n (%)	n (%)
Family	125 (73)	128 (75)	32 (19)	26 (15)	103 (60)
Husband	94 (86)	89 (81)	14 (13)	40 (36)	87 (79)
Friends	55 (32)	116 (67)	21 (12)	6 (4)	58 (34)
Work	9 (12)	34 (45)	5 (7)	2 (3)	10 (13)
SGs	4 (6)	27 (40)	46 (68)	10 (15)	4 (6)
Community	12 (7)	29 (17)	3 (2)	2 (1)	7 (4)
Healthcare professionals	14 (8)	80 (46)	142 (82)	42 (24)	14 (8)
Nobody	4 (2)	3 (2)	4 (2)	25 (15)	4 (2)
Not needed	8 (5)	1 (1)	3 (2)	45 (36)	4 (2)

Support groups

39% (68/173) of women had attended support groups, of which 14% attended more than one group. A Chi-square test revealed a significant association between women who attended support groups and ethnic identity ($\chi^2 (2, n = 173) = 7.45, p < 0.05, phi = 0.21$), with more South Asian (45%) and Black (53%) women attending support groups compared to White women (29%).

1 X^2 was performed only on those who had husband and partners.

2 X^2 was performed only on those who attended support groups.

3 X^2 was performed only on those who were in employment.

Support groups reported as having been attended included Asian Women's Breast Cancer Group (7%), Breast Cancer Care (including online support; 17%), Macmillan Cancer Support group (34%), White House cancer support (7%), Breast friends (3%), Cancer Black Care (3%), Maggies Centre (3%), The Haven (3%), Breakthrough Breast Cancer (1%), Naya Rasta (1%), Paul D'Auria support centre (1%), Penny Brohn (1%), Umeed (1%) and local cancer support groups (14%). Healthcare professionals (61%) played a major role in signposting the women to such support groups, followed by the internet (17%), family/friends (12%) and 9% heard about the support group via other means. All the women, regardless of ethnicity found the support groups to be very useful/helpful ($\bar{x} = 8.67$, $sd = 1.58$; $p > 0.05$).

The main reason given for not attending support groups was because they did not feel the need to go and/or they had enough support from family, friends and other cancer patients (88%). Other reasons included: not having the time (3%), not knowing about any support groups (8%) and not having any groups local to them (3%).

Appearance-related products

Wigs

Of the 108 women who underwent chemotherapy treatment, 97 (90%) reported wearing wigs. Seventy-seven (79%) received these via the NHS and 20 (21%) bought the wigs themselves. On the whole, women were satisfied with the wigs ($\bar{x} = 6.79$, $sd = 2.81$, range 1 - 10). One-way ANOVA showed a significant difference on satisfaction with the wigs between the ethnic groups ($F(2, 94) = 5.34$, $MSE = 7.24$, $p < 0.05$). Further examination of this via Tukey's showed that White women ($\bar{x} = 7.67$, $sd = 2.34$) reported higher levels of satisfaction than Black women ($\bar{x} = 5.52$, $sd = 2.97$).

Content analysis of the reasons for women's satisfaction/dissatisfaction is presented in table 7.11. Of the 97 women who reported wearing a wig, 67 stated their opinions. The table below shows that more White women reported being satisfied with the wigs, with their primary reason being that the wigs looked similar to their own hair; whereas a greater number of Black and South Asian women felt that the wigs did not meet their cultural needs, in terms of colour, style and texture.

Table 7.11: Evaluation of wigs

Reasons for satisfaction/dissatisfaction (n = 67)	Ethnic identity	N	%
Dissatisfied: Uncomfortable to wear (hot, itchy)	White	7	10
	Black	3	4
	South Asian	6	9
Dissatisfied: Unnatural looking/limited choice	White	3	4
	Black	12	18
	South Asian	6	9
Satisfied: Similar to own hair	White	15	22
	Black	1	1
	South Asian	7	10
Satisfied: Conceal cancer	White	7	10
	Black	1	1
	South Asian	2	3

Scarves

Sixty-two women reported using scarves to cover up their hair loss, of which 24 stated their reasons of satisfaction/dissatisfaction (table 7.12). The majority of scarves were self-bought ($n = 56$) and women reported high levels of satisfaction with this product ($\bar{x} = 7.64$, $sd = 2.51$). One-way ANOVA showed no significant difference between the groups ($p > 0.05$).

Table 7.12: Evaluation of Scarves

Reasons for satisfaction/dissatisfaction: Scarves Vs Wigs (n = 24)	Ethnic Identity	N	%
Dissatisfied: Uncomfortable to wear	White	1	4
Dissatisfied: Hard to conceal cancer	White	2	8
Satisfied: Comfortable to wear	White	8	33
	Black	3	13
	South Asian	2	8
Satisfied: More variety than wigs	White	6	25
	Black	4	17
	South Asian	2	8

Breast prosthesis

Of the 57 women who had a mastectomy without immediate or delayed reconstruction, 50 reported wearing a breast prosthesis and 25 stated their opinions about this product (table 7.13). The majority of women obtained their prosthesis via the NHS ($n = 49$) and were satisfied with their product ($\bar{x} = 6.66$, $sd = 2.78$). One-way ANOVA showed no significant difference between the groups ($p > 0.05$).

Table 7.13: Evaluation of breast prosthesis

Reasons for satisfaction/dissatisfaction (n = 25)	Ethnic Identity	N	%
Dissatisfied: Limited choice – colour	Black	6	24
	South Asian	1	4
Dissatisfied: Uncomfortable to wear (heavy)	White	2	8
	Black	4	16
	South Asian	4	16
Dissatisfied: Poor fit (uneven)	White	4	16
	South Asian	4	16
Satisfied: Increased body and self confidence	White	3	12
Satisfied: With colour of the prosthesis	Black	3	12

Lymphoedema sleeve

Of the 39 women who reported suffering from lymphoedema, 23 used a lymphoedema sleeve and 7 stated their opinions about the product (table 7.14). The majority of women got this from the NHS ($n = 21$) and were satisfied with it ($\bar{x} = 7.48$, $sd = 2.17$). One-way ANOVA showed no significant difference between the groups ($p > 0.05$).

Table 7.14: Evaluation of lymphoedema sleeves

Reasons for satisfaction/dissatisfaction (n = 7)	Ethnic Identity	N	%
Dissatisfied: Limited choice – colour	South Asian	1	14
Dissatisfied: Uncomfortable to wear	White	1	14
	Black	1	14
	South Asian	1	14
	South Asian	3	43
Satisfied: Serves its purpose	South Asian	3	43

Make-up

Twenty women reported using make-up to cover up side effects from treatment (e.g. loss of eyebrows and eye-lashes as a result of chemotherapy), and 11 stated their opinions about their products (table 7.15). Most women bought these products themselves ($n = 11$) but were taught how to apply the make-up by attending a ‘look good, feel good’ workshop. Women reported high levels of satisfaction with their products ($\bar{x} = 8.21$, $sd = 2.02$). One-way ANOVA showed no significant difference between the groups ($p > 0.05$).

Table 7.15: Evaluation of make-up

Reasons for satisfaction/dissatisfaction (n = 11)	Ethnic Identity	N	%
Dissatisfied: Limited choice	Black	3	27
Satisfied: Increase confidence ‘look good, feel good’	White	3	27
	Black	2	18
	South Asian	3	27
	South Asian	3	27

Lingerie/swimwear

Twenty-eight women reported purchasing specialised lingerie and swimwear to accommodate for their loss of breast, of which 20 stated their opinions about their item(s) of clothing (table 7.16). The majority bought the products themselves ($n = 27$) and were satisfied with them ($\bar{x} = 6.59$, $sd = 2.44$). One-way ANOVA showed no significant difference between the groups ($p > 0.05$).

Table 7.16: Evaluation of lingerie/swimwear

Reasons for satisfaction/dissatisfaction (n = 20)	Ethnic Identity	N	%
Dissatisfied: Limited choice (size/style)	White	3	15
	Black	4	20
	South Asian	3	15
Dissatisfied: Expensive	White	1	5
	Black	1	5
	South Asian	1	5
Satisfied: Able to continue partaking in social activities (i.e. swimming)	White	3	15
Satisfied: Range of items available	White	2	10
	Black	1	5
	South Asian	1	5

Healthcare experience

Women reported high levels of satisfaction with their overall healthcare experience ($\bar{x} = 8.56$, $sd = 2.01$, range 1 – 10). One-way ANOVA showed a significant difference on healthcare experience between the ethnic groups ($F(2, 167) = 3.57$, $MSE = 3.93$, $p < 0.05$). While the one-way ANOVA provides some evidence of an effect, the Tukey's post hoc test does not show any significant difference between the ethnic groups ($p > 0.05$). However, a simple comparison using the independent sample t-test shows that White women ($\bar{x} = 9.00$, $sd = 1.96$) reported higher levels of satisfaction with their health care than Black ($\bar{x} = 8.20$, $sd = 2.08$) and South Asian women ($\bar{x} = 8.17$, $sd = 1.94$).

Language

Of the 42 South Asian women who reported a language other than English as their mother tongue, 8 (19%) reported receiving the breast cancer information in their mother tongue language. This was reported as being very helpful/useful ($\bar{x} = 8.1$, $sd = 1.55$, range 1 – 10) and the main reason stated by all the women was that it aided understanding of the cancer. Of the 34 (81%) who did not receive information in their own language, 15 (41%) stated that they would have liked to receive information or talk to someone about the cancer in their mother tongue language.

Gender

Fifteen (9%) women reported being treated only by male healthcare professionals, 63 (37%) by females only and 94 (55%) reported being treated by both males and females.

Gender preference

Twenty (12%) women had a preference for who they wanted to be treated by, whereby all the women stated a preference of wanting to be treated by female healthcare professionals. Chi square revealed a significant association between gender preference and ethnic identity ($\chi^2(4, n = 171) =$

34.69, $p < 0.05$, $\phi = 0.45$), where more South Asian women ($n = 17$) reported a preference of being treated by females than Black ($n = 2$) or White women ($n = 1$). Fifteen women gave their reasons for this and 8 stated why they did not have a preference. Content analysis (table 7.17) was undertaken to tally the reasons for having or not having a preference. Interestingly, reasons regarding cultural aspects based around modesty and feeling embarrassed about showing their body to male healthcare professionals was reported by the South Asian women only, while the importance of professionalism of the healthcare professional, regardless of gender was reported mostly by the White women.

Table 7.17: Gender preference of healthcare professional

Preference for a female (n = 23)	Ethnic Identity	N	%
Cultural reasons – modesty	South Asian	3	13
Embarrassment in exposing body to male healthcare professionals	South Asian	6	26
Greater understanding/empathy from female healthcare professionals	White	1	4
	South Asian	4	17
	Black	2	9
No preference			
Importance placed on professionalism and understanding from healthcare professionals	White	7	30
	South Asian	1	4

7.4 Discussion

The findings from this study show how psychosocial factors contribute to breast cancer survivors' quality of life and that differences between ethnic groups exist. These 2 aspects will now be discussed in relation to previous research.

7.4.1 Psychosocial impact of breast cancer on quality of life

The first set of inferential findings show that various factors can have a profound impact on quality of life. These factors include age, type of treatment (mastectomy and/or chemotherapy), having lymphoedema, and psychosocial factors: psychological functioning, social comparison tendencies, beliefs about control over cancer, body image concerns, support and health care experience.

Many of these factors (i.e. age, type of treatment, psychological impact, body image and support) have been widely reported within the broader breast cancer literature, in affecting quality of life (Falagas et al, 2007; Fobair et al, 2006; Golant, Altman & Martin, 2003; Helms et al, 2008; Knobf, 2007; Pikler & Winterowd, 2003; Shapiro et al, 2001). For example, the finding of this study, that older women reported a better quality of life is in line with previous research, whereby a consistent

finding shows that younger women report a lower quality of life than older women (Knobf, 2007; Baucom et al, 2006). This tendency can be attributed to the fact that younger women are at different stages in their life than older women and therefore experience greater levels of distress. While undergoing a breast cancer diagnosis and treatment can also be distressing for older women (Ganz et al, 2003), younger women are more likely to be working, married or in a relationship and have young children or may want children in the future (Knobf, 2007). Each different aspect of a young woman's life can be affected by the cancer experience, especially in relation to treatment. Treatments such as mastectomy can result in greater body image concerns and cause lymphoedema, while side effects of chemotherapy, which tend to be more prominent in younger women, (Baucom et al, 2006) can set off early menopause, causing infertility; all of which can have an adverse impact on quality of life.

The hierarchical regression analysis found that psychological functioning, support and receiving chemotherapy treatment are the most important factors that account for overall quality of life.

Emotional distress, pertaining to high levels of anxiety and depression, resulting in poor quality of life, have been reported to be the two most common psychological problems experienced by breast cancer patients (Burgess et al, 2005; Deshields et al, 2006; Fann et al, 2008; Knobf, 2007; Reich et al, 2008; Shapiro et al, 2001; Thewes et al, 2004; Vachon, 2006). Levels of anxiety and depression can occur and vary at different time points of the breast cancer journey. For example, emotional distress can heighten whilst awaiting treatment, it may decrease during treatment in a supportive environment with healthcare professionals (or increase due to the side effects of treatment which can impair body image, physical and cognitive abilities) and often increases at the end of treatment, when patients feel the most vulnerable (healthcare visits and support start to reduce, fears of recurrence are present; Fann et al, 2008; Knobf, 2007). Furthermore, other personal and psychosocial factors (past history of psychiatric illness, limited availability of support and poor interpersonal relationships) can increase levels of depression and anxiety which in turn can reduce quality of life and even survival (Fann et al, 2008).

The type of treatment that a patient receives can also impact quality of life. This study found that chemotherapy is an important factor in determining quality of life. This is not surprising considering the various adverse short and long-term (including permanent) side effects that are associated with such an aggressive treatment. Although a relationship between chemotherapy with other variables such as body image or psychological functioning were not examined in this study, it is likely that side effects of chemotherapy, such as hair loss, weight gain/loss and the onset of early menopause (which induces infertility and hot flushes) can increase body image concerns and raise issues such as not feeling feminine (Arndt et al, 2005; Casso, Buist & Talpin, 2004; Helms et al, 2008; Pelusi, 2006). The findings of this study did show that greater levels of body image dissatisfaction are associated with poor quality of life. Side effects of chemotherapy can also raise issues around sexuality (Kissane et al, 2004). Reported problems include altered sexual functioning, loss of libido, poor self-image and affect intimate relationships (Baucom et al, 2006; Fobair et al, 2006; Ganz et al, 2004). All of these issues can increase psychological distress and consequently affect all aspects of quality of life (Kissane et al, 2004).

7.4.2 Group differences

The second part of the analyses examined group differences in Black, South Asian and White women's experiences. Group differences were observed for the majority of the variables. Interestingly, these differences were predominantly between White and South Asian breast cancer survivors. For example, South Asian women displayed higher levels of anxiety and depression, poorer quality of life, higher levels of internal and fatalistic beliefs pertaining to cancer, higher levels of engaging in downward identification comparisons, and lower levels of engaging in downward contrast comparisons than White women. For each of the mentioned variables, it can be inferred that Black women display similar levels with both the White and South Asian women (with the exception of fatalism and downward identification comparisons, whereby South Asian women displayed higher levels than Black women). Thus, while the experiences of Black and South Asian women in this study are similar, Black and White women's experiences are also more alike than different. These findings provide some support to the existing literature but also contradict some findings.

While some studies have found lower levels of distress in BME women compared to White women (Culver et al, 2002 – depression), others have found distress levels are higher in BME women (Roy et al, 2005; Schlebush & van Oers 1999 – depression), and some papers report no difference (Roy et al, 2005; Schlebush and van Oers 1999 – anxiety; Paskett et al, 2008 - depression). For example, Roy et al (2005) assessed differences in coping and adaptation to cancer in White and South Asian patients. While no difference was found on anxiety levels, South Asian women reported higher levels of depression and had a greater fatalistic attitude towards the cancer. Similarly, Paskett et al (2008) found no difference in depression between their Black and White breast cancer participants, but did find a difference in quality of life, with Black women reporting a poorer quality of life than White women; concluding that breast cancer has a greater impact on Black women. This statement has some weighting as Black women are often diagnosed with more aggressive forms of cancer and therefore undergo treatments such as chemotherapy that come with many adverse side effects. Contrary to Paskett et al (2008), Maly et al (2008) and Ashing-Giwa, Ganz & Peters (1999) support the present findings that Black and White breast cancer survivors report similar levels of quality of life.

A possible reason for the present findings (South Asian women having higher levels of depression, anxiety and poorer quality of life than White women) can be attributed to the women's age. The South Asian women in this study were diagnosed at a younger age than White women, and as mentioned above, breast cancer has a greater adverse impact on younger women.

Another possible explanation can be dictated by the women's cultural norms of stoicism which is very common in ethnic minority communities (Culver et al, 2002). As mentioned in chapter 6, stoicism is a characteristic that exists in many BME cultures (Versola-Russo, 2006). Ethnic minority women have been reported to describe their experiences in a stoic manner (Howard et al 2007) and often suppress their emotions; whether this is because of cultural taboos of keeping the illness private or not knowing how to seek appropriate help. Consequently, this can result in high levels of depression, anxiety and poor quality of life (Reynolds et al, 2000). This may be particularly true in first generation immigrants (majority of ethnic minority women in this study were first generation

immigrants) who have been known to maintain strong cultural norms and beliefs from their country of origin (Meneses & Yarbro, 2007).

The present findings (which also corroborate with findings from the qualitative studies) show that Black and South Asian women have a greater belief that God is in control of the cancer than White women. This is further supported by the examination of sources of support, whereby more Black and South Asian women turn to religion/spirituality for support during their cancer experience than White women. Although there were no differences between Black and South Asian women, South Asian women tend to rely more on God for support and believe that he is in control of the cancer. Therefore, a fatalistic attitude such as 'it's written for me' and the belief that 'God is in control of the cancer' can easily be interpreted to mean the same thing as concepts such as fate are often perceived to be influenced by God. This was a common belief during the findings from the qualitative studies. Furthermore, the variables chance locus of control and God health locus of control have been found to positively correlate with each other (Chaplin et al, 2001; Wallston, 2005). This can offer some explanation as to why South Asian and Black women differ on their levels of belief pertaining to chance.

The coping with breast cancer and ethnicity literature has consistently found that ethnic minority women rely heavily on religion as a source of support (Bourjolly, 1998; Bourjolly & Hirschman, 2001; Culver et al, 2002; 2004). While all these studies make comparisons with Black and White cancer patients, Culver et al (2002, 2004) included Hispanic women too. No studies have included or made comparisons with South Asian women. Nonetheless, the present findings corroborate with previous findings (and the qualitative studies of this research) that ethnic minority women are more likely to turn to God for support than White women, and therefore explains the greater belief that God is in control of their cancer.

Interestingly, South Asian women reported high levels of internal and external (chance and God) locus of control. It is possible that the cancer can be perceived to be under one's control and also under the control of external forces (Taylor et al, 1984). This is known as vicarious control, where there is a belief that together with powerful others, be it a doctor, other people or God, the individual is in control of their illness (Naus et al, 2005). This has been associated with better adjustment to cancer and lower levels of depression and anxiety (Helgeson, 1992; Naus et al, 2005). Although the present study found South Asian women to exhibit high levels of depression, anxiety, body image concerns and poor quality of life, it is possible that this group believed their cancer was determined by external forces such as God and fate, but with this understanding believed that there were also aspects of the cancer that was in their control, thus had a high level of vicarious control. This was also found in the qualitative studies, where women believed that the cancer was out of their control but sought to take control of it in other ways, such as regaining their sense of independence or cutting their hair, rather than wait for it to fall out.

Black and South Asian women also reported greater body dissatisfaction than White women. This finding concurs with Schleich and van Oers' (1999) study, who investigated body image and coping post treatment in Black and White women in South Africa. The authors also found that Black women reported higher levels of body image dissatisfaction compared to White women. Again, these findings can be attributed to the cultural tendency of stoicism amongst ethnic groups. In the present study, body image concerns were found to be higher in South Asian compared to White women who

had a lumpectomy, and in those who received chemotherapy. This suggests that ethnic minority women, particularly South Asian women, experience greater body image concerns following treatment. This too may be due to their cultural needs not being adequately met and/or because of a lack of knowledge of services that can help them manage their body image concerns (Schlebush & van Oers, 1999). Content analysis of the available appearance-related items revealed that compared to White women, more South Asian and Black women were unhappy with products such as wigs because they did not look natural. This has the potential to increase body dissatisfaction.

In contrast to the above findings, Pickler and Winterowd (2003) found no difference in body image dissatisfaction between White and ethnic minority breast cancer survivors. However this could be due to the small sample size (61 White and 31 ethnic minority women), the fact that the ethnic minority group consisted of Black, Native American and East Asian women and were therefore assumed to be a homogenous group (sub-groups were too small to test), or because of the measure used to assess body image (apperception scale). While this scale has been validated in the breast cancer population (Petronis, Carver, Antoni & Weiss, 2003), the scale measures investment in body image and items such as 'I am very careful about my diet' and 'It's important to me to look my best all the time' may not be sensitive enough to detect body image dissatisfaction in this particular breast cancer group.

As well as religion, support plays an important role in women's breast cancer experiences (and has also been found to be a key aspect throughout the qualitative studies in this research), regardless of ethnicity. For all three groups, family, husband/partner, friends and healthcare professionals were identified as the main sources who provided practical, emotional, moral and informational support. The importance of support on cancer patients' wellbeing, quality of life and survival have been well documented (Boyle, 2006; Friedman et al, 2006; Helgeson, Snyder & Seltman, 2004; Knobf, 2007) and concur with the present findings. While the sources of support mentioned so far do not differ between the groups, community groups as a source of support were found to differ between the ethnic groups, with more Black and South Asian women receiving support from their community groups than White women. Women who have a strong affiliation to religion may be more involved in community groups such as places of worship, where there is the potential to receive social, practical and emotional support (Koffman et al, 2008).

Based on the principles of religious/spiritual support through intrapersonal (seeking strength and support within a divine being) and interpersonal resources (seeking support from church-based community members; discussed in chapter 6), Fischer et al (2010) argue that ethnic minorities are more oriented towards engaging in collective, interpersonal religious sources. This concept can help explain why ethnic minority women in the present study were more likely to gain support from community groups/members than the White women. Although community groups have also been found to be helpful for White women (Koopman et al, 2001), it can be speculated from the present findings that White women may be more likely to use religion/spirituality from an intrapersonal perspective and therefore less likely to seek support from community groups (Fischer et al, 2010).

Finally, all the women reported being satisfied with the care and support they received from healthcare professionals. However, White women reported greater levels of satisfaction than Black and South Asian women. While the difference in the mean scores is not big, it is evident from the South Asian women's responses that culture affected their experiences. The varying informational

needs of ethnic minority groups were highlighted. A great proportion of women stated the need to receive cancer information in their own language and the small number of women who received information in their own language found this to be highly beneficial. This supports Kumar et al's (2004) work who found that over half of English speaking South Asian women would prefer to discuss their cancer diagnosis and receive information in their mother-tongue language. The issue of preferring to be treated by a female healthcare professional was also highlighted (in Kumar et al's and the present study) in relation to cultural modesty. Both findings on language barriers and modesty have also been described amongst the South Asian breast cancer survivors in the qualitative studies. This has been discussed in greater detail in chapter 6.

7.5 Conclusion

This chapter has presented the final study of this thesis; a quantitative study exploring the psychosocial impact of breast cancer in a larger group of Black, South Asian and White women. This is one of the very few UK based studies that have compared breast cancer experiences between different ethnic groups. The study highlights the psychosocial factors that affect a survivor's quality of life and shows that differences and similarities in women's breast cancer experiences exist, according to ethnicity, and on the whole, support the findings from the qualitative studies. The findings of this study provide valuable information for healthcare professionals, raising many implications for research and practice. These issues are discussed in the next chapter.

8 Summary and implications of the research

8.1 Introduction

This concluding chapter begins by outlining the purpose of the research, followed by a summary of the studies and their findings, with a focus on practical and research implications. Finally, the use of a mixed methods approach is evaluated, bringing a close to the thesis with a final conclusion.

8.2 Purpose of this research

The aim of this research was to explore the psychosocial impact of breast cancer in Black and South Asian women living in the UK, given the lack of work in this area. It was important to study this group in order to gain a better understanding of the unique experiences that are influenced by one's ethnic and cultural background so that appropriate and culturally competent care can be provided to ethnic minority breast cancer survivors.

8.3 Summary of the research studies

A mixed methods (pragmatic) approach was adopted to gain a detailed understanding of a topic that has received very little attention in the breast cancer literature. An exploratory sequential design was employed, whereby the research dominance was given to the qualitative paradigm. Four studies were carried out, 3 qualitative studies whose findings were used to inform the design of the quantitative study. The first study used exploratory semi-structured one-to-one interviews with 11 Black and 11 South Asian breast cancer survivors. This led to 2 further qualitative studies, the first consisting of 4 focus group interviews with 10 Black and 10 South Asian women followed by interviews with South Asian Indian, Gujarati-speaking (with LEP) women. The findings from these qualitative studies informed the development of a questionnaire study on White, Black and South Asian women, investigating and comparing the impact of breast cancer on quality of life (n = 173: 80 White, 40 Black and 53 South Asian).

8.4 Summary of findings

It is evident from the qualitative and quantitative findings that psychosocial factors such as emotional distress, body image concerns, support, and cultural factors such as religious beliefs are highly influential in shaping ethnic minority women's experiences of breast cancer. Thematic analyses of studies 1 and 2 and interpretative phenomenological analysis of study 3 revealed 6, 3 and 5 key themes, respectively:

- Study 1: Familial concerns, social support, spirituality, body image concerns, healthcare experiences and life post-cancer.
- Study 2: Social support needs, loss of control and cultural taboos and expectations.
- Study 3: 'Making sense of the cancer', 'A shared experience', 'Replacing the negative with the positive', 'Healthcare experiences' and 'Accepting an altered appearance'.

These themes capture similar aspects of the women's experiences across the studies, but are framed in a way to show the psychosocial impact on the participants in each study. For example, 'social support', 'social support needs' and 'a shared experience' encapsulate support as an influential aspect of the women's experiences. Figure 6.1 (chapter 6) describes how the themes are similar and different across the qualitative studies.

Study 4 showed that psychosocial (anxiety, depression, social comparison tendencies, control beliefs, body image, support and healthcare experience) and demographic factors (time since diagnosis, type of treatment and ethnicity) can impact on breast cancer survivors' quality of life; with depression, anxiety, support and receiving chemotherapy treatment playing the biggest role. Differences in breast cancer experiences between the ethnic groups were also reported. For the majority of the psychosocial variables (quality of life, anxiety, depression, internal and chance locus of control), differences were found between the White and South Asian participants (with South Asian women reporting higher levels of anxiety, depression, internal and chance locus of control and poorer quality of life than White women). South Asian women also reported a higher level of chance locus of control than Black women. Both Black and South Asian women reported higher levels of belief that God was in control of their cancer and greater body image concerns than White women. With regards to support, more Black and South Asian women sought support through religion/spirituality, community groups and support groups, and White and Black women were more likely to receive support from work colleagues than South Asian women. From a cultural perspective, the ethnic minority participants expressed their dissatisfaction with products such as wigs because they did not meet their cultural needs. South Asian women highlighted the importance of receiving information in their own language and the preference of being treated by female healthcare professionals based on the emphasis of modesty in their cultures.

8.5 Practical Implications

The findings of this research highlight a number of psychosocial and cultural implications that need to be addressed at a policy, practice and research level. These include psychological distress, body image concerns, support and cultural specific influences pertaining to beliefs and knowledge of cancer and the issues of language barriers in accessing appropriate care and support.

The core duty of the NHS is to promote equality and deliver high quality care to their patients (National Cancer Equality Initiative (NCEI), 2010). As a result, many policy documents have set guidelines and recommendations to ensure cancer patients receive a world class service at each stage of their journey (e.g. Cancer Reform Strategy, 2007; NICE, 2002; 2004; 2009). For example, the

2004 NICE guidance to improve support and palliative care for cancer patients is based on a service model which recognises that a) patients have individual support needs at different time points in their cancer journey, b) the role families play in supporting patients, c) the need for specialist services for some patients, and d) the need for services to be ethnically and culturally sensitive.

While guidelines have been established, the provision and quality of psychosocial support offered to breast cancer patients is varied (NICE, 2004). Patients' needs may not always be met because they are unaware of the service and support available to them or because healthcare professionals do not realise the benefits of the services in meeting patients' needs and therefore do not offer or refer patients. Alternatively, it is possible that services may not be universally available (Department of Health, 2002). Cancer services need to ensure that patients' physical, psychological, social and spiritual needs are being fully met. For this reason, a more recent guidance was published which aimed to focus on areas of clinical practice where there is a variation in the care and support provided (NICE, 2009). In order to see improvements in patients' cancer experiences, it is vital that local commissioners and/or cancer networks ensure that guidance provided are being implemented (NICE, 2009).

The following sections make recommendations on how BME patient's care and support needs can be addressed.

8.5.1 Provision of psychosocial care and support

8.5.1.1 Psychological distress

Despite evidence that depression and anxiety significantly impact quality of life, it is often misdiagnosed and undertreated amongst breast cancer patients (Brunault et al, 2012; Penttinen et al, 2011). This may be because oncologists are not familiar in detecting depressive symptoms at a clinical level (Greenberg, 2004) or because increasing workloads prevent them from routinely screening for such disorders (Mitchell, 2007). Alternatively patients may not feel comfortable in voluntarily discussing symptoms of distress to healthcare professionals or realise that they are under serious amounts of distress, particularly if they are engaging in negative coping strategies such as denial to manage their illness (Roy et al, 2005).

While 'normal' levels of distress are likely to be present in breast cancer patients, it is important that patients are assessed at different stages of the breast cancer journey (diagnosis, during and post treatment) in order to identify those who are highly distressed and might benefit from appropriate care and support. Psychological support can be offered at 4 levels: Levels 1 and 2 involve general psychological support which can be offered by members of the healthcare team through informational support, compassionate communication, and providing relaxation and problem solving techniques. For patients who are severely distressed, they need to be referred to specialists such as counsellors, psychiatrists or health and clinical psychologists (Levels 3 and 4) (Cancer Reform Strategy, 2007). Furthermore, the 2009 NICE guidelines recommend that patients should be assigned to a specialist breast care nurse to support them through their cancer journey. This includes providing patients with appropriate psychological support and referring them to psychiatric or

counselling services when necessary. It is also important that healthcare professionals assess patients' distress levels via appropriate measures that are designed to diagnose psychological disorders at the Diagnostic and Statistical Manual of Mental Disorders (4th Edition; DSM-IV) standard. There is strong clinical evidence that appropriate psychosocial interventions can reduce levels of psychological distress and improve quality of life (NICE, 2009; Osborn, Demoncada & Feuerstein, 2006; Raingruber, 2011). The findings of the quantitative study showed that South Asian women experienced greater levels of psychological distress than White women, suggesting that they may be in greater need of psychological support.

8.5.1.2 Body image concerns

The diverse effects that result from treatments such as chemotherapy, radiotherapy, mastectomy, lumpectomy and hormonal therapy have been found to have a negative impact on patients' body image which can worsen quality of life. To improve patient experience, appropriate psychosocial support is necessary within this context (NICE, 2004). However, it has been recognised that patients and healthcare professionals may not always feel comfortable in addressing body image concerns, especially if they are related to sexual concerns (NICE, 2004). As a result appropriate support may not be offered or sought. To overcome this challenge, it may be beneficial for local cancer networks to ensure that healthcare professionals receive adequate training on offering this type of support or refer patients to appropriate services.

Many of the ethnic minority women in the studies voiced their concerns regarding the limited availability in skin colour matching breast prosthesis or lymphoedema sleeves and appropriate wigs on the NHS. As a result, BME women can be left waiting between 6-12 weeks to receive an appropriately coloured prosthesis or end up purchasing their wigs elsewhere (Trevatt, 2010). This suggests that there is a need to provide BME women with a greater range of products that are culturally suitable and readily available. For example, a wig for a Black woman would need to be of a similar texture and colour to her original hair. Recommendations have been made to ensure that a range of wigs and breast prosthesis tailored to BME women are available and easily accessible to these groups (Breast Cancer Care, 2006; National Chemotherapy Advisory Group, 2009). It would be beneficial for policy makers to work closely with cancer networks and manufacturers who provide such products on a national level to ensure that a range of culturally appropriate products are being offered to breast cancer patients. Alternatively, it is recommended that healthcare professionals are aware of other services that can meet BME women's cultural needs and signpost them to services such as *betterdays* (www.betterdays.uk.com) – an organisation that provides culturally sensitive information and support to Black breast cancer survivors.

8.5.1.3 Support

The findings from the qualitative and quantitative studies show that support from family members plays an influential role in women's experiences. Furthermore, religious and/or spiritual and culturally specific support groups are important sources of support for BME women, suggesting their support needs may differ from White women's.

As family have been identified as an important source of support, it is important that their and carer's informational and support needs are met. It would be beneficial for a member of the breast cancer healthcare team to provide them with information to increase their understanding of the disease and ways in which they can manage their emotions and provide support to the patient. It may also be beneficial to make them aware of services that they can access for support such as Macmillan Cancer Support or Breast Cancer Care.

There is a need to recognise the profound meaning of religion and spirituality as a source of support for breast cancer survivors. The NICE (2004) guidelines recommend that health and social care professionals provide appropriate care and support within a religious and spiritual context. Research has shown that patients would like healthcare professionals (such as physicians, oncology nurses/consultants) to address their religious and spiritual needs (Gallup, 1997; King & Bushwick, 1994), and nurses and consultants see themselves as responsible in addressing such issues (Kristeller, Zumbun & Schilling, 1999). Yet spiritual support needs are frequently unrecognised by healthcare professionals (NICE, 2004). In cases where healthcare teams have provided religion and/or spiritual support, patients have found this to be highly useful in helping them to cope with their illness (Simon et al, 2007). However, this is not always high on the list of psychosocial issues to be addressed and healthcare providers often do not know how to approach such topics or feel confident in doing so (Kai et al, 2007; Kristeller, et al, 1999).

It is therefore recommended that healthcare professionals are provided with adequate training that enhances their understanding in the significance of this type of support and confidence in offering it. It would also be beneficial for healthcare professionals to be aware of local community networks that they can signpost to patients. This can include support groups, a place of worship, or recommendations to classes or retreats (i.e. meditation) that focus more on spirituality than religion.

However, healthcare professionals also need to be aware that a) not all ethnic minority women will rely on religion and spirituality for support, b) religious and spiritual support is not exclusive to BME women, and White women are also likely to find this beneficial (Fischer et al, 2010), and c) they should be open and respectful of others' beliefs, regardless of whether they reflect or contradict their own (Simon et al, 2007).

Cancer survivors also value receiving support from other breast cancer survivors, especially with people they can relate to from a cultural perspective. This type of support should be made available to all patients, either by allowing them to talk to other patients in the hospital or signpost them to appropriate resources, such as support groups. Many women in the qualitative studies highlighted a need for breast cancer support groups specifically for ethnic minority women and some went as far as setting up a group. Patients rely heavily on informational support from healthcare professionals and are more likely to join support groups when told by someone they trust (Avis et al, 2008). Therefore, it is recommended that healthcare professionals recognise the cultural sensitivities of patients and ensure that support is available to them from other breast cancer survivors from the same cultural or ethnic background. This recommendation was also made by NICE (2004). Communication between healthcare professionals and support group facilitators is necessary to ensure that patients are made aware of relevant services.

It would also be beneficial if cancer policy makers set out guidelines to highlight the importance and need for culturally sensitive support groups. While a few cultural specific support groups have been set up in areas with a high ethnic minority population (e.g. CBC, AWBCG and Asian Cancer support group in London, support group for Asian cancer patients in Manchester and Asha in Leicester), more service user led organisations/charities need to be set up to address BME women's psychosocial and cultural needs. Patients can be signposted to Macmillan Cancer Support, who are equipped to support service users in setting up local support groups (Macmillan Cancer Support, 2012b). However, in order to achieve this, adequate funding opportunities need to be made available by organisations such as the Department of Health.

8.5.2 Provision of culturally competent care

Since the Cancer Reform Strategy (CRS) (Department of Health; 2007), where one of the major goals was to reduce inequalities in cancer services, the Department of Health (2011) and NCEI (2010) have also highlighted the need to improve cancer care by reducing inequalities. A lot of progress has been made to minimise this gap. The first annual report shows how the National Cancer Action Team (NCAT) have been liaising with BME cancer charities to develop a National BME Cancer Patient Advisory Panel. This panel will give BME patients and carers the opportunity to voice their cancer experiences which will be used to improve and develop cancer services that meet BME cancer patients' needs (Allberry, 2008). While cancer services have improved, the care and support provided to BME groups is still varied, suggesting that more needs to be done to ensure that the NHS is equipped to meet BME patients' cancer needs from a cultural perspective; at both a local and national level (Department of Health, 2007).

A UK focus group study found that healthcare professionals do not always feel comfortable when treating BME patients due to their lack of awareness and understanding of different cultures. Participants acknowledged their perceived cultural ignorance and were afraid of being culturally inappropriate or appearing racist or discriminatory (Kai et al, 2007). They wanted training in how to address BME patients' needs in a competent manner. Along with Kai et al's study, the findings from the present studies highlight the need for healthcare professionals to recognise that ethnic minority women's healthcare needs may differ to White women's needs, from a cultural perspective. Therefore, the psychosocial care and support provided to breast cancer patients ought to be culturally sensitive and tailored to meet individual's needs. Local commissioners and cancer networks should work closely with workforce development confederations to ensure that education and cultural awareness training are available for all staff (as recommended in the NICE (2004) guidance). Recommendations for how this can be achieved have been documented in the NCEI (2010) report. For example, oncology healthcare professionals need to be provided with adequate training in cultural competence which goes beyond the diversity training currently provided by the NHS.

This can be achieved by ensuring that healthcare professionals are provided with training and education that includes cultural awareness skills and diversity issues to tackle inequalities, especially in highly BME populated areas. Training programmes such as PROCEED (Professionals Responding to Cancer in Ethnic Diversity – a programme funded by Cancer Research UK to develop healthcare

professionals' skills in meeting health needs of BME populations) (Kai, 2005) and Train The Trainer programmes (TTT) can prove to be beneficial in educating and equipping healthcare professionals with adequate knowledge and skills (Karayurt, Gursoy, Tasci & Gundogdu, 2010; Meneses & Yarbrow, 2007). TTT programmes help to develop, design and deliver high quality learning and training through cognitive-behaviour strategies and skills building methods. It has been successfully used in a variety of contexts, including training in culturally competent care in breast cancer settings (Meneses & Yarbrow, 2007). Furthermore, healthcare professionals who have taken part in cultural diversity training programmes have reported an increased awareness, confidence and ability to care for BME populations (Chevannes, 2002).

8.5.2.1 Awareness and knowledge of cancer

In order to overcome the cultural taboos and stigma of breast cancer, increase understanding and knowledge, eradicate misconceptions that cancer is a 'White woman's disease', or contagious, and to encourage openness, it is vital to educate and raise breast cancer awareness within the BME communities, especially amongst women with LEP and first generation immigrants who are less acculturated to the western ways of living. This is particularly important as lack of knowledge and understanding can affect compliance to treatment or attendance for future breast examinations (Johnson et al, 1999). This can be achieved by a) healthcare professionals, who can address any misconceptions and provide them with accurate and culturally sensitive information and b) through community development and outreach programmes to educate and raise awareness within the wider BME community, by targeting local community groups (e.g. non-profit organisations such as community centres or places of worship) which are accessed by BME patients on a regular basis.

It would also be beneficial if local cancer networks are given adequate funding resources to train specific members of the BME communities on general awareness of cancer and how to access information and cancer services which they can advocate to their community members (NICE, 2004). This has the potential to reduce taboos and stigma and allow serious health topics like cancer to be discussed openly and in a positive light. Community development programmes are known to be particularly important and effective in reaching BME populations (Gurm et al, 2008; NCEI, 2010). This could be highly successful if healthcare professionals (such as community nurses or health visitors) worked in partnership with BME community members to promote community development.

It is important to note that beliefs such as 'cancer is a punishment from God', 'inherited', or 'contagious' have also been known to exist in the White community (Lodge, 2001). While such beliefs are more prevalent in the BME community, healthcare professionals need to be aware that White women can also hold these beliefs.

The media has been identified as an important source for information. This is especially true for BME groups who do not have a direct experience or know anyone with cancer, and therefore gather information from their immediate environment (Ajose-Adeogun & Qureshi, 2012). It is therefore recommended that BME men and women are more visible in cancer awareness campaigns or produce media campaigns that specifically target BME groups and promoted through mediums which are frequently accessed by BME groups. For example culturally specific radio and television channels such as the BBC radio Asian network or Sunrise radio – Asian community station in highly

populated BME cities such as Hounslow, Bradford, Coventry and Wolverhampton or Asian television channels such as Star Plus or Zee TV.

8.5.2.2 Language barriers

When patients' informational needs are adequately met, they experience less emotional distress and report a better quality of life, as they have a better understanding of the diagnosis, and can be prepared for treatment and accompanying side effects (Husson, Mols & van de Poll-Franse, 2010). Guidelines on improving breast cancer patients' needs recommend that all patients should be offered full, clear and objective information concerning all aspects of the cancer diagnosis and treatments. This should be tailored to the patient's needs and made culturally appropriate (NICE, 2009). Healthcare professionals need to recognise the importance of meeting BME patients', especially patients with LEP, informational needs. It is important that patients with LEP are provided with cancer information in their own language, so they have an understanding of their diagnosis and treatment and an opportunity to ask questions. English speaking BME women may also find this useful. Such information should therefore be offered to all BME patients.

In the past, the availability of information in other languages was highly limited (NICE, 2004). However, progress has been made in this area whereby breast cancer information leaflets are now available in many South Asian languages (Macmillan Cancer Support, 2012a). Furthermore, Macmillan have set up the first national interpreting telephone cancer helpline service, which is available in over 200 languages. While written information translated in relevant languages is useful, it may not be effective across languages, where there is no written form (such as Sylheti) or where words such as cancer do not exist, or for patients who are unable to read and write in their own language (Watts et al, 2004). For example, Ghosh (1998) found that only 61% of Punjabi men and 10% of Punjabi women living in Hertfordshire were able to read and write in their mother tongue language. Therefore, information via other mediums such as audio, in the form of tapes, CDs, DVDs or videos would be beneficial in overcoming barriers of literacy, and have been reported to be an effective mode of delivering information to patients with LEP (Husson et al, 2010; Trevatt & Kelly 2006; Watts et al, 2004).

However, it is not enough to simply translate information. This also needs to be culturally appropriate and tailored to BME groups (NICE, 2009). Therefore it is necessary to include culturally sensitive information, based on cultural beliefs and traditions, diet and nutrition, religion/spirituality, issues around skin healing post treatment, and guidance on accessing appropriate wigs and breast prosthesis (as discussed above). While charities such as Macmillan and Cancer Black Care have been working on producing high quality, culturally sensitive information (Trevatt & Kelly, 2006), this needs to be addressed at a policy level, to ensure that appropriate services and information are being developed to reflect a multi-ethnic society and appropriately disseminated. It is also necessary for healthcare professionals to be aware and provide or sign-post patients to relevant information and specialist services. Information in one's mother tongue language should be made available in the community and GP practices, not just in hospitals settings.

A provision of high quality interpreting services is also necessary in meeting informational needs and overcoming language barriers. Despite NHS Information Authority and the National Cancer Director's

(2000) recommendation that service providers should ensure that competent interpreters are available during consultations for patients with LEP, the use of interpreters in primary care has been reported to be rather minimal (Aspinall, 2007). Furthermore, recommendations have been made to ensure availability of trained interpreters for patients with LEP (NICE, 2004).

This has implications for cancer policy makers to reiterate the need for professional, medical interpreters and for healthcare professionals to be aware and make use of this service, be it face-to-face or through telephone interpretation help-lines. Healthcare professionals need to recognise that relying on family and friends as interpreters is not appropriate. However, they may be used in extraordinary circumstances, during basic consultations and if the patient refuses the use of a professional interpreter (Alexander, Holder, Jackson & Barge, 2009; NICE, 2004). It is also recommended that healthcare professionals are appropriately trained in working effectively with interpreters. Such training would need to involve how to access interpreters and consider interpreter characteristics. For example, the need for same sex interpreter, when dealing with sensitive health concerns (especially in BME communities who value issues of privacy and modesty), and aiming to use the same interpreter throughout the patient's cancer journey, so that rapport and trust can be developed between the patient and interpreter. At present, various NHS Trusts offer their own guidelines and operate on similar policies on accessing and working with interpreter services (e.g. NHS Peterborough (Pankhania, 2011); NHS Sheffield (Johnson, 2009)). It would be beneficial if policy makers can produce guidance on the provision of interpreter services that can be utilised across cancer networks.

It is important to note that while healthcare professionals may be doing their best to use interpreter services, the onus is not entirely on them. It is possible that they are unaware that patients (especially those they are seeing for the first time) are not able to communicate well in English and are in need of an interpreter. This can be particularly challenging if interpreters need to be booked in advance. In a similar vein, patients may fail to inform healthcare professionals that they need an interpreter because they are unaware of such services. This was the case for the women in study 3. Another recent study also found that BME groups are unaware that healthcare professionals can access interpreting services during medical appointments (Barron et al, 2010). This problem can be overcome if the patient's language ability and need for an interpreter is recorded and/or made known at referral processes so that adequate arrangements can be made. The first point of contact for patients is in primary care. Therefore, it may be useful for this information to be recorded in this first instance and passed on to secondary care. It would also be beneficial for GPs to inform and make patients aware of interpreter services, so that they can request them.

Finally, government policies need to ensure that appropriate resources and funding is available in order to access professional interpreting services within the NHS.

8.6 Research implications

More research is needed to enhance our understanding in this area. This has been reiterated and identified by the NCEI (2010) as an important area which can help reduce cancer inequalities. Future research should continue to explore the psychosocial impact of breast cancer in BME women, both qualitatively to gain an in-depth understanding and quantitatively with a large BME population to

further investigate predictors of distress and quality of life. Particular attention should be paid to involve groups with LEP in research. Furthermore, research should not be limited to breast cancer but aim to enhance understanding of the psychosocial impact of other types of cancer amongst BME groups (including men's experiences).

When designing quantitative research, consideration should be given to the measures used. The majority of measures are mainly assessed on White, English speaking populations (Shelby et al, 2006). Consequently, some measures may not reflect the concerns and problems that may be present in BME samples. Therefore, when researching ethnic minority groups, it is important to include and/or develop culturally sensitive measures to enhance understanding of a particular group. For example, Holt et al (2003, 2007) developed a multi-dimensional and culturally appropriate spiritual health locus of control measure for Black women, comprising of active and passive beliefs in relation to the role God plays in one's health. It is important to ensure that measures selected are appropriate to the sample being assessed (Koopman et al, 2001). However, this can be challenging when researching different ethnic populations and making comparisons according to ethnicity as a cultural specific measure designed for the Black population may not be culturally appropriate for another ethnic group. It is for this reason that the God Health Locus of Control measure was used in study 4 as opposed to Holt et al's measure.

It would also be beneficial to translate measures into other languages. For example, the Hospital Anxiety and Depression Scale (HADS) has been validated in Urdu (Roy et al, 2005), and Mental Adjustment to Cancer (MAC) scale has been validated amongst patients of other ethnicities and countries (Akechi et al, 2000; Cayrou, Dickes, Gauvain-Piquard & Roge, 2003; Ho et al, 2003; Mystakidou et al, 2005). This would encourage the inclusion of BME groups in research. The methodological challenges of recruiting a 'hard to reach' population was initially found to be very challenging (discussed in chapter 3; 3.2.2). Some recruitment strategies are more successful than others when researching ethnic minority populations (see chapter 2, part 2). Accommodating BME groups' language needs is not enough to encourage participation in research. Other recruitment strategies also need to be considered. The recruitment challenges encountered in this research provides future researchers with an awareness of methods that can increase participation rates with BME communities. These include community networking and snowball sampling. Community networking would involve engaging with the community and establishing relationships with key gatekeepers such as community group members and leaders. Future researchers may also benefit in giving consideration to offering incentives, targeting areas with a high BME population and using interpreters to aid the recruitment process.

The role of support also warrants attention in BME breast cancer survivors. Family are an integral source of support for breast cancer survivors and it has been recommended that appropriate psychosocial support is also made available to them (NICE, 2004). Future research can explore the impact of breast cancer on BME patients' family members. Further research can also carry out an in-depth exploration of religion and spirituality in BME women's cancer experiences.

Many of the BME women who participated in this research were first generation immigrants. It is possible that their experiences may be influenced by levels of acculturation (defined as the "process of cultural adaptation and change that occurs when two different cultures come into contact with each other" (Ghorpade, Lackritz & Singh, 2004 p1209)). This aspect may be worth exploring in future

research and possibly seeing if differences in cancer experiences exist between first generation immigrants and second generations Britons.

Further research can help in developing effective interventions to address BME women's informational and support needs and enhance health education and awareness. At present, there is very little evidence on effective interventions that address BME women's needs (NCEI, 2010). The psychosocial interventions already available (i.e. CBT type workshops or group counselling sessions) need to be evaluated to see if they are effective in meeting BME women's cultural and language needs. Many of the South Asian women in studies 1 and 2 mentioned a workshop, Naya Rasta (New Way), which was designed to support cancer survivors from a cultural perspective. This was perceived to be very helpful to the Asian women. Future research could assess the effectiveness of this intervention to see if it would be worth implementing in other hospitals, and consideration can be given in designing a similar workshop to address Black women's needs.

Future research can also be aimed at healthcare professionals, to gain an understanding of their role and experiences of treating BME breast cancer patients, including patients with LEP.

In order to take the present research forward, adequate streams of funding opportunities need to be made available to researchers (Molassiotis & Jacobs, 2012). The National Cancer Research Institute (NCRI) strategic planning group made a number of recommendations to improve the research environment (NICE, 2004). These include funding more post-doctoral researchers and targeting funding in areas such as supportive and palliative care and psychosocial oncology. Charitable organisations such as Breast Cancer Campaign and Cancer Research UK (CRUK) provide a large amount of funding. However, CRUK no longer provide funding for palliative and supportive care research and will have a large impact on future research funding opportunities (Molassiotis & Jacobs, 2012).

8.7 Reflections on methodology

In this section I will outline my experiences of conducting the qualitative and quantitative studies. This will be followed by an account of conducting mixed methods research. Within the reflection process, my role as a researcher from the insider/outsider perspective and working with interpreters need to be acknowledged. These have been detailed in chapters 2 (part 3) and 5, respectively.

8.7.1 Qualitative studies

The exploratory nature of the qualitative studies provided the opportunity to gain an in-depth understanding of women's breast cancer experiences. The two different methods of data collection (one-to-one and focus group interviews) revealed similar findings that were both detailed and insightful, and therefore increase the validity of the findings.

The one-to-one interviews allowed the women to tell their story in great detail. It also allowed me to gain a deeper understanding and further explore the type of issues that shaped women's experiences. It was the first time I had conducted an interview study and therefore I was nervous in

meeting the first participant. However, as the interview started, the conversation flowed naturally and I found the participant was open and willing to share her experiences. As the interview and subsequent interviews took place, my confidence in interviewing increased, and developing a rapport with them came easily. Establishing a rapport with the participant is an important part of the interview process as this can determine the level of disclosure and participant's comfort in sharing their stories (Liamputtong & Ezzy, 2005). The women were all willing to share their experiences openly. There were instances where I had to probe and encourage some women (more than others) to elaborate on certain aspects of their experiences. Nonetheless I was able to gather rich and insightful data from all the women who took part.

Having familiarised myself with the breast cancer literature, I was prepared to hear emotion-provoking stories and was aware of being empathetic to the women's stories, in order for them to continue sharing their experiences. To my surprise, the first few (and majority of) participants shared their stories with such positivity, which was empowering to hear. This was not the case for all the women. I was therefore quite taken aback when a few women became emotional during the interviews. It made me realise that conducting sensitive research can be emotionally draining on the researcher, particularly if it's the first time participants are sharing their experiences (Dickson-Swift et al, 2007). Keeping a reflective journal and the support from my supervisors helped to manage the emotions and develop skills which prepared me for future interviews.

Similarly, the focus group interviews provided an opportunity for the women to share their experiences, but also to hear from other breast cancer survivors. One particular advantage of the use of focus group interviews was the interaction between participants, who could respond to others' experiences which is not possible in a one-to-one setting (Kitzinger, 1994). This method of data collection proved to be particularly useful for the participants who took the opportunity to raise concerns and ask questions to the group. It almost became a source of support, especially for women who had not been around other breast cancer survivors before. For example, in one of the focus groups, a woman who was suffering with hot flushes asked the group if they experienced this and how they manage it. All of a sudden women took out their mini-portable fans. This resulted in information being shared on how to purchase one.

A disadvantage of focus group interviews is that some participants may not feel comfortable sharing their views if it deviates from everyone else's views (Kitzinger, 1994). This was not perceived to be the case in study 2 because participants in all four focus groups were able to relate and/or differentiate their experiences from other group members, which encouraged further discussions. This was further encouraged with the use of positive and negative vignettes. Using vignettes proved to be a useful technique as it helped to stimulate discussions.

Compared to one-to-one interviews, I found that running the focus groups was a more complex process. This was because whilst listening to the discussions, and following the interview schedule, I also had to be aware of the group dynamics and ensure everyone had a fair opportunity to contribute to the discussions. There were incidences where some women, who were sharing their experiences for the first time, were overly keen to have their stories heard and often prohibited others from contributing. I found this rather hard to manage, as I did not want to seem insensitive in stopping them half way through their stories and ask to hear from others. I felt for these women, one-to-one interviews may have been more useful. Given the time frame, at times it was also hard

to bring participants back to the focus of discussion when they went off the topic, especially if it was in relation to another personal experience. On reflecting after each focus group, my skills to run them developed and the latter group interviews were better managed.

The women in all 3 studies were keen to share their experiences and often thanked me for listening and giving them the opportunity to reflect and express their feelings. Women felt that talking about their experiences helped them and were particularly motivated in taking part if such research can improve future women's cancer experiences. I was also touched that talking to me helped the women and for me personally, reiterated the importance of conducting this research.

The majority of the participants (over 90%) were recruited through breast cancer specific support groups, suggesting they were actively seeking support or wanting to offer it to others. Also, the support group facilitators announced the research at several monthly meetings and made personal phone calls to members who may not always attend the meetings. Taking into account that the facilitators stated that their support groups consisted of 50 plus members, consideration needs to be given to the particular women who agreed to participate. It is possible that women may have been too busy to take part or have no interest in research. However, it is likely that the women who did participate were self-motivated and comfortable in expressing their experiences (Rees & Bath, 2000; Shelby et al 2008). Therefore, these women's experiences may be different to non-support group users and thus findings cannot be applied to non-support group users. This emphasises the difficulty in accessing typically hard to reach groups. At the same time this was one of the very few recruitment strategies undertaken that was deemed successful.

8.7.2 Quantitative study

The quantitative design of study 4 provided the opportunity to gain an understanding of the attitudes and experiences of breast cancer within a larger BME population in comparison to White breast cancer patients.

There were many advantages of the way in which participants were recruited. Firstly, participants were recruited through cancer-specific support groups and the NHS in the hope to achieve a large and representative sample. Recruiting through the NHS was found to be particularly beneficial; as not everyone attends support groups, and many potential participants can be identified from hospital records and given the opportunity to participate. The study was eligible to be included on the NIHR portfolio. This proved to be particularly beneficial as research staff have an allocated time to conduct and assist with research. It is also in their vested interest to recruit as many participants as possible due to the financial incentive which can effect hospital funding. Therefore, the research nurses were keen to assist with recruitment. This was the main reason many Trusts were sent a large number of questionnaire packs.

There were incidences where Trusts were confident in their ability to recruit ethnic minority patients, yet response rates were low. It is possible that patients were not interested in participating or research nurses tried to recruit as many participants as they could to meet their targets, which resulted in over-recruitment of White participants and ineligible participants (i.e. women with secondary cancer or another ethnicity such as East Asian). It is important to note that this may not

have always been the research team's error as the identification of ethnic minority women based on their name is not the most accurate method. However, this was not the only way women were identified. Recruitment also took place during clinics where potential participants were directly approached by research nurses or the consultant. This would be more beneficial as the research team can accurately identify eligible participants.

The recruitment process took longer than initially anticipated. I tried to overcome this by maintaining regular contact with the research nurses to check the status of their recruitment process and encourage them to recruit. It is possible that this may have increased their response rate. However, another reason for the low response rate could be due to the fact that many patients were sent a questionnaire pack but were not interested in taking part; either as they were struggling with their cancer experience, were too busy or found the size of the questionnaire too long and burdensome (McIllmurray et al, 2001). It is also possible that unbeknown to the research team, patients who were identified from a database were non-English speaking and therefore were unable to participate. Nonetheless, many participants were recruited through the NHS, allowing me to get a large enough sample size in order to run appropriate statistical tests.

The standardised measures are widely accepted tools in breast cancer research. In addition, the use of self-constructed and open ended items allowed for the collection of valuable data which could be further explored.

8.7.3 Use of mixed methods

The integration of qualitative and quantitative research methods whilst adopting a pragmatic epistemological stance was considered to be highly appropriate for the applied nature of this research. The exploratory phase of the research allowed me to delve into the topic from a broad perspective. As a consequence, I was able to understand the range of psychosocial and cultural issues that played a significant role in shaping the women's breast cancer experience. These issues were then used to guide the quantitative phase, which allowed the research question to be further examined through specific variables and on a larger scale, so that appropriate generalisations can be inferred.

One of the reasons for using a mixed methods approach was to attain triangulation, complementarity and development; all of which were achieved. The use of multiple methods within the qualitative paradigm (use of different methodological and analytic procedures produced similar findings) and across both qualitative and quantitative paradigms enabled a range of insightful data to be gathered and allowed for a comprehensive understanding of the research question, which would not have been possible if just one of the research approaches had been used (triangulation). The qualitative phase allowed the research phenomenon to be explored in detail and to hear women's lived breast cancer experiences. Furthermore, the initial qualitative study helped guide the rest of this research (development). Such a method is deemed suitable when little is known about the research topic (Creswell & Plano Clark, 2007). The data from both the quantitative and qualitative phases produced similar findings (complementarity). Therefore, the use of a mixed method, pragmatic approach helped to obtain a comprehensive understanding of the psychosocial impact of breast cancer in Black and South Asian women; whereby the range of evidence can be

perceived to be credible to various audiences, including stakeholders (i.e. the funders of this research: Breast Cancer Campaign), healthcare professionals, patients and organisations who provide support to patients such as support groups.

Prior to conducting this research, I had no experience of conducting qualitative research, although I had an understanding of the theoretical underpinnings of qualitative research. Consequently, I was more confident in conducting, collecting and analysing quantitative data. Adopting a mixed methods approach has been an important learning process as my skills have developed in conducting and analysing data qualitatively. Using both methods has enabled me to gain a deeper understanding of both types of research and the value and appreciation of integrating qualitative and quantitative approaches in health research.

8.8 Conclusion

The qualitatively driven mixed methods approach adopted for this thesis has explored and enhanced our understanding of the psychosocial impact of breast cancer diagnosis and treatment in Black and South Asian women. The four studies make a significant contribution to an area of research that has received very little attention in the UK. The qualitative studies demonstrate breast cancer experiences in a group of both English speaking and ethnic minority women with LEP, while the quantitative study shows how ethnicity influences women's experiences. The work carried out shows that differences and similarities exist between ethnic minority and White breast cancer survivors. This research supports work carried out by the National Cancer Action Team and National BME Cancer Patient Advisory Panel and recognises that variations in cancer services' ability to meet BME women's needs are evident. The research also highlights practical and research implications that can help address patients' needs and have a positive impact on their quality of life. A great emphasis is placed on the need to provide culturally sensitive care and support to breast cancer patients. While this research adds to the current BME breast cancer literature, progress in this area needs to continue in order to improve BME women's, particularly patients with LEP, healthcare needs and experiences. This will enable the inequalities gap to narrow and accomplish an important goal set by the Department of Health (2007).

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Appendices

Appendix 1: Glossary of medical breast cancer terms

Adjuvant therapy: Additional treatment(s) that are offered after a surgical procedure, designed to target microscopic traces of tumour which may have been left behind.

Arimidex (also known as anastrozole): An example of an aromatase inhibitor. *See aromatase inhibitors.*

Aromatase inhibitors: A type of hormonal therapy that reduces the levels of oestrogen in the body by blocking aromatase, an enzyme which helps to form oestrogen from other steroids. Examples include Anastrozole (Arimidex), Letrozole and Exemestane.

Breast reconstruction: The formation of a breast shape after a total mastectomy (*see mastectomy*), using a synthetic implant or tissue from the woman's body.

Chemotherapy: The use of anti-cancer drugs to destroy cancer cells. This treatment can be given alone or as part of adjuvant therapy.

Ductal Carcinoma In Situ (DCIS): Type of non-invasive breast cancer, where the cancer cells are in the ducts of the breast, but have not started to spread into the surrounding breast tissue.

Herceptin (also known as Trastuzumab): Type of biological therapy used to reduce the risk of breast cancer coming back in women with HER2 positive breast cancer (type of breast cancer).

Hormonal therapy: Type of treatment used to inhibit the growth of hormones in the body which are responsive to cancer cells (*also see: Arimidex, Aromatase inhibitors and Tamoxifen*).

Invasive breast cancer: Type of breast cancer where the cancer cells have spread outside the lining of the ducts or lobules into the surrounding breast tissue.

Lumpectomy (also known as breast conserving surgery or wide local excision): Surgical removal of a lump from the breast.

Lymphoedema: Swelling of the arm or breast due to a build-up of lymphatic fluid.

Mastectomy: Surgical removal of the breast.

Metastasis (also known as secondary breast cancer): The spread of cancer to other organs in the body.

Neo-adjuvant treatment: Initial treatment given to shrink a tumour before the main (often surgical) treatment.

Primary breast cancer: Breast cancer which is confined to the breast and/or the surrounding area such as lymph nodes.

Radiotherapy: Type of treatment which uses high energy x-rays to destroy cancer cells

Tamoxifen: Type of hormonal therapy which uses an anti-oestrogen drug to prevent oestrogen in the body from attaching to breast cancer cells.

Appendix 2: List of support and community organisations (approached during recruitment)**Community organisations**

Organisation	Contact Name	Contact details
Asian Health and Social Care Assoc	Manager	Easton Community Association, Kilburn Street Easton, Bristol, BS5 6AW T: 0117 9540178
Asian Women's Project – Your hopes	Amina Ahmad	107 Wells Road Totterdown, Bristol T: 0117 9716770 E: amy.greenslade@ywca.org.uk
Awaz Utoah	Simi Chowdry	415 Stapleton Road Easton, Bristol, BS5 6NE T: 0117 935452 E: awazutaoh@aol.com
Bangladesh Association Women's Group	Farhana Masuk	Bangladesh Centre, 35 Mvart Road, Easton, Bristol, BS5 6JF T: 0117 9519777
Bangladesh Woman's Group	Rehana miah	14 Machen Place Riverside, Cardiff, CF11 6ER
Bhat Sangat Sandesh	Jaswant Singh	3 Mansfield Street Riverside, Cardiff, CF11 6EE T: 07974 098 416 E: jaswantmail@yahoo.co.uk
Black and Minority Ethnic Women's Network	Manager	5 Russell Town Avenue Redfield, Bristol, BS5 9LY
Black Development Agency	Rana Dildar Singh/ Folami Prehaye	5 Russell Town Avenue, Redfield, Bristol, BS5 9LY T: 0117 9396645 E: Balbir@blackdeva.org.uk
Bristol Indian Association	Manager	48 Mayfield Park North Fishponds, Bristol, BS16 3NJ
Bristol Pakistani Community Welfare Organisation	Nargis Haq	454 Stapleton Road Easton, Bristol, BS5 6PA T: 0117 9523031 E: nargishaq@hotmail.co.uk
Dekh Bhal	Daisy Rajput	42 Ducie Road Barton Hill, Bristol, BS5 0AX T: 0117 9556971
Humdard: St Paul' Asian women' group	Jamila Aftab	Halston Drive St Pauls, Bristol, BS2 9JN T: 0117 9550895 E: jAMILAaftab@yahoo.co.uk
Hindu Temple	Manager	163b Church Road Redfield, Bristol, BS5 9LA
Minority Ethnic Women's Network (MEWN) Cymru	Manager	11-12 Mount Stuart Square Cardiff, CF10 5EE T: 02920 464445 E: administration@mewn-cymru.org.uk
Saheli group	I Shrimaker	9 Franklin's Way Claverham, Bristol, BS49 4ND T:01934 838 746 E: ila@btinternet.com

Sanatan Dharma Mandal & Hindu Community Centre	Manager	22 The Parade Roath, Cardiff, CF2 3AB
Sehatmand Aurat (Asian women Health Project)	Hetal Mistry	6 West Street Old Market, St Phillips, Bristol, BS2 0BH T: 0117 9412983 E: hetal@wellwoman.freeserve.co.uk
Shree Swaminarayan Temple	Manager	4 Merches Place Grangetown, Cardiff, CF11 6RD T: 029 20371128 E: info@swaminarayanwales.org.uk
Sikh Resource Centre	Narinder Kaur	114 St Marks Road Easton, Bristol, BS5 3JD T: 0117 9525023 E: sikhresourcecentre@supanet.com
South Riverside Community Development Centre	Mashuma	Brunel Street Riverside, Cardiff, CF11 6ES T: 02920 220309
Women of African and Caribbean Heritage	Sadie Rogers	31 Highfield Close Stoke Gifford, Bristol, BS34 8YB
Malcolm X Centre	Manager	141 City Road St Pauls, Bristol, BS2 8YH T: 0117 901 3889

Cancer support groups/charities

Organisation	Contact name	Contact details
Afiya Trust**	Meena Patel	27-29 Vauxhall Grove, Vauxhall, Lambeth, United Kingdom, SW8 1SY T: 020 7582 0400 E: meena.patel@afiya-trust.org
African Caribbean Cancer Group(Nottingham)	Manager	afrocaribcancersupp.nott@yahoo.com
Asian Cancer Support Group (North London)	Trupti Morzaria	Birchwood, 184 Highfield Way, Rickmansworth, Hertfordshire, WD3 7PJ T: 01923 776 176 E: cancer@oewa.org.uk
Asian Cancer Support Group (South London)	Mrs Nayana Shah	37 Florida Road Thornton Heath, Surrey, CR7 8EW T: 020 8764 8928 E: info@oewa.org.uk
Asian Cancer Support Group (West London)	Saroj Sethi	Dormerswells Community Center, Dormerswells Lane, Southall, UB1 3HX T: 07723 083007 E: asiancancersgwl@yahoo.co.uk
Asian Women's Breast Cancer Support Group (AWBCG)**	Bharti Patel/ Mita Kotecha	T: 07790 538499/07968 386798 E: email: info@awbcg.co.uk
Betterdays Cancer Care	Ms Marina Raime	87 The Meads Barnet, Edgware, HA8 9HE T: 0208 9063734 E: betterdaysbarnet@yahoo.co.uk
Breast Cancer Care** (Breast cancer voices)	Karen Scanlon	T: 0207 960 3467 E: Karen.scanlon@breastcancercare.org.uk
Breast Care Haven	Mrs Julia Harrington	Effie Road, London SW6 1TB T: 020 7384 0044 E: jeh@breastcancerhaven.org.uk
Bridges, Murryhall Community Trust	Manjula Patel	Neptune Health Park, Sedgley Road West, Tipton, West Midlands DY4 8LU T: 0121 607 6404 E: murrayhall@which.net
Cancer Black Care**	Jean Gilkes	79 Acton Lane London, NW10 8UT T: 020 8961 4151 E: jean@cancerblackcare.org
Cancer Support Centre (Dudley)**	Pam Cartwright	T: 01384 231232 E: info@support4cancer.org.uk
Cancer You Are Not Alone (CYANA)	Bilquis	31 snowhill road Manor Park, London, E12 6BE T: 0208 5535366 E: bilquis.cyana1@tiscali.co.uk
Coping with Cancer	Nayna Amlani	Helen Webb House, 35 Westleagh Road Leicester, LE3 0HH T: 0116 223 0055 E: post@c-w.c.org.uk
Macmillan Cancerlink Cancer VOICES Project**	Damyanti Patel	89 Albert Embankment London, SE1 7UQ T: 020 7091 2004 E: dpatel@macmillan.org.uk
The Paul D'Auria Cancer Support Centre	Beverley Van der Molen	20 – 22 York Road Clapham, London, SW11 3QA T: 020 7924 3924 E: support@paulscancersupportcentre.org.uk

** Very helpful

Appendix 3: Community group letter



Faculty of Health & Life Sciences
University of the West of England
Centre for Appearance Research Coldharbour Lane
Bristol
BS16 1QY

18th May 2009

Dear Sir/Madam,

RE: Research into breast cancer experiences in Black and South Asian women

I am a PhD researcher from the University of the West of England, working with Dr Diana Harcourt, Mr Habib Naqvi and Prof. Nicky Rumsey, researching the experiences of Black and South Asian women who have been diagnosed as having breast cancer.

I am writing to ask for your help and whether members of your group would be interested in taking part in this research.

Until now, most research looking at women's experiences of breast cancer has been focused on Caucasian women and there is very little work that captures the experiences of Black and Minority Ethnic women (BME). In order to improve current care and understanding, it is important that the experiences of breast cancer amongst BME women are adequately researched. The aim of my research is to provide guidance to health professionals in order that culturally sensitive and appropriate care is provided to Black and South Asian women with breast cancer.

I have enclosed an information sheet which outlines the nature of the study in more detail and would be very pleased to discuss it with you. If you are interested, I can be contacted on 0117 328 1895 or by email at Geeta2.Patel@uwe.ac.uk to discuss the possibility of your group's involvement in this research. I am more than happy to meet with your community group members to raise awareness of breast cancer issues amongst Black and South Asian women.

Thank you for your time.

Yours Faithfully

Miss Geeta Patel

Supervised by Dr Diana Harcourt
Email: Diana2.Harcourt@uwe.ac.uk
Telephone: 0117 3282192

Information Sheet

Breast cancer experiences in Black and South Asian women

Research Objective

Having breast cancer can be a significant life event for women and their families. The purpose of this study is to understand what it is like to be diagnosed with breast cancer and how treatment affects people's lives. Until now, most research has focused on the experiences of Caucasian women and there has been very little research into the experiences of Black and South Asian women who have been diagnosed as having breast cancer.

This study is therefore investigating how breast cancer affects the lives of Black and South Asian women. If we have a better understanding of how breast cancer affects women's lives, we may be able to improve the care and support for other ethnic minority women.

Method

Women who choose to take part in this research will be individually interviewed in their own homes (at a time that is suitable for them), where they will be given a chance to talk about their experiences of breast cancer treatment and diagnosis. The interviews will be tape recorded and can take between 60-90 minutes. An interpreter will be available for women who wish to take part in the interview in a language other than English.

Who can take part?

The research is aimed at Black and South Asian women who are over the age of 18 and have been diagnosed with breast cancer.

Your involvement

If you are able to help with this research, it would be greatly appreciated if you can pass on the details of this study to potential participants. Alternatively, your help in distributing participant information letters inviting them to take part would also be appreciated. Letters in postage paid envelopes and address labels will be provided.

If your support group is able to help and would like to know more about the research, then the researchers would be very pleased to meet you, at your convenience.

Your help in promoting this study to Black and South Asian women would be highly beneficial in order that we can influence the provision of appropriate care and support for women who are diagnosed with breast cancer in the future

Ethical approval

This study has been reviewed and approved by the University of the West of England, School of Life Sciences Ethics Committee (Ref: HLS08-476).

Further information

If you would like further information, or have any questions, please contact me:

Geeta Patel, on 0117 328 1895 or at Geeta2.Patel@uwe.ac.uk.

Supervised by Dr Diana Harcourt

Email: Diana2.Harcourt@uwe.ac.uk; Telephone: 0117 3282192

Thank you for taking the time to read this information

Appendix 4: Study 1 Poster





Breast Cancer in
African, Caribbean & South Asian women
I am interested in
hearing about YOUR experiences!

Having breast cancer can be a life changing event for women and their families. Until now, most research has focused on the experiences of White women with very little research exploring the experiences of Black and South Asian women.

I am therefore interested in hearing about your experiences of having lived with Breast Cancer.

Women interested in taking part will be interviewed by the researcher at a time and place of your convenience. Interpreters are available if you would like to be interviewed in your own language. Your responses will be kept strictly private and your name will not be used in the study.

If you would like to share your experiences or know of someone who may be interested, please contact, Geeta Patel for further information on 0117 328 1895 or by email at Geeta2.Patel@uwe.ac.uk.

Appendix 5: Study 1 and 3 Interview schedule

Interview schedule

Firstly I would like to thank you for taking part in my research and for signing the consent form. I would also like to remind you that you do not have to answer any questions that you do not feel comfortable talking about. You are free to stop the interview at any time or if you feel you need a break, please let me know. With your permission, the interview will be recorded but be assured that what you say will be kept confidential and anonymous and the tape will be destroyed at the end of this research.

I am interested in your experiences of being diagnosed with breast cancer and the treatments you received, in particular if your experiences have in any way been affected by your ethnicity. There are no right or wrong answers so please feel free to talk as honestly and openly as possible. If there is anything I have missed out that you feel you would like to talk about, please feel free to bring it up anytime.

Does that sound okay? Any questions before we start?

Diagnosis and treatment experiences

I would like to start by asking you about your breast cancer diagnosis.

How did you find out about your breast cancer? *Screening? Self-discover?*

How were you told? *Was it clearly explained? Were you reassured?*

What type of cancer was it? *Stage?*

How did you feel at this stage? *Or shortly after diagnosis?*

I am also interested in the treatments that you received and the decisions you made about your treatment.

What kind of treatment did you receive?

Mastectomy/lumpectomy/chemo/radiotherapy/tamoxifen/ reconstruction/breast prosthesis?

How long did the treatment last?

How did you feel about having this treatment?

Were you offered a choice in the treatment? Were surgical options discussed? What factors influenced your decision-making? Was the decision difficult to make? Did you make the decision on your own or with others? Do you feel that your decision was in any way influenced by your ethnic identity?

Surgical treatment:

Mastectomy/Lumpectomy: *What influenced your decision to have the surgery that you had?*

Breast reconstruction: *Would/did you consider breast reconstruction? Yes/ no why?*

What made you decide to go for breast reconstruction?

How did you feel? Have you experienced any physical changes? If so what? Were you satisfied with the surgery? Did you feel you received adequate information or do you wish you had been told more? Was the surgery immediately after the mastectomy or a bit later?

Breast prosthesis: *Would/did you consider breast prosthesis? Yes/ no why?*

What's it like wearing a prosthesis? *What made you decide to go for breast prosthesis? How did you feel? What was it like to get fitted for the prosthesis? What was the fitter like? How often did you wear it? Were there certain circumstances when you would wear it and others when you would not? Have you experienced any physical changes since having the prosthesis? What impact did the prosthesis have on you personally? Do you feel the prosthesis makes a difference?*

How did you feel during and after the treatment?

Did you experience any side effects (Hair loss, tiredness)? Were you satisfied with the treatment? Did anyone prepare you for what it would be like?

When did you complete your treatment?

How did you feel about the care/information you received from your GP/consultants?

How did you feel about going to the hospital for treatments? How well do you think the staff and the services at the hospital met your own needs? Was there adequate support/information available to you? Did you look for information from anywhere other than the hospital? Where? Was this easy/difficult to find?

Did you tell anyone about the cancer? Who?

How did your [family/partner/friends] react to your diagnosis/ treatment? (Who else did you tell? How did they react?

Has having breast cancer affected your relationships with family/friends?

In what way?

Has having breast cancer affected your relationship with your husband/ partner in any way?

Any aspect better than it was? Any aspect not so good?

Has it made any difference to your physical or intimate relationship? If so how? Have you talked about this with your partner?

While undergoing treatment, some women experience changes to their appearance while others do not, and for some women this is a concern whilst for others its not.

Has undergoing treatment changed the way you feel about your appearance or body? If so, in what way?

How did you feel about your body/appearance before the diagnosis?

Since your cancer, do you see yourself differently in terms of your physical appearance?

Has having had cancer affected the way you see yourself as a woman? In what way?

Women tend to deal with their cancer in many different ways.

Were there any things that you felt you had to cope with or deal with as a result of your cancer diagnosis and treatment?

If so, what were they? How did you try to manage those things? *Anything you found difficult?* Did you feel well supported? Support groups?

Experiences of breast cancer and ethnicity

I am interested in hearing about your ethnicity and if your experiences have in any way been affected by your ethnicity.

Can you tell me a bit about your ethnic identity?

How would you describe your ethnicity? What was it like growing up in an Asian/Black culture?

How does your culture (or people in your community) deal with illnesses?

Is it openly talked about? How would you describe their understanding/knowledge of illnesses or breast cancer? What was your understanding of breast cancer? Did you try to find meaning as to why you got the cancer?

Breast cancer is often portrayed as a “White woman’s disease”.

What are your feelings/views on this?

Do you think your experiences were different because of your colour/ethnicity?

Some women turn to religion/spirituality to help them cope and deal with their breast cancer experiences.

Has this been important for you during your experiences?

Are you religious? Would you feel comfortable talking about this to your GP/consultants?

Overall thoughts

What are your overall thoughts and feelings about your experience?

Is there anything you do or do not do differently? Activities?

What has been the hardest point of your breast cancer experiences? How did you get through that?

How do you feel now?

What’s changed? Why/ how?

Were there any positive outcomes from your experience?

Do you have any concerns or feelings about the future?

Recurrence? Children? Intimate relationships?

What advice would you give another woman like yourself if she has just been diagnosed with breast cancer?

So if I had to summarise what you’ve told me, it would be that... (Summarise main issues). Is there anything else that you’d like to talk about or add to what you have already said?

Thank you for your time.

Appendix 6: Study 1 Participant Information Sheet

University of the
West of England

Participant Information Sheet**Breast cancer experiences in Black and South Asian women**

You are being invited to take part in a research study. Before you decide whether to take part or not, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

What is the purpose of the study?

Having breast cancer can be a significant life event for women and their families. The purpose of this study is to understand what it is like to be diagnosed with breast cancer and how treatment affects people's lives. Until now, most research has focused on the experiences of Caucasian women and there has been very little research into the experiences of Black and South Asian women who have been diagnosed as having breast cancer.

This study is therefore investigating how breast cancer affects the lives of Black and South Asian women and this is why we are interested in hearing about your experiences. If we have a better understanding of how breast cancer affects women's lives, we may be able to improve the care and support for other ethnic minority women.

Why have I been chosen?

We are inviting Black and South Asian women over the age of 18, who have been diagnosed with breast cancer to share their experiences. We would like to interview 18 women.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. If you decide not to take part or later choose to withdraw from the study, doing so will not affect the health care you receive in any way, now or in the future.

What do I have to do?

If you choose to take part in the research you will be interviewed by a researcher, Geeta Patel, in your home at a time that suits you. The interview will be informal and relaxed and the researcher will ask you questions about your experiences of having breast cancer. There are no right or wrong answers and you do not have to respond to any questions that you do not feel comfortable answering. The interview can last between 60 to 90 minutes, however you are free to talk as much or as little as you would like to. With your permission, we would like to tape record the interview. If you would prefer to be interviewed in your own language, an interpreter might be available and we will discuss this possibility with you, before the interview takes place.

Will my taking part in this study be kept private?

All information which you provide will be kept strictly private. We will not use your name in our study. Your responses will be kept in a safe place and will only be used for research purposes. Only the researchers working on this study will have access to your responses. All recorded information will be destroyed once the study is finished.

What are the possible benefits of taking part?

This is your chance to talk about your experiences. The information you give will help us understand your experiences better and we may be able to use this information to improve healthcare services for ethnic minority women with breast cancer.

What are the possible disadvantages of taking part?

We realise that being diagnosed with breast cancer and having treatment for it can be a very personal and distressing experience which you may find difficult to talk about at times. If you do decide to take part in this study, you can ask to stop the interview at any time or choose not to answer questions you feel are too personal to talk about.

How can I withdraw from the study?

If you decide that you no longer want to take part in the study, you can get in touch with the researcher and quote your participation number. Your data will then be destroyed and will not be used in the study. You have up to 6 months to do this.

What will happen to the results of this study?

The results of this study will be shared with health professionals and other breast cancer related organisations (such as the charity Breast Cancer Campaign, who are funding this research). In addition the results may be discussed in academic journals or presented at conferences, but you will not be named or identified in any outputs that come from the research.

Who has reviewed this study?

This study has been reviewed and approved by the University of the West of England, School of Life Sciences Ethics Committee to make sure that it is being carried out in an appropriate manner.

What do I do now?

If you are interested in taking part or would like any further information, you can contact the researcher, Geeta Patel, on 0117 328 1895 or at Geeta2.Patel@uwe.ac.uk.

If you have any concerns about breast cancer, you can contact the following breast cancer organisations for further support: Breast Cancer Care Helpline on 0808 800 6000, NHS Direct on 0845 4647 or alternatively contact your GP.

Thank you for taking the time to read this information and for thinking about taking part in this research.

Geeta Patel, PhD Student

Supervised by Dr Diana Harcourt

Email: Diana2.Harcourt@uwe.ac.uk Telephone: 0117 3282192

Centre for Appearance Research

University of the West of England, Bristol

BS16 1QY

Version 1 date: 25/02/09

Appendix 7: Study 1 Consent Form**CONSENT FORM****Title of Project:** Breast cancer experiences in Black and South Asian women**Name of Researcher:** Geeta Patel

Please initial box

1. I confirm that I have read and understood the information sheet dated 25/02/09 for the above study and have had the opportunity to ask questions.
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason and without my healthcare or legal rights being affected.
3. I agree to my interview being tape recorded.
4. I agree to take part in the above study.

 Name of Participant

 Signature

 Date

 Researcher

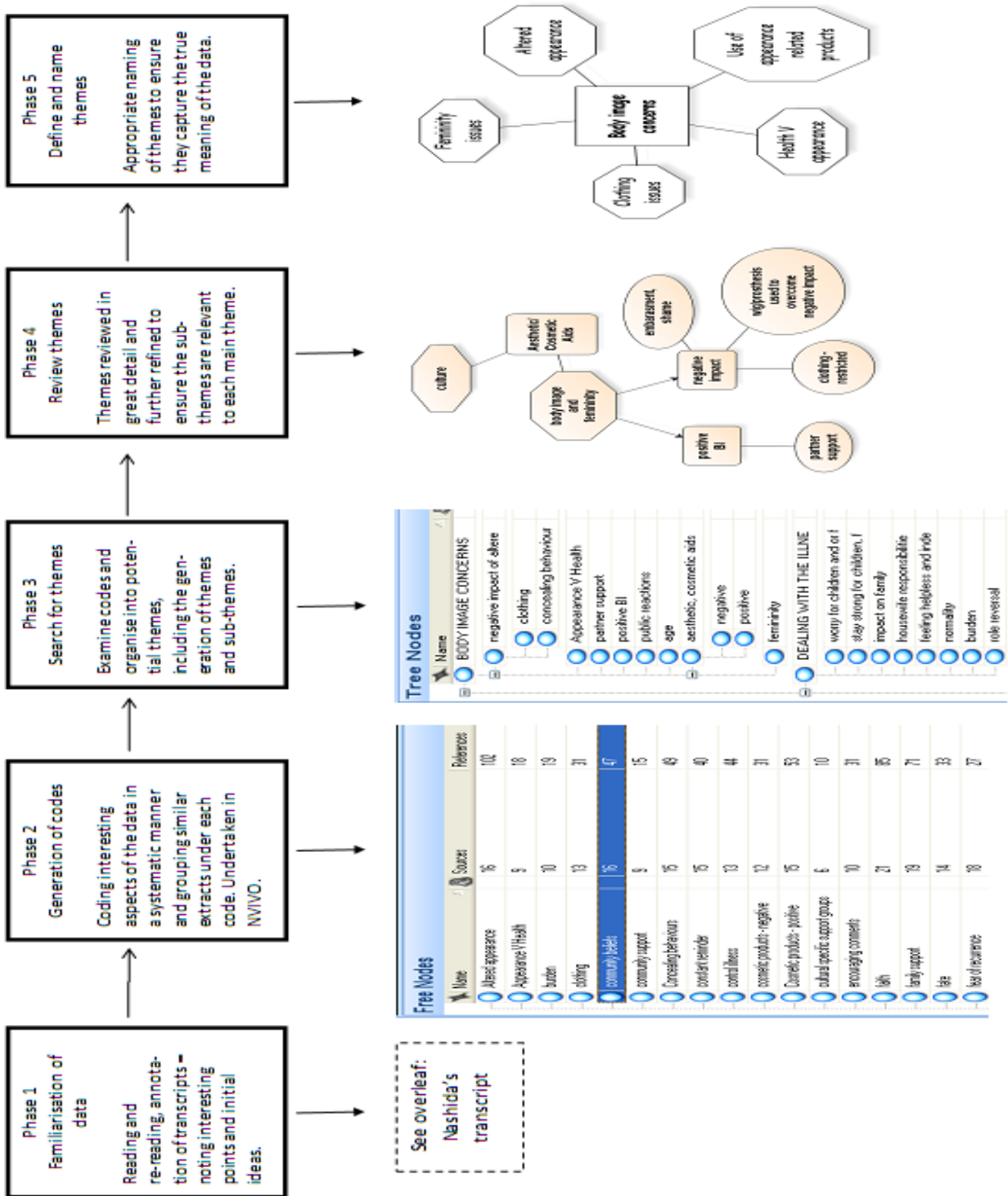
 Signature

 Date

1 copy for participant; 1 copy for researcher

Appendix 8: Applying thematic analysis and IPA to the datasets

Worked example of carrying out thematic analysis on the dataset (as outlined by Braun & Clarke, 2006); see also transcript of interview with Nashida, overleaf.



Worked example of carrying out thematic analysis on the dataset (as outlined by Braun & Clarke 2006): Nashida's transcript

Study 1: Thematic Analysis

Nashida, Aged 50, South Asian: Pakistani

What kind of surgery did you have?

The left... they wanted to remove the whole and then they... maybe they thought of my age or something so they said that they will cut it and they showed me that big lump. Horrible black, in the plate it was and um... 4-5 days I stayed in hospital and I came back home and I started getting you know... it was healing but it was very painful. Oh very painful. They gave me morphine injection to release my pain. After that they told me that I'm going to have chemo. So in August I had my surgery.

August, September, October, November, December, January - yeah I think after 4 months, they started my chemo and I had 6 doses of that chemo. It was... it makes me oooo I still remember, I used to take it

and come back and... I can't explain it. It was making me sick, couldn't eat for 1 whole week then ALL my hair was gone. I lost ALL my hair, I had long nice straight hair, they were ALL going, so ALL bald. And

I never went out for 2 years! 2 years I stayed home. I was too shy, too nervous to go out, tell people, a part from my appointments. I used to have a black scarf; I still have that I didn't throw it, in my box, I used to wear and people thought I become a very religious lady now [laughs]. "suddenly what happened to her? She so religious, she don't come out now. She's become spiritual or something". I said "I am, I am". Because my face was very pale at that time and I never used to do any make up.

These were gone also [eyebrows?] yeah. These eyelashes [eyelashes as well?], eyebrows, eyelashes all ...I was looking horrible, black. All black and my complexion was so pale and I was looking like an old

lady and I always used to think I'm going to die next week maybe after when I will have this chemo again and I will die, I will write everything, tell my children where my money is, where my jewellery is.

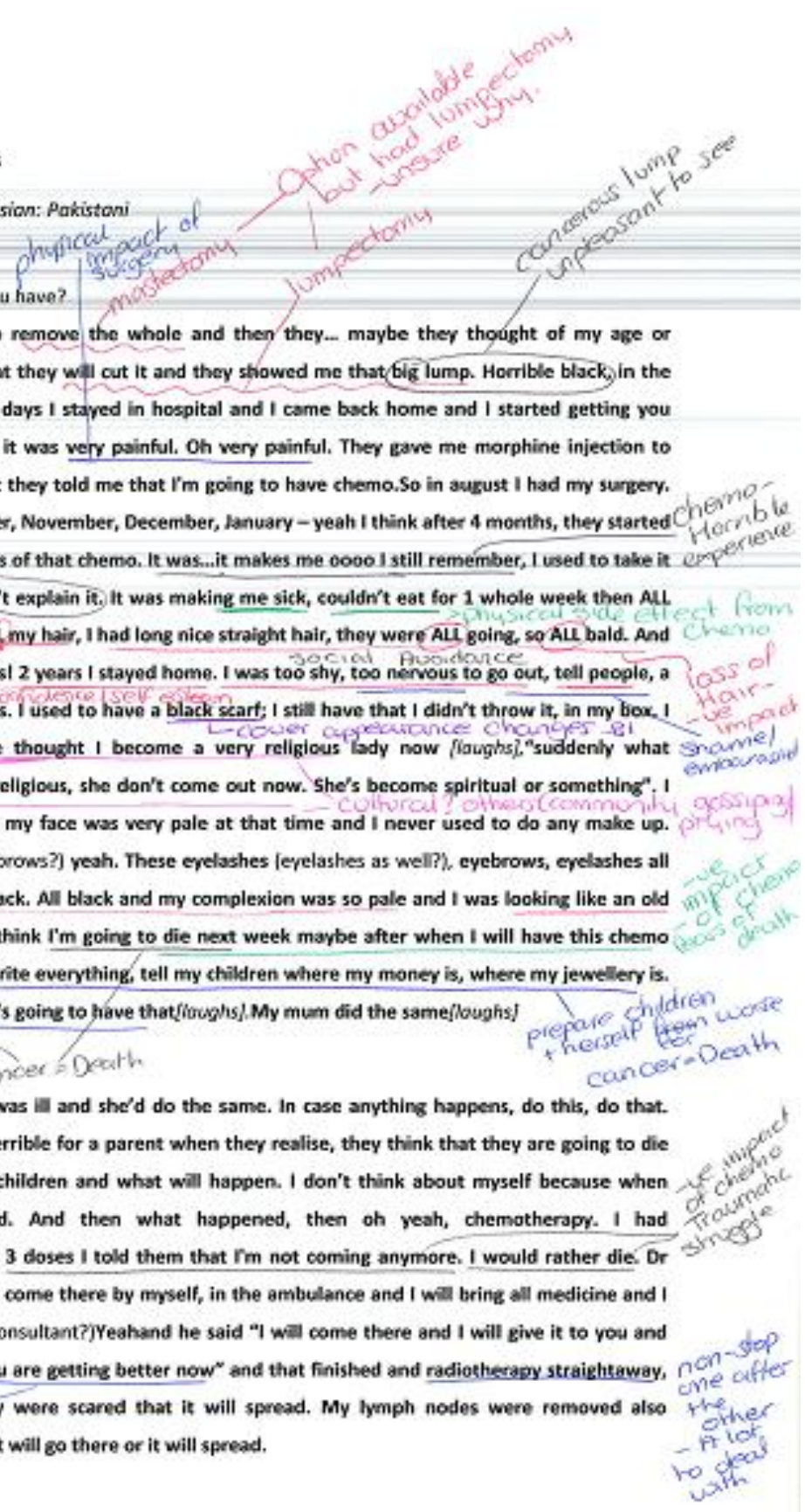
She's going to have this, he's going to have that [laughs]. My mum did the same [laughs]

Your mum had cancer?

Not cancer but when she was ill and she'd do the same. In case anything happens, do this, do that.

They worry. Yeah and it's terrible for a parent when they realise, they think that they are going to die and they think about the children and what will happen. I don't think about myself because when you're dead, you're dead. And then what happened, then oh yeah, chemotherapy. I had chemotherapy, when I had 3 doses I told them that I'm not coming anymore. I would rather die. Dr

****, he said to me "I will come there by myself, in the ambulance and I will bring all medicine and I will GIVE it to you!" [Your consultant?] Yeah and he said "I will come there and I will give it to you and you will have it because you are getting better now" and that finished and radiotherapy straightaway, after 2 weeks because they were scared that it will spread. My lymph nodes were removed also because they thought that it will go there or it will spread.



Chemo - traumatic experience

physical side effect of chemo

Body image concerns

Chemo to appearing old + frail

worry for family

Support HCP + the

the HCP support re-assurance provided encouragement

Chemo - Horrible experience

physical side effect from chemo

loss of hair - be impact shame/embarrassed

cultural? other of community gossiping

prepare children + herself been worse for cancer = Death

the impact of chemo Traumatic struggle

non-stop one after the other - A lot to deal with

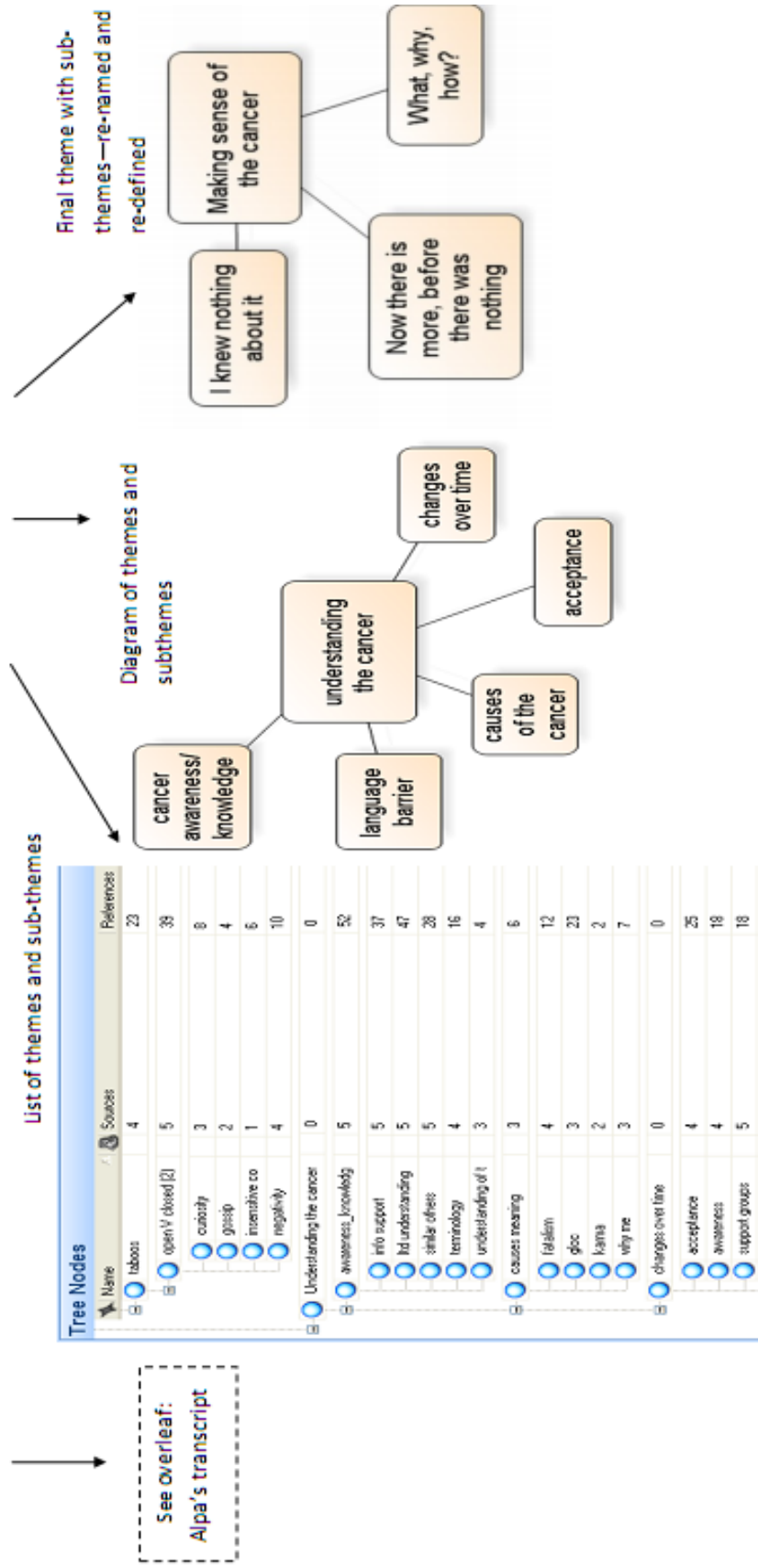
Worked example of carrying out IPA on the dataset (as outlined by Smith & Osborn, 2003); see also transcript of interview with Alpa, overleaf.

Phase 1
Looking for themes

- Transcript was read several times.
- Left-hand margin used to note interesting aspects of the participant's experience throughout the transcript.
- Returning to the beginning of the transcript, the right-hand margin was used to note down initial codes/themes that emerge (based on notes from left-hand margin).

Phase 2
Connecting the themes

- Emergent themes were listed and organised into cluster of themes (in NVIVO).
- Themes and sub-themes reviewed to ensure they encapsulate important aspects of the data and capture the true meaning of the participant's experiences. Relevant extracts were placed under each theme/sub-theme.
- Themes/sub-themes constantly modified and further developed until a master of themes was created.
- Final set of themes defined and translated into narrative accounts.



See overleaf:
Alpa's transcript

Appendix 9: Summary of qualitative findings for participants

[UWE headed paper]

October 2012

Dear

Black and South Asian women's experiences of being diagnosed and treated for breast cancer

Since 2008 I have been researching breast cancer experiences in Black and South Asian women. I have conducted 3 interview studies and you have taken part in one of these studies.

I would like to thank you again for your time and participation in my research. The information you shared was very interesting and insightful, and has enhanced our understanding about ethnic minority women's breast cancer experiences.

Please find enclosed a summary of the findings from the interview studies that I carried out. I hope you find this useful. Please feel free to get in touch if you have any comments or further questions about this research.

Best Wishes

G.Patel

Geeta Patel

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Black and South Asian women's experiences of being diagnosed and treated for breast cancer

Funded by Breast Cancer Campaign

Feedback for participants and support group facilitators

Background to the research

The diagnosis and treatment of breast cancer can be a challenging and distressing experience for any individual, yet very little is known about Black and Minority Ethnic (BME) women's experiences of breast cancer, especially in the UK. It is possible that their experiences may differ from White women's which may be influenced by their cultural beliefs and values. It is important to understand patient's experiences in detail to ensure that ethnic minority women receive appropriate care and support that is culturally sensitive to their needs. Therefore, the aim of my research was to explore British Black and South Asian women's experiences of being diagnosed and treated for breast cancer.

The studies

Three interview studies were carried out:

1. One-to-one interviews were conducted with 11 Black and 11 South Asian English speaking women to gain a better understanding of their breast cancer experiences.
2. 4 group interviews were conducted with 10 Black and 10 South Asian English speaking women to understand how women manage their breast cancer experiences.
3. One-to-one interviews were conducted with 5 Indian Gujarati-speaking breast cancer survivors, who have a limited understanding of the English language.

Findings

On the whole, the women found their breast cancer experience to be physically and mentally draining. They were very emotive in the way they described their experiences and expressed feelings of shock, devastation, worry, distress, anxiety, depression and anger. The shock of the news made it hard for many of the women to accept their diagnosis, although this changed over time. It was a life altering experience and one that will not be easily forgotten.

Study 1

Six main themes emerged from the interviews. These are described below.

1. Familial concerns

The cancer experience did not just affect the individual but was described as an emotional time for everyone around them, particularly family members. All the women emphasised how their breast cancer had a negative impact on their family members. This often resulted in many women putting their family member's needs before their own by downplaying the illness so their family would worry less.

2. Social support

The majority of the women spoke of receiving unlimited support from their family members, friends, work colleagues, church members, healthcare professionals and support groups. The women described their sources of support to provide invaluable practical (help with household chores such as shopping, cooking and cleaning), emotional (listening ear, words of encouragement and positivity), moral (visiting them at hospitals and/or their homes and going to hospital appointments with them) and informational support (advice/leaflets about breast cancer).

Whilst the majority of the women were very well supported; a few talked about how they had no family to turn to and, in some cases, their work colleagues were not understanding or supportive. This affected these women in a negative manner and they felt that they had to be proactive in finding appropriate care and support. A few women found that not all their friends were supportive and some did not bother at all due to the possible fears and taboos associated with cancer.

Support groups were described as a great source of support by many of the women. Here, the emphasis was placed on being around other breast cancer survivors who could understand what they were going through. Moreover, support groups that were designed to provide culturally specific support were found to be highly beneficial in addressing the women's cultural needs and concerns.

3. Spirituality

Many women held a strong belief that God was in control of their illness and would help them get through their cancer journey. Women engaged in religious activities such as praying, reciting mantras, reading holy books, and listening and singing religious hymns. However, some women felt that the cancer was a form of punishment from God for bad deeds. This belief was further encouraged by members of their community who would imply that they must have done something to deserve it.

4. Body image concerns

Many women spoke about the negative impact that treatment had on their appearance and body image. The loss of a breast and/or undergoing hair loss was devastating, with many reporting feelings of distress, shame, embarrassment and having little confidence in the way they looked and

felt about their bodies. Although changes to appearance had a negative impact on them, some women psychologically prepared themselves by taking control of the illness. This included getting appropriate information from others, maintaining their appearance (regardless of the changes), and being proactive in managing the side effects of treatment (e.g. exercising to control weight gain and shaving their hair off rather than waiting for it to fall out).

Although products such as wigs, breast prosthesis and lymphoedema sleeves were available to help women deal with their altered appearance, many expressed their dissatisfaction and felt that culturally, they did not meet their needs. For example, some women explained how wigs were designed for White women and therefore did not look natural on them. They described how wigs designed specifically for South Asian and Black women were limited and not readily available on the NHS and they had to go elsewhere to buy a suitable wig.

5. Healthcare experiences

Women's healthcare experiences varied. The majority of the women were extremely satisfied with the care that they received. Healthcare professionals, particularly breast care nurses, were described as being caring, sympathetic and very supportive. Consultants and nurses clearly explained all aspects of the breast cancer process including treatment side effects. The women were assured at each stage of their illness and felt the nurses were invaluable in the informational, practical and emotional support they provided.

However, some women felt that their healthcare team were not always supportive or attentive to their needs. Some felt that information regarding treatment was not clearly explained and, occasionally treatment nurses lacked empathy.

Modesty plays a big role in BME cultures. Many of the South Asian women talked about feeling uncomfortable when treated by male nurses and found it very embarrassing and shameful the first time they had to expose themselves to male healthcare professionals.

6. Life post-cancer.

Finally, all the women spoke of how they felt once treatment had ended, comparing the difference in their quality of life before and after cancer. For many, the side effects from treatment limited daily chores and activities such as cooking or long distance driving. However, not everyone let the negative changes bother them. Many remained positive and were keen to adopt a healthy lifestyle. All the women took the time to reflect on this life-threatening experience and stated having a newfound appreciation for life and living it to its fullest.

Women were also highly motivated to make a difference and did so by supporting other cancer patients and educating and raising awareness of breast cancer within their communities in the hope of reducing the cultural taboos and stigmas attached towards illnesses such as cancer.

Study 2

The findings from this study revealed three main themes.

1. Social support needs

Similar to study 1, women spoke of the ample support received from various sources and the importance of receiving the right amount of support in order to help them cope with their cancer experiences. In particular the importance of receiving informational support from healthcare professionals, being around other cancer patients (particularly culturally specific support groups and its ability to provide on-going support, especially once treatment is over) and relying on God as a source of support played a big role in helping the women manage their experiences.

A small number of women explained how some aspects of their support needs were not fully met by family, friends or members of their healthcare team. There were also instances where many women felt over-supported and were trying to manage this support along with dealing with the cancer experience.

2. Loss of control

All the women were looking for explanations for why they got the cancer. They felt they needed to be able to understand why they got it and take proactive steps in order to accept and manage it better. Many felt that the cancer was pre-determined by an external force such as their God's will and accepted it as part of their fate, while others expressed their beliefs of Karma. Accepting the cancer was out of their control; women needed to gain some control and did so by dealing with the cancer in a positive manner. For example, a few women who had to undergo chemotherapy treatment took control by cutting their hair short rather than waiting for it to fall out. Women did not want the cancer to take over their lives and were determined to preserve as much normality in their lives as possible.

3. Cultural taboos and expectations.

A recurrent discussion within all the groups was based on how their community and family members' cultural beliefs and attitudes affected the women's breast cancer experience. In both the Black and South Asian communities, life threatening illness such as cancer can be a very private matter and is not openly talked about. The South Asian women explained that in their culture it is not acceptable to talk about a private body part (especially in front of male relatives) or to reveal their body to anyone but their husband. Cultural stigma of breast cancer includes the negative impact it can have on the family's reputation, especially if there are daughters involved as it can hinder future marriage proposals. Many women also felt that they were being culturally judged and had to listen to negative and insensitive comments which implied they must have done something wrong in life and therefore deserved to be punished.

This often resulted in women being frustrated with the perceived narrow minded views, which enhanced feelings of isolation. Again, the women managed this in a positive manner by being open about their cancer and re-interpreting the negative attitudes in a positive light. Many were also keen to abolish cultural taboos and stigma by educating community members and raising breast cancer awareness.

However, throughout the discussions, women acknowledged that over time, attitudes and awareness towards cancer have changed and people are more accepting of the illness now than they were 10 years ago.

Study 3

The Indian Gujarati-speaking women's breast cancer experiences were captured through 5 main themes.

1. 'Making sense of the cancer'

It was important for the women to be able to understand the concept of cancer and make sense of it in order to accept what was happening to them. Some women had very limited knowledge of breast cancer. This included an unawareness that a lump can be something serious and potentially related to cancer or that cancer can occur without showing any obvious signs such as a lump. As a result, the unexpected diagnosis combined with the lack of knowledge of cancer was found to be a highly shocking and distressing experience for all the women. A limited understanding of cancer also resulted in many women holding inaccurate beliefs such as cancer can be caught or only White women get it.

The fact that the women were not literate in the English language also affected their ability to gain a full awareness and understanding of the cancer. Even if they wanted to, some women felt they were unable to ask questions or gain a better understanding because of their limited ability in speaking or understanding English. Some women also found that, at the time of their cancer diagnosis, information in their own language was not available to them. However, over time this has become available prompting women to understand and learn more about breast cancer and other types of cancers.

Women in this study were also looking for causes and explanations for why they got the cancer and often felt that it was because of stress or accepted that these things happen and it was God's will.

2. 'A shared experience'

As well as having a strong faith in God, family members played an important role in these women's experiences and were described as being very supportive. Due to the English language being a barrier, the women were dependent on them to translate their breast cancer information. This meant that someone would always have to take the women to their hospital appointments and act as translators. While some women felt they had no choice but to rely on their family members to support them, others did not want to be a burden and would often go to their appointments alone and try to get by with their little understanding of English. These women did this even though they knew they could not ask further questions or fully understand what they were being told. Relying on others to translate information often meant that family members were involved in helping women make treatment decisions or decide the best treatment for them.

3. 'Replacing the negative with the positive'

The cancer experience as a whole was very shocking and upsetting for all the women. Nonetheless, they were all determined to get through the experience, and did so with a positive attitude. Women tried not to let the side effects of treatment get them down. They did this by doing activities and daily chores within their ability and taking the time to appreciate being alive. Being open to talk about their cancer meant they could seek support from other sources such as friends, family or other cancer patients. Some women kept their diagnosis hidden to avoid negative reactions from community members. Avoiding negative people helped these women deal with their experience in a positive manner.

4. 'Healthcare expectations'

The women's breast cancer experiences were also shaped by the type of healthcare they received. In overcoming the language barrier and feeling well supported by their family members and others around them, healthcare providers also played a role in the women's experiences. All the women placed great trust in healthcare professionals to provide the best care and were described as being very caring and supportive. The only time women felt their needs were not fully met was due to their cultural beliefs and lifestyle. This included having a culturally specific diet and therefore some were unable to eat hospital food, and due to their cultural values of modesty which left them feeling embarrassed when treated by male healthcare professionals.

5. 'Accepting an altered appearance'.

Concerns about changes to their appearance and how they felt about their bodies were very much dependent on the type of treatment and severity of the side effects that were experienced. Those who lost a breast (mastectomy) spoke of the negative impact it had on the way they felt about their appearance more than those who had a lump removed (lumpectomy). These women spoke of how they did not feel feminine enough and would be self-conscious when going out in public. However, 3 of the 5 women were not so concerned by their appearance changes (especially temporary changes such as hair loss) as they placed greater emphasis on their health and being alive.

How have the results been used and what's next?

These studies have been presented at various health and cancer related conferences, and will also be published in academic journals.

The findings provided a lot of valuable and insightful information. This has been used to develop a questionnaire in order to explore these interesting areas in more detail amongst a larger group of Black, South Asian and White breast cancer survivors.

Overall we hope the findings from this research will inform the development of recommendations for healthcare professionals and other relevant organisations, and inform the provision of culturally sensitive care and support to ethnic minority breast cancer patients.

What do you think?

Thank you again for participating in this research. I hope this summary provides you with useful information about this research and the study you were involved in. If you have any comments or would like to know more about the research, please feel free to get in touch with me.

Best Wishes

G.Patel

Geeta Patel

Telephone: 0117 3281895

Email: Geeta2.Patel@uwe.ac.uk

Appendix 10: Study 2 poster



Breast Cancer in African & Caribbean Women



I am interested in hearing about **YOUR** experiences!

Benefits of taking part:

- Your opportunity to share your experiences
- £20 Marks & Spencer Voucher to thank you for sharing your experiences.



Having breast cancer can be a life changing event for women and their families. Until now, most research has focused on the experiences of White women with very little research exploring the experiences of Black and Minority Ethnic women.

I am therefore interested in hearing about your experiences of having lived with Breast Cancer.

Women interested in taking part will be interviewed in a group setting (approx. 5 women per group) by the researcher at a time and place of your convenience. Your responses will be kept strictly private and your name will not be used in the study.

If you would like to share your experiences or know of someone who may be interested, please contact, Geeta Patel for further information on 0117 328 1895 or by email at Geeta2.Patel@uwe.ac.uk.

Appendix 11: Study 2 Interview Schedule

Perceptions of support needs and the extent to which these are met

Introduction

Good morning/afternoon. My name is Geeta Patel and this is my colleague Y. Firstly I would like to thank you all very much for coming today and taking part in this research. I'm conducting this study to explore the experiences of breast cancer in Black and South Asian women. The research is being funded by Breast Cancer Campaign and the aim is to understand Ethnic Minority women's experiences of breast cancer so that appropriate and culturally sensitive care and support can be provided.

A little bit about focus groups for those who may not know. A focus group is a relaxed discussion where people share their own views and experiences, but also hear from other people. You have all consented to the discussion being recorded but be assured that what you say will be kept confidential and anonymous and the tape will be destroyed at the end of this research. I also ask you all to respect each other's views even if you do not agree with them and please do not discuss what you hear within the group to others outside the group.

You should not wait to be invited into the discussion however I would appreciate it if only one person talks at a time. There are no right or wrong answers so please feel free to talk as honestly and openly as possible.

The discussion will last approximately one and a half hours. There is a lot I want to discuss, so at times I may move us along a bit.

Does that sound okay? Any questions before we start?

Firstly, please tell the group your name and when your cancer was diagnosed.

I am interested in hearing about your breast cancer experiences. In particular I would like to understand your experiences from a cultural perspective and way in which you managed your experiences.

I'm going to read out a scenario of 2 women's experiences. Please listen carefully and think about how these women's experiences compare to your own.

When Mrs Vara/Smith went through her cancer experience, she was surrounded by a lot of friends and family members who were very caring and supportive. She found her family members and, partner in particular, to be highly supportive. They would sit with her; do things around the house like cooking, cleaning and shopping. They would always try to lift her spirits by encouraging her with positive words and would take her to hospital appointments.

However, Mrs Kerai/Howard went through her cancer experience all by herself. While she had family around her, they were not very supportive. She went to her treatments by herself and would come home and cook and clean for her husband and children. Her work colleagues were also not very supportive and gave her quite a hard time for the amount of time she had to take off.

- **How important do you think support is in helping one manage their breast cancer experience?** *Did you feel well supported like Mrs. Smith or did you feel you had no support during your cancer.*

E.g. – from own experience?

Who or what were your main source(s) of support?

How did this help you deal with your cancer?

Was there any aspect where you feel you could've been better supported?

Emotionally or practically.

Women that I have previously interviewed felt they had to downplay their illness for their family member's sake as it had a negative effect on them. Therefore, many found themselves supporting their family during their illness.

Is this something that you experienced?

Do you think there's such a thing as too much support?

Did you seek any support from cancer support groups or charities? Were you made aware of national or local support organisations (by healthcare professionals)?

What were your reasons for wanting to join a support group/seeking such support?

Did you attend other support groups or charities?

Yes: What were they like? No: why not?

How helpful do you think cancer support networks such as cancer support groups, help-lines, on-line chat rooms and forums are for a breast cancer survivor?

How important was it for you to meet and talk to other South Asian/Black breast cancer survivors?

Healthcare

I'm going to read out another scenario of 2 women's healthcare experiences. Please listen carefully and think about how these women's experiences compare to your own.

Scenario 2:

Mrs Vekaria/Lewis felt that her doctors and nurses were fantastic and she could not have asked for better care. She described them as very caring, understanding and empathetic. Everything was clearly explained to her at diagnosis and at each stage of her different treatments. Her breast care nurse would make frequent calls or visits to see how she is getting on. She would listen to her concerns and advise her with appropriate information.

However, **Mrs Shah/McKenzie** felt that her breast care nurse and the consultants were not very sympathetic. She did not feel she was given appropriate information and had to do her own research to find out more about her diagnosis and the different types of treatments she could opt for. She also felt that the nurses were unfriendly and unapproachable.

- **Can you relate to any of these ladies experiences? What were your healthcare experiences like?**

To what extent do you feel that healthcare professionals and cancer support networks such as support groups meet Asian/Black women's needs culturally?

I.e. information/advice provided, wig fitting, prosthesis fitting services, lymphodema sleeves. Did you have a problem being treated by male nurses/doctors? language barriers? Do you think healthcare professionals could have done more to meet your support needs? If so, How?

Ethnicity

I would like to talk about ethnicity in relation to your experiences.

How does your culture (or people in your community) deal with illnesses such as cancer?

*Is it openly talked about?
Were you open about your breast cancer? With who?
How would you describe your community's understanding/beliefs about illnesses such as breast cancer?
In terms of your understanding of breast cancer, did you try to find meaning as to why you got the cancer?*

Findings from my first study showed that some people within the South Asian community and sometimes even family members can appear to be unsupportive and make remarks that might seem hurtful.

Was this something you experienced?

Some women turn to religion/spirituality to help them deal with their breast cancer experiences.

Has this been important for you during your experiences?

In what way/to what extent?

Would you feel comfortable talking about your spiritual beliefs with your GP/consultants?

Final thoughts

Aside from things you have already mentioned, was there anything else you did to help you manage your cancer experience? I.e. use of humour, social avoidance, positive thinking, anger?

What affect, if any, has breast cancer had on your overall quality of life?

Is there anything positive that has come out of your experience?

Is there anything anyone would like to add or discuss in more detail?

Thank you for sharing your experiences. Your comments and time are very much appreciated. Just to reiterate, your responses are confidential and please respect the confidentiality of your group member's comments.

Appendix 12: Study 2 Participant information sheet**Participant Information Sheet****Breast cancer experiences in Black and South Asian women**

You are being invited to take part in a research study. Before you decide whether to take part or not, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and decide whether or not you wish to take part. Please ask if there is anything that is not clear or if you would like more information. Thank you for reading this.

What is the purpose of the study?

Having breast cancer can be a significant life event for women and their families. The purpose of this study is to understand what it is like to be diagnosed with breast cancer and how treatment affects people's lives. Until now, most research has focused on the experiences of Caucasian women and there has been very little research into the experiences of Black and South Asian women who have been diagnosed as having breast cancer.

This study is therefore investigating how breast cancer affects the lives of Black and South Asian women and this is why we are interested in hearing about your experiences. If we have a better understanding of how breast cancer affects women's lives, we may be able to improve the care and support for other ethnic minority women.

Why have I been chosen?

We are inviting Black and South Asian English speaking women over the age of 18, who have been diagnosed with breast cancer to share their experiences.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. If you decide not to take part or later choose to withdraw from the study, doing so will not affect the health care you receive in any way, now or in the future.

What do I have to do?

If you choose to take part in the research you will be invited to share your experiences in a focus group setting (with approximately 4-6 breast cancer survivors). The other women in the group will be of the same ethnicity as you. The focus group will be facilitated by two researchers, Geeta Patel, and her research assistant. The discussion will focus on your experiences of breast cancer diagnosis and treatment. No questions will be directed to you individually, but instead will be posed to the group. The focus group will last approximately 90 minutes. With your permission, we would like to tape record the discussion.

Will my taking part in this study be kept private?

All information which you provide will be kept strictly private. We will not use your name in our study. Your responses will be kept in a safe place and will only be used for research purposes. Only the researchers working on this study will have access to your responses. All recorded information will be destroyed once the study is finished.

We ask you to please respect everyone's comments and do not discuss what you hear within the group to others. Even though we will emphasize to all participants that comments made during the focus group session should be kept confidential, it is possible that participants may repeat comments outside of the group at some time in the future. Therefore, we encourage you to be as honest and open as you can, but remain aware of our limits in protecting confidentiality.

What are the possible benefits of taking part?

This is your chance to talk about your experiences. The information you give will help us understand your experiences better and we may be able to use this information to improve healthcare services for ethnic minority women with breast cancer.

What are the possible disadvantages of taking part?

We realise that being diagnosed with breast cancer and having treatment for it can be a very personal and distressing experience which you may find difficult to talk about at times. If you do decide to take part in this study, you can opt out of the discussion at any time or choose not to answer questions you feel are too personal to talk about.

How can I withdraw from the study?

If you decide that you no longer want to take part in the study, you can get in touch with the researcher and quote your participation number. Your data will then be destroyed and will not be used in the study. You have up to 6 months to do this.

What will happen to the results of this study?

The results of this study will be shared with health professionals and other breast cancer related organisations (such as the charity Breast Cancer Campaign, who are funding this research). In addition the results may be discussed in academic journals or presented at conferences, but you will not be named or identified in any outputs that come from the research.

Who has reviewed this study?

This study has been reviewed and approved by the University of the West of England, School of Life Sciences Ethics Committee to make sure that it is being carried out in an appropriate manner.

What do I do now?

If you are interested in taking part or would like any further information, you can contact the researcher, Geeta Patel, on 0117 328 1895 or at Geeta2.Patel@uwe.ac.uk.

If you have any concerns about breast cancer, you can contact the following breast cancer organisations for further support: Breast Cancer Care Helpline on 0808 800 6000, NHS Direct on 0845 4647 or alternatively contact your GP.

Thank you for taking the time to read this information and for thinking about taking part in this research.

Geeta Patel, PhD Student

Supervised by Dr Diana Harcourt

Email: Diana2.Harcourt@uwe.ac.uk Telephone: 0117 3282192

Centre for Appearance Research

University of the West of England, Bristol

BS16 1QY

Version 2 date: 30/10/09

Appendix 13: Study 2 Consent form

CONSENT FORM

Title of Project: Breast cancer experiences in Black and South Asian women

Name of Researcher: Geeta Patel

Please initial box

- 1. I confirm that I have read and understood the information sheet dated 30/10/09 for the above study and have had the opportunity to ask questions.

- 2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason and without my healthcare or legal rights being affected.

- 3. I understand that this focus group will be tape recorded.

- 4. I agree to take part in the above study.

Name of Participant Signature Date

Researcher Signature Date

1 copy for participant; 1 copy for researcher

Appendix 14: Study 2 demographic information formDemographic information

- Age: _____
- Marital status: Single Married Divorced Separated
 Widow Other _____
- Children: _____
- Occupational status: _____
- Ethnicity: Indian Pakistani Bangladeshi
- Country of birth: _____
- How old were you when you were diagnosed? _____
- How were you diagnosed? Screening/Mammogram Self examination
- Type of breast cancer? _____
- What kind of treatment(s) did you receive?
 - Mastectomy Lumpectomy Other _____
 - Chemotherapy Radiotherapy
 - Tamoxifen Arimidex Herseptine Other _____
 - Breast reconstruction Breast prosthesis
- Do you suffer from Lymphoedema: Yes No
- How long did your treatments last in total? _____

Appendix 15: Study 3 Participant information sheet**Participant Information Sheet****Breast cancer experiences in Black and South Asian women**

You are being invited to take part in a research study. Before you decide whether to take part or not, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

What is the purpose of the study?

Having breast cancer can be a significant life event for women and their families. The purpose of this study is to understand what it is like to be diagnosed with breast cancer and how treatment affects people's lives. Until now, most research has focused on the experiences of Caucasian women and there has been very little research into the experiences of Black and South Asian women who have been diagnosed as having breast cancer.

This study is therefore investigating how breast cancer affects the lives of Black and South Asian women and this is why we are interested in hearing about your experiences. If we have a better understanding of how breast cancer affects women's lives, we may be able to improve the care and support for other ethnic minority women.

Why have I been chosen?

We are inviting South Asian women over the age of 18, who have been diagnosed with breast cancer to share their experiences. We would like to interview 6 *non-English speaking women*.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. If you decide not to take part or later choose to withdraw from the study, doing so will not affect the health care you receive in any way, now or in the future.

What do I have to do?

If you choose to take part in the research you will be interviewed by a researcher, Geeta Patel, in your home at a time that suits you. The interview will be informal and relaxed and the researcher will ask you questions about your experiences of having breast cancer. There are no right or wrong answers and you do not have to respond to any questions that you do not feel comfortable answering. The interview can last between 60 to 90 minutes, however you are free to talk as much or as little as you would like to. With your permission, we would like to tape record the interview. The interview will take place in your preferred language. An interpreter will be available and we will discuss this possibility with you, before the interview takes place.

Will my taking part in this study be kept private?

All information which you provide will be kept strictly private. We will not use your name in our study. Your responses will be kept in a safe place and will only be used for research purposes. Only the researchers working on this study will have access to your responses. All recorded information will be destroyed once the study is finished.

What are the possible benefits of taking part?

This is your chance to talk about your experiences. The information you give will help us understand your experiences better and we may be able to use this information to improve healthcare services for ethnic minority women with breast cancer.

What are the possible disadvantages of taking part?

We realise that being diagnosed with breast cancer and having treatment for it can be a very personal and distressing experience which you may find difficult to talk about at times. If you do decide to take part in this study, you can ask to stop the interview at any time or choose not to answer questions you feel are too personal to talk about.

How can I withdraw from the study?

If you decide that you no longer want to take part in the study, you can get in touch with the researcher and quote your participation number. Your data will then be destroyed and will not be used in the study. You have up to 6 months to do this.

What will happen to the results of this study?

The results of this study will be shared with health professionals and other breast cancer related organisations (such as the charity Breast Cancer Campaign, who are funding this research). In addition the results may be discussed in academic journals or presented at conferences, but you will not be named or identified in any outputs that come from the research.

Who has reviewed this study?

This study has been reviewed and approved by the University of the West of England, School of Life Sciences Ethics Committee to make sure that it is being carried out in an appropriate manner.

What do I do now?

If you are interested in taking part or would like any further information, you can contact the researcher, Geeta Patel, on 0117 328 1895 or at Geeta2.Patel@uwe.ac.uk.

If you have any concerns about breast cancer, you can contact the following breast cancer organisations for further support: Breast Cancer Care Helpline on 0808 800 6000, NHS Direct on 0845 4647 or alternatively contact your GP.

Thank you for taking the time to read this information and for thinking about taking part in this research.

Geeta Patel, PhD Student

Supervised by Dr Diana Harcourt

Email: Diana2.Harcourt@uwe.ac.uk Telephone: 0117 3282192

Centre for Appearance Research

University of the West of England, Bristol

BS16 1QY

Version 2 date: 08/06/10

Appendix 16: Study 3 consent form

CONSENT FORM

Title of Project: Breast cancer experiences in Black and South Asian women

Name of Researcher: Geeta Patel

Please initial box

- 1. I confirm that I have read and understood the information sheet dated 08/06/10 for the above study and have had the opportunity to ask questions.

- 2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason and without my healthcare or legal rights being affected.

- 3. I agree to my interview being tape recorded.

- 4. I agree to take part in the above study.

Name of Participant

Signature

Date

Researcher

Signature

Date

1 copy for participant; 1 copy for researcher

Appendix 17: Study 3 Interpreter confidentiality agreement form**Confidentiality Agreement****Project title:** Experiences of breast cancer in non-English speaking South Asian women**Researcher's name:** Geeta Patel

This study is being undertaken by Geeta Patel to understand the experiences of breast cancer in non-English speaking South Asian women. An interpreter will be present to translate information between the interviewer and interviewee. All conversations during the interview should be kept confidential and not disclosed to others. Maintaining this confidentiality is of utmost importance

The interpreter will:

1. Respect confidentiality at all times - all documents and other information disclosed to the interpreter shall be treated in the strictest confidence.
2. Not discuss or pass on any information to any third parties.
3. Ensure that all research information (including any notes that are taken during the interview) is destroyed safely on completion of the interview.
4. Make it known to the researcher if the participant is personally known or related.

I agree to act according to the above constraints

_____	_____	_____
Interpreter [PRINT name]	Signature	Date
_____	_____	_____
Researcher	Signature	Date

Occasionally, the conversations that take place during the interview can be distressing to hear. If you should find it upsetting, please speak to the researcher.

Appendix 18: Study 4 Questionnaire



Experiences of breast cancer in Black, South Asian & White women

Instructions

Please read the instructions on the following pages carefully. Please answer all the questions as openly and honestly as possible. There are no right or wrong answers, and your responses will be treated with the strictest confidence. You do not have to answer any questions that make you feel uncomfortable.

Your completion of this questionnaire will be taken as consent to participate.

Demographic information

The following questions will be used to understand the sample of data collected, and will be used for statistical purposes only, not to identify any individual. Please remember that all responses are anonymous.

About yourself

1. Please state your age _____

Please tick **one** box from the following options:

2. How did you hear about this study?

- My consultant/breast care nurse My local support group
 Other (*Please specify*)

3. Which city do you live in?

- Birmingham Leicester
 Bristol Inner London
 Cardiff Outer London
 Other (*Please specify*)

4. What is your employment status?

- Working full time Student
 Working part time Retired
 Self-employed Unemployed
 Other

5. What is your marital status?

- Single Separated
 In a relationship Divorced
 Married Widowed

6. What is the highest level of education that you have completed?

- | | |
|--|--|
| <input type="checkbox"/> GCSE/O-Level or equivalent | <input type="checkbox"/> Masters degree |
| <input type="checkbox"/> A Level or equivalent | <input type="checkbox"/> PhD or equivalent |
| <input type="checkbox"/> Higher education certificate or diploma | <input type="checkbox"/> No qualification |
| <input type="checkbox"/> Undergraduate degree (BSc, BA) | |

7. What is your ethnic group?

Choose **ONE** section from A-D, then tick **one** box to best describe your ethnic group or background.

A: White

- British
- Irish
- Any other White background (*Please specify*) _____

B: Mixed/multiple ethnic groups

- White and Black, Caribbean
- White and Black, African
- White and Asian
- Any other Mixed background (*Please specify*) _____

C: Asian/Asian British

- Indian
- Pakistani
- Bangladeshi
- Any other Asian background (*Please specify*) _____

D: Black/African/Caribbean/Black British

- African
- Caribbean
- Any other Black/African/Caribbean background (*Please specify*) _____

8. What is your religion or belief?

- | | |
|------------------------------------|---|
| <input type="checkbox"/> Christian | <input type="checkbox"/> Muslim |
| <input type="checkbox"/> Bhuddist | <input type="checkbox"/> Sikh |
| <input type="checkbox"/> Hindu | <input type="checkbox"/> No religion/belief |
| <input type="checkbox"/> Jewish | <input type="checkbox"/> Any other religion (<i>Please specify</i>) _____ |

9. What is your main language?

- English (*please go to Question 12*) Other (*please go to question 10*)

10. What is your preferred or first language?

- | | |
|-----------------------------------|--|
| <input type="checkbox"/> Bengali | <input type="checkbox"/> Farsi |
| <input type="checkbox"/> Gujarati | <input type="checkbox"/> Hindi |
| <input type="checkbox"/> Kurdish | <input type="checkbox"/> Punjabi |
| <input type="checkbox"/> Somali | <input type="checkbox"/> Tamil |
| <input type="checkbox"/> Urdu | <input type="checkbox"/> Other (<i>Please specify</i>) _____ |

11. How well can you speak English?

- Very well Well Not well Not at all

12. If in question 7 you selected your ethnic identity from:

- a) Section **A**, then go to the **next section: About your breast cancer**
 b) Sections **B-D**, please answer **question 13**.

13. Which generation do you belong to?

- First generation – I was born in a country other than the UK. (*Please answer questions 14 & 15*)
 Subsequent generation – I was born in the UK. (*Go to the next section: About your cancer*)

14. Which country were you born in? _____

15. How long have you been living in the UK? _____

About your breast cancer

1. Do you have a family history of breast cancer?

Yes No

2. How long ago were you diagnosed with your breast cancer? _____ years _____ months

3. How was the lump found?

Screening/Mammography Physician (GP)
 Breast self examination Via partner/Companion
 Other (*Please specify*) _____

4. What type of breast cancer was it?

Invasive breast cancer Not sure
 Non-invasive breast cancer (e.g. DCIS) Other

5. What type of surgical treatment did you receive?

Mastectomy *without* breast reconstruction Lumpectomy
 Mastectomy with *immediate* breast reconstruction No surgical treatment
 Mastectomy with *delayed* breast reconstruction Not sure

Please enter how long after your mastectomy you had the reconstruction

6. What other treatment, if any, did you receive? (*Please tick all that apply*)

Chemotherapy None
 Radiotherapy Not sure

7. What type of hormonal therapy, if any, did you receive? (*Please tick all that apply*)

Tamoxifen
 Aromatase Inhibitor (e.g. Anastrozole (Arimidex), Exemestane, Letrozole)
 Other Not sure None

8. Do you suffer from Lymphoedema (swelling of the arm or hand)?

Yes No

Section 1: Your health and well-being

Below is a list of statements that other people with your illness have said are important. Please circle one number per line to indicate your response as it applies to **the past 7 days**.

<u>Physical well-being</u>	Not at all	A little bit	Some-what	Quite a bit	Very much
1. I have a lack of energy	0	1	2	3	4
2. I have nausea	0	1	2	3	4
3. Because of my physical condition, I have trouble meeting the needs of my family	0	1	2	3	4
4. I have pain	0	1	2	3	4
5. I am bothered by side effects of treatment	0	1	2	3	4
6. I feel ill	0	1	2	3	4
7. I am forced to spend time in bed	0	1	2	3	4

<u>Social/Family well-being</u>	Not at all	A little bit	Some-what	Quite a bit	Very much
8. I feel close to my friends	0	1	2	3	4
9. I get emotional support from my family	0	1	2	3	4
10. I get support from my friends	0	1	2	3	4
11. My family has accepted my illness	0	1	2	3	4
12. I am satisfied with the family communication about my illness	0	1	2	3	4
13. I feel close to my partner (or the person who is my main support)	0	1	2	3	4

Regardless of your current level of sexual activity, please answer the following question. If you prefer not to answer it, please mark this box and go to the question 15.

14. I am satisfied with my sex life	0	1	2	3	4
--	---	---	---	---	---

<u>Emotional well-being</u>	Not at all	A little bit	Some-what	Quite a bit	Very much
15. I feel sad	0	1	2	3	4
16. I am satisfied with how I am coping with my illness	0	1	2	3	4
17. I am losing hope in the fight against my illness	0	1	2	3	4
18. I feel nervous	0	1	2	3	4
19. I worry about dying	0	1	2	3	4
20. I worry that my condition will get worse	0	1	2	3	4

<u>Functional well-being</u>	Not at all	A little bit	Some-what	Quite a bit	Very much
21. I am able to work (include work at home)	0	1	2	3	4
22. My work (include work at home) is fulfilling	0	1	2	3	4
23. I am able to enjoy my life	0	1	2	3	4
24. I have accepted my illness	0	1	2	3	4
25. I am sleeping well	0	1	2	3	4
26. I am enjoying the things I usually do for fun	0	1	2	3	4
27. I am content with the quality of my life right now	0	1	2	3	4

28. Since your breast cancer, how would you rate your overall quality of life?

Very poor excellent

1 2 3 4 5 6 7 8 9 10

Section 2: Social support

Cancer support group/organisation 2: _____

How helpful did you find this source of support?

Not at all helpful										Very helpful
1	2	3	4	5	6	7	8	9	10	

How did you hear about this source of support?

- | | |
|---|---|
| <input type="checkbox"/> Healthcare professionals (e.g. Nurse/consultant) | <input type="checkbox"/> Internet |
| <input type="checkbox"/> Family/friends | <input type="checkbox"/> Other (please specify) |

Cancer support group/organisation 3: _____

How helpful did you find this source of support?

Not at all helpful										Very helpful
1	2	3	4	5	6	7	8	9	10	

How did you hear about this source of support?

- | | |
|---|---|
| <input type="checkbox"/> Healthcare professionals (e.g. Nurse/consultant) | <input type="checkbox"/> Internet |
| <input type="checkbox"/> Family/friends | <input type="checkbox"/> Other (please specify) |

Only answer this question if you ticked 'NO' to question 1.

3. What were your reasons for not seeking out any social support groups or other cancer support networks? *(Please tick all that apply)*

- I did not feel the need to
- There were not any support groups/support networks local to me
- I did not have time to go
- I did not want to be around other cancer patients
- I did not know about any support groups or other support networks
- Other *(please explain your reasons)* _____
-

4. Listed below are a variety of sources that may have provided you with **overall support** during your cancer experience.

a. Please tick all those that apply to you.

b. Next, from the ones that you have selected, please rank these sources in terms of who/what you found to be the most supportive to you during your breast cancer experience (in ascending order – where 1 = the most important).

	Tick	Rank		Tick	Rank
Family			Husband/Partner		
Friends			Cancer support networks (i.e. support groups/on-line forums)		
Work colleagues			Community groups (i.e. places of worship such as church)		
Religion/spirituality			Healthcare professionals (i.e. breast care nurse/consultants)		
Other (please specify) _____					

The next few questions ask you about the type of support you received and by whom.

1. Who was/were your main source(s) that provided you with appropriate **practical support** (for example: helping with daily chores such as cooking/cleaning/shopping)? *(Please tick all that apply).*

- | | |
|--|--|
| <input type="checkbox"/> Family | <input type="checkbox"/> Community groups (i.e. places of worship e.g. church) |
| <input type="checkbox"/> Husband/Partner | <input type="checkbox"/> Healthcare professionals (i.e. nurses/consultants) |
| <input type="checkbox"/> Friends | <input type="checkbox"/> Nobody |
| <input type="checkbox"/> Work colleagues | <input type="checkbox"/> I did not need any practical support |
| <input type="checkbox"/> Cancer support networks
(i.e. support groups/on-line forums) | <input type="checkbox"/> Other (please specify) _____ |

2. Who was/were your main source(s) that provided you with appropriate **emotional support** (for example: words of encouragement and reassurance, someone to talk to)? *(Please tick all that apply).*

- | | |
|--|--|
| <input type="checkbox"/> Family | <input type="checkbox"/> Community groups (i.e. places of worship e.g. church) |
| <input type="checkbox"/> Husband/Partner | <input type="checkbox"/> Healthcare professionals (i.e. nurses/consultants) |
| <input type="checkbox"/> Friends | <input type="checkbox"/> Nobody |
| <input type="checkbox"/> Work colleagues | <input type="checkbox"/> I did not need any emotional support |
| <input type="checkbox"/> Cancer support networks
(i.e. support groups/on-line forums) | <input type="checkbox"/> Other (please specify) _____ |

3. Who was/were your main source(s) that provided you with appropriate **informational support** (for example: advice, written information, leaflets/diagrams)? *(Please tick all that apply).*

- | | |
|--|--|
| <input type="checkbox"/> Family | <input type="checkbox"/> Community groups (i.e. places of worship e.g. church) |
| <input type="checkbox"/> Husband/Partner | <input type="checkbox"/> Healthcare professionals (i.e. nurses/consultants) |
| <input type="checkbox"/> Friends | <input type="checkbox"/> Nobody |
| <input type="checkbox"/> Work colleagues | <input type="checkbox"/> I did not need any informational support |
| <input type="checkbox"/> Cancer support networks
(i.e. support groups/on-line forums) | <input type="checkbox"/> Other (please specify) _____ |

4. Who was/were your main source(s) that provided you with appropriate **financial support** (for example: parking at the hospital/free hospital transport)? *(Please tick all that apply).*

- | | |
|--|--|
| <input type="checkbox"/> Family | <input type="checkbox"/> Community groups (i.e. places of worship e.g. church) |
| <input type="checkbox"/> Husband/Partner | <input type="checkbox"/> Healthcare professionals (i.e. nurses/consultants) |
| <input type="checkbox"/> Friends | <input type="checkbox"/> Nobody |
| <input type="checkbox"/> Work colleagues | <input type="checkbox"/> I did not need any financial support |
| <input type="checkbox"/> Cancer support networks
(i.e. support groups/on-line forums) | <input type="checkbox"/> Other (please specify) _____ |

5. Who was/were your main source(s) that provided you with appropriate **moral support** (for example: accompany you to hospital appointments, sit with you)? *(Please tick all that apply).*

- | | |
|--|--|
| <input type="checkbox"/> Family | <input type="checkbox"/> Community groups (i.e. places of worship e.g. church) |
| <input type="checkbox"/> Husband/Partner | <input type="checkbox"/> Healthcare professionals (i.e. nurses/consultants) |
| <input type="checkbox"/> Friends | <input type="checkbox"/> Nobody |
| <input type="checkbox"/> Work colleagues | <input type="checkbox"/> I did not need any moral support |
| <input type="checkbox"/> Cancer support networks
(i.e. support groups/on-line forums) | <input type="checkbox"/> Other (please specify) _____ |

6. Overall, how supported did you feel during your breast cancer experience?

Not at all supported										Very well supported
1	2	3	4	5	6	7	8	9	10	

Section 3: Your emotions and feelings

This section helps us to understand how you are feeling. Please read every sentence carefully and tick the option that best describes how you have been feeling during the **last 7 days**. You do not have to think too much to answer. In this section, spontaneous answers are more important.

1. I feel tense or 'wound up'

- Most of the time
 A lot of the time
 From time to time (occasionally)
 Not at all

2. I feel as if I am slowed down

- Nearly all the time
 Very often
 Sometimes
 Not at all

3. I still enjoy the things I used to enjoy

- Definitely as much
 Not quite as much
 Only a little
 Hardly at all

4. I have lost interest in my appearance

- Definitely
 I don't take as much care as I should
 I may not take quite as much care
 I take just as much care

5. I get a sort of frightened feeling as if something awful is about to happen

- Very definitely and quite badly
 Yes, but not too badly
 A little, but it does worry me
 Not at all

6. I feel restless as I have to be on the move

- Very much indeed
 Quite a lot
 Not very much
 Not at all

7. I can laugh and see the funny side of things

- As much as I always could
 Not quite so much now
 Definitely not so much now
 Not at all

8. I look forward with enjoyment to things

- As much as I ever did
 Rather less than I used to
 Definitely less than I used to
 Hardly at all

9. Worrying thoughts go through

10. I get sudden feelings of panic

my mind

- | | |
|---|--|
| <input type="checkbox"/> A great deal of the time | <input type="checkbox"/> Very often indeed |
| <input type="checkbox"/> A lot of the time | <input type="checkbox"/> Quite often |
| <input type="checkbox"/> From time to time, but not often | <input type="checkbox"/> Not very often |
| <input type="checkbox"/> Only occasionally | <input type="checkbox"/> Not at all |

11. I feel cheerful

- Not at all
 Not often
 Sometimes
 Most of the time

12. I can enjoy a good book or radio/TV program

- Often
 Sometimes
 Not often
 Very seldom

13. I can sit at ease and feel relaxed

- Definitely
 Usually
 Not often
 Not at all

14. I get a sort of frightened feeling like "butterflies" in the stomach

- Not at all
 Occasionally
 Quite often
 Very often

Section 4: You and other cancer patients

Most people compare themselves from time to time with others. For example, they may compare the way they feel, their opinions, their abilities, and/or their situation with other people. There is nothing particularly “good” or “bad” about this type of comparison, and some people do it more than others. I would like to find out how often you compare(d) yourself with other cancer patients.

Please indicate your level of agreement to each statement by circling the appropriate number.

		Strongly Disagree	Disagree	Neither Agree or Disagree	Agree	Strongly Agree
1.	When I see others who experience more difficulties than I do, I am happy that I am doing so well myself.	1	2	3	4	5
2.	When I see others who experience more difficulties than I do, I feel relieved about my own situation.	1	2	3	4	5
3.	When I see others who experience more difficulties than I do, it makes me realise how well I am doing.	1	2	3	4	5
4.	When I see others who are doing worse than me, I experience fear that my health status will decline.	1	2	3	4	5
5.	When I see others who are doing worse than me, I fear that my future will be similar.	1	2	3	4	5
6.	When I see others who are doing worse than me, I fear that I will go along the same way.	1	2	3	4	5
7.	When I think about others who are doing better than I am, I sometimes feel frustrated about my own situation.	1	2	3	4	5
8.	When I think about others who are doing better than I am, it is threatening to notice that I am not doing so well.	1	2	3	4	5
9.	When I think about others who are doing better than I am, I feel depressed knowing that I am not so well off.	1	2	3	4	5
10.	When I meet others who are experiencing less problems than I am, it makes me happy realising that it is possible for me to improve.	1	2	3	4	5
11.	When I meet others who are experiencing less problems than I am, I am pleased that things can get better.	1	2	3	4	5
12.	When I meet others who are experiencing less problems than I am, I have good hope that my situation will improve.	1	2	3	4	5

Section 5: Beliefs about cancer

I am interested in your personal beliefs in relation to your condition (breast cancer). Each item below is a belief statement about your breast cancer; with which you may agree or disagree.

Using the key below, please indicate your level of agreement to each statement by circling the appropriate number.

	Strongly Disagree (SD)	Moderately Disagree (MD)	Slightly Disagree (D)	Slightly Agree (A)	Moderately Agree (MA)	Strongly Agree (SA)			
	1	2	3	4	5	6			
				SD	MD	D	A	MA	SA
1.	If my condition worsens, it is my own behaviour which determines how soon I will feel better again.			1	2	3	4	5	6
2.	As to my condition, what will be will be.			1	2	3	4	5	6
3.	If I see my doctor regularly, I am less likely to have problems with my condition.			1	2	3	4	5	6
4.	Most things that affect my condition happen to me by chance.			1	2	3	4	5	6
5.	Whether or not my condition improves is up to god.			1	2	3	4	5	6
6.	Whenever my condition worsens, I should consult a medically trained professional.			1	2	3	4	5	6
7.	I am directly responsible for my condition getting better or worse.			1	2	3	4	5	6
8.	God is directly responsible for my condition getting better or worse.			1	2	3	4	5	6
9.	Other people play a big role in whether my condition improves, stays the same, or gets worse.			1	2	3	4	5	6
10.	Whatever goes wrong with my condition is my own fault.			1	2	3	4	5	6
11.	Luck plays a big part in determining how my condition improves.			1	2	3	4	5	6
12.	Most things that affect my condition happen because of god.			1	2	3	4	5	6

Section 5: Beliefs about cancer (continued)

	Strongly Disagree (SD)	Moderately Disagree (MD)	Slightly Disagree (D)	Slightly Agree (A)	Moderately Agree (MA)	Strongly Agree (SA)
	1	2	3	4	5	6
	SD	MD	D	A	MA	SA
13. If my condition worsens, it's a matter of fate.	1	2	3	4	5	6
14. If I am lucky, my condition will get better.	1	2	3	4	5	6
15. If my condition takes a turn for the worse, it is because I have not been taking proper care of myself.	1	2	3	4	5	6
16. The type of help I receive from other people determines how soon my condition improves.	1	2	3	4	5	6
17. If my condition worsens, it is up to god to determine whether I will feel better again.	1	2	3	4	5	6
18. Whatever happens to my condition is god's will.	1	2	3	4	5	6
19. In order for my condition to improve, it is up to other people to see that the right things happen.	1	2	3	4	5	6
20. Whatever improvement occurs with my condition is largely a matter of good fortune.	1	2	3	4	5	6
21. The main thing which affects my condition is what I myself do.	1	2	3	4	5	6
22. God is in control of my condition.	1	2	3	4	5	6
23. Following doctor's orders to the letter is the best way to keep my condition from getting any worse.	1	2	3	4	5	6
24. I deserve the credit when my condition improves and the blame when it gets worse.	1	2	3	4	5	6

Section 6: Your appearance

This section contains statements asking how you feel about your physical appearance since developing breast cancer.

Using the scales listed below; please indicate your level of agreement to each statement by circling the appropriate number.

When answering, consider how you have felt over the **past month**.

		Strongly Disagree	Disagree	Neither Agree or Disagree	Agree	Strongly Agree
1.	I try to hide my body.	1	2	3	4	5
2.	The feeling in my arm is normal.	1	2	3	4	5
3.	I avoid looking at my scars from breast surgery.	1	2	3	4	5
4.	I feel less feminine since cancer.	1	2	3	4	5
5.	I would feel comfortable changing in a public changing-room.	1	2	3	4	5
6.	I am satisfied with the appearance of my arm.	1	2	3	4	5
7.	I feel that part of me must remain hidden.	1	2	3	4	5
8.	I am afraid of touching the scars from breast surgery.	1	2	3	4	5
9.	I avoid close physical contact such as hugging.	1	2	3	4	5

The following questions pertain to your feelings about your breast or mastectomy site.

If you are *missing a breast(s)* (if you have had a mastectomy without breast reconstruction), **please answer question 10.**

If you are *not missing a breast* (if you have had a lumpectomy, a mastectomy with immediate/delayed breast reconstruction, or no surgical treatment to your breasts), **please skip question 10 and answer questions 11 to 14**

Only answer question 10 if you have had a mastectomy without breast reconstruction.

	Strongly Disagree	Disagree	Neither Agree or Disagree	Agree	Strongly Agree
10. I feel comfortable looking at my mastectomy.	1	2	3	4	5

	Strongly Disagree	Disagree	Neither Agree or Disagree	Agree	Strongly Agree	Not applicable
11. I am happy with the position of my nipple.	1	2	3	4	5	6
12. I am satisfied with the size of my breast.	1	2	3	4	5	6
13. I feel comfortable when others see my breasts.	1	2	3	4	5	6
14. The appearance of my breast could disturb others.	1	2	3	4	5	6

Section 6: Your appearance (Continued)

With the next set of statements, please circle the number which best matches your response.

	Never/ Almost never	Infrequently	Sometimes	Often	Always/ Almost always
16. I feel that people are looking at my chest.	1	2	3	4	5
17. I avoid physical intimacy.	1	2	3	4	5
18. I feel that people are looking at me.	1	2	3	4	5
19. I hide my body when changing clothes.	1	2	3	4	5
20. I need to be reassured about the appearance of my bust.	1	2	3	4	5
21. I feel sexually attractive when I am nude.	1	2	3	4	5
22. Swelling of my arm is a problem for me.	1	2	3	4	5
23. I would keep my chest covered during sexual intimacy.	1	2	3	4	5
24. I think my breasts appear uneven to others.	1	2	3	4	5
25. Arm pain is a problem for me.	1	2	3	4	5
26. I feel people can tell my breasts are not normal.	1	2	3	4	5

The following questions pertain to your feelings about your breast or mastectomy site.

If you are *missing a breast(s)* (if you have had a mastectomy without breast reconstruction), **please answer question 27.**

If you are *not missing a breast* (if you have had a lumpectomy, a mastectomy with immediate/delayed breast reconstruction, or no surgical treatment to your breasts), **please skip question 27 and answer question 28.**

	Never/ Almost never	Infrequently	Some- times	Often	Always/ Almost always
27. I worry about my prosthesis or padding slipping.	1	2	3	4	5
28. My breast is painful to touch.	1	2	3	4	5

I am interested in hearing your thoughts on the range of products that are available to a breast cancer patient.

Please tick **all the products** that you use/used and answer the following questions.

If you did not/do not use any products listed below then please go to **section 7: Your healthcare experience.**

Wigs

1. Where did you get this product from?

NHS

Self-bought

Other

2. How satisfied are/were you with this product (*in terms of colour, fitting, texture*)?

Very dissatisfied										Very satisfied
1	2	3	4	5	6	7	8	9	10	

3. Please explain your reasons (*e.g. Do you feel this product(s) suits your needs culturally?*)

Scarves

1. Where did you get this product from?

NHS

Self-bought

Other

2. How satisfied are/were you with this product?

Very dissatisfied										Very satisfied
1	2	3	4	5	6	7	8	9	10	

3. Please explain your reasons (*e.g. Do you feel this product(s) suits your needs culturally?*)

Breast prosthesis

1. Where did you get this product from?

NHS

Self-bought

Other

2. How satisfied are/were you with this product (*in terms of colour, fitting, texture?*)

Very dissatisfied										Very satisfied
1	2	3	4	5	6	7	8	9	10	

3. Please explain your reasons (*e.g. Do you feel this product(s) suits your needs culturally?*)

Lymphoedema sleeve(s)

1. Where did you get this product from?

NHS

Self-bought

Other

2. How satisfied are/were you with this product (*in terms of colour, fitting, texture*)?

Very
dissatisfied

1

2

3

4

5

6

7

8

9

Very
satisfied

10

3. Please explain your reasons (*e.g. Do you feel this product(s) suits your needs culturally?*)

Make-up

1. Where did you get this product from?

NHS

Self-bought

Other

2. How satisfied are/were you with this product?

Very
dissatisfied

1

2

3

4

5

6

7

8

9

Very
satisfied

10

3. Please explain your reasons (*e.g. Do you feel this product(s) suits your needs culturally?*)

Lingerie and swimwear (*please specify*) _____

1. Where did you get this product from?

NHS

Self-bought

Other

2. How satisfied are/were you with the range of lingerie and/or swimwear available to you (*in terms of colour, fitting, texture*)?

Very dissatisfied											Very satisfied
1	2	3	4	5	6	7	8	9	10		

3. Please explain your reasons (*e.g. Do you feel these products suit your needs culturally?*)

Other (*please specify*) _____

1. Where did you get this product from?

NHS

Self-bought

Other

2. How satisfied are/were you with this product (*in terms of colour, fitting, texture*)?

Very dissatisfied											Very satisfied
1	2	3	4	5	6	7	8	9	10		

3. Please explain your reasons (*e.g. Do you feel this product(s) suits your needs culturally?*)

Section 7: Your healthcare experience

1. What type of health care did you receive?

- NHS care
- Private care
- Both (*Please explain why and how you received both types of care*)

2. Please read each statement, and indicate your level of agreement to **each** statement by circling the appropriate number.

	Strongly Disagree	Disagree	Neither Agree or Disagree	Agree	Strongly Agree
My breast cancer diagnosis was explained in words that I could understand.	1	2	3	4	5
All aspects regarding my breast cancer treatment, along with its side effects, was explained in words that I could understand.	1	2	3	4	5
I wish I had received more information about my cancer diagnosis and treatment.	1	2	3	4	5
I felt that the healthcare teams were there for me emotionally.	1	2	3	4	5
I felt I was treated like a person and not just another case.	1	2	3	4	5

Think about a member of hospital staff who is/was your **main point of contact**, (with whom you can talk to about all aspects of the cancer; including treatment and follow ups). For example, this could be a breast care nurse or a consultant.

3. Please select the person you have had the most contact with.

- Breast care nurse
 Consultant
 Other (*please specify*) _____

Keeping this person in mind, from the list of words below, please **circle the words** that best describe this person. You can circle as many words as you would like. Feel free to add your own words/descriptions if you wish.

Caring	Supportive	Impatient	Unhelpful	Assuring	Kind
Sympathetic	Unfriendly	Dismissive	Aloof	Empathetic	Patient
Approachable	Inconsiderate	Rude	Warm	Distant	Indifferent
Other _____					

If English is your mother-tongue language (first language) please go to question 7.

For women whose English is their second language, please answer question 4.

4. Did you receive your breast cancer information in your mother-tongue language (other than English)?

Yes (*go to question 5*)

No (*go to question 6*)

5. How useful was this for you?

Not at all helpful/useful										Very helpful/useful
1	2	3	4	5	6	7	8	9	10	

Please explain why you found or did not find this useful.

6. Would you have liked to receive the information or talk to somebody (i.e. healthcare professional) in your own language?

Yes

No

Think about the gender of your healthcare team.

7. Who were you **mostly** treated by?

- Male staff
 Female staff
 Both(equally)

8. Did you have a preference in who you would like to be treated by?

- Yes No

9. If you ticked 'yes' to **question 8**, please indicate the gender of the healthcare professional(s), by whom you would have preferred to be treated by.

- Male healthcare professionals Female healthcare professionals

Please explain your reasons.

10. Overall, how satisfied are you with the healthcare that you received?

Very dissatisfied 1 2 3 4 5 6 7 8 9 10 Very Satisfied

THE END

Thank you for completing this questionnaire.

Your time spent taking part in this study is very much appreciated.



Research participants needed: To explore experiences of breast cancer in Black, South Asian & White women

Purpose of the research

- To understand women's experiences, needs and concerns.
- To identify ways of ensuring future patients receive culturally appropriate and sensitive care.

Who is eligible?

- Women who are aged 18 and over,
- who have been diagnosed with primary breast cancer
- and are between 6 months and 5 years post diagnosis and free of chemotherapy and radiotherapy treatment.

What will participants be asked to do?

- To complete a questionnaire which asks you about your breast cancer experiences.
- The questionnaire can be completed on paper or online and will take approximately 30-45 minutes to do.

For more information

Contact Geeta Patel (lead researcher) on: 0117 328 1895
or email Geeta2.Patel@uwe.ac.uk

Appendix 20: Study 4 Invitation letter from Healthcare professional

NHS headed paper

Consultant's address and telephone number

Patient's address

Date

Dear [*name of patient*]

I am writing to give you information about a research project that may be of interest to you.

The research is being conducted by Geeta Patel, from the University of the West of England, Bristol. She is conducting a PhD (funded by Breast Cancer Campaign) to explore the experiences of breast cancer in Black, South Asian and White women. The aim of this research is to understand women's breast cancer experiences better in order to provide future patients with culturally sensitive care and support.

The study would involve completing a questionnaire about your breast cancer experience.

Please be reassured that you are under no obligation to take part and, if you chose not to, your future medical care will not be affected in any way. You can also withdraw from the study at any time.

Please read the attached participant information sheet carefully before deciding whether or not you wish to participate. The information sheet outlines the aims of the study and explains in detail what would be involved, should you choose to take part.

If you would be interested in taking part or would like further information, please contact Geeta on 0117 328 1895 or email her at Geeta2.Patel@uwe.ac.uk, who will be happy to answer your questions or provide you with further information.

Please complete and return the enclosed questionnaire directly to Geeta in the sealed addressed envelope provided. The questionnaire can also be completed on-line at the following address: tinyurl.com/breastcancerstudy

Thank you for reading this letter.

Yours Sincerely

[Name of consultant]

(Position)

Version 2: 21/06/10

Appendix 21: Study 4 Invitation letter from support group facilitator

Dear

I am writing to give you information about a research project that may be of interest to you.

The research is being conducted by Geeta Patel, from the University of the West of England, Bristol. She is conducting a PhD (funded by Breast Cancer Campaign) to explore the experiences of breast cancer in Black, South Asian and White women. The aim of this research is to understand women's breast cancer experiences better in order to provide future patients with culturally sensitive care and support.

Please help support Geeta with her research by completing the enclosed questionnaire, which asks about your breast cancer experience.

Please be reassured that you are under no obligation to take part and, if you chose not to, your future medical care will not be affected in any way. You can also withdraw from the study at any time.

Please read the attached participant information sheet carefully before deciding whether or not you wish to participate. The information sheet outlines the aims of the study and explains in detail what would be involved, should you choose to take part.

If you would be interested in taking part or would like further information, please contact Geeta on 0117 328 1895 or email her at Geeta2.Patel@uwe.ac.uk, who will be happy to answer your questions or provide you with further information.

Please complete and return the enclosed questionnaire and consent form directly to Geeta in the stamped addressed envelope provided. The questionnaire can also be completed on-line at the following address: tinyurl.com/breastcancerstudy.

Thank you for reading this letter.

Yours Sincerely

Appendix 22: Study 4 Participant information sheet

Participant Information Sheet

Breast cancer experiences in Black, South Asian and White women

You are being invited to take part in a research study. Before you decide whether to take part or not, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

What is the purpose of the study?

Having breast cancer can be a significant life event for women and their families. The purpose of this study is to understand Black, South Asian and White women's breast cancer experiences and to see how their experiences compare or differ to each other's.

If we have a better understanding of how breast cancer affects women's lives, we may be able to improve cancer experiences for other breast cancer patients and provide them with care and support that is culturally sensitive and appropriate.

Why have I been chosen?

We are inviting Black, South Asian and White women over the age of 18, who have been diagnosed with primary breast cancer and who are between 6 months and 5 years post-diagnosis. We are inviting women from breast cancer clinics and cancer-related support groups across England to take part in the study.

Please note that you will be unable to take part in the study if you are still undergoing either chemotherapy or radiotherapy treatment at 6 months post diagnosis.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep. Deciding to not take part will not affect the health care you receive in any way, now or in the future.

What will happen to me if I take part?

If you choose to take part in the research you will be asked to complete a questionnaire that is enclosed with this information sheet. This questionnaire will ask you questions about your experience of breast cancer diagnosis and treatment. It can be completed on paper and sent back to the researcher in the stamped addressed envelope, which is provided. Alternatively, the questionnaire can be completed on-line at tinyurl.com/breastcancerstudy. This questionnaire has been designed on a secure website. The questionnaire will take approximately 30-45 minutes to complete.

What are the possible disadvantages and risks of taking part?

We are required to tell you about any possible disadvantages or risks to you should you agree to take part in the research. In this instance we are not aware of any such risks to you. It does not involve any additional medical treatment.

We realise that being diagnosed with breast cancer and having treatment for it can be a very personal and distressing experience. If you get distressed during this research, we

recommend that you contact your personal breast care nurse or you can call the following help-lines for information, advice and support:

- MacMillan Cancer Support help-line – 0808 808 0000; Cancer support specialists are available Monday to Friday, 9am-8pm.
- Breast Cancer Care – 0808 800 6000; available Monday to Friday, 9am-5pm or on Saturdays, 9am-2pm.
- NHS Direct – 0845 4647; available 25 hours a day, 7 days a week.

What are the possible benefits of taking part?

Although we cannot promise that this study will help you personally, we hope that having the opportunity to share your experiences will be a positive experience; knowing that your contribution to this research has the potential to improve future cancer patients' breast cancer experiences.

Will my taking part in this study be kept confidential?

All information which you provide will be kept strictly confidential and anonymous; not even your breast care nurse or consultant will see the completed questionnaires. Your responses will be kept in a safe place and will only be used for research purposes. The same applies if you choose to complete the questionnaire on-line. All your information will be securely stored and will not be accessible by anyone but the researcher.

Can I withdraw from the study?

Your completion of the questionnaire will be seen as consent for taking part in this study. Once the questionnaire has been returned to the researcher, you will not be able to withdraw from the study as it will not be possible to identify your data since your response will be anonymous.

What will happen to the results of this study?

The results of this study will be shared with health professionals and other breast cancer related organisations (such as the charity Breast Cancer Campaign, who are funding this research). In addition the results may be discussed in academic journals or presented at conferences, but you will not be named or identified in any outputs that come from the research.

Who has reviewed this study?

This study has been reviewed and approved by a NHS Research Ethics Committee and the University of the West of England, School of Life Sciences Ethics Committee to make sure that it is being carried out in an appropriate manner.

Contact for further information

If you have any questions about this study and what are being asked to consider, or if you have any queries at any time in the future, please contact the researcher, Geeta Patel on 0117 328 1895 or email her at Geeta2.Patel@uwe.ac.uk.

If you wish to discuss this study with someone other than the researcher then please contact Geeta's supervisor, Dr Diana Harcourt, on 0117 3282192 or email her at Diana2.Harcourt@uwe.ac.uk.

Thank you for taking the time to read this information and for thinking about taking part in this research.

Appendix 23: Study 4 Form to request findings

If you would like to receive a summary of the findings from this study, please write your postal address in the box below and send it back in the enclosed envelope.

Please note: These details will not be used to identify you personally at any point.

<p>Name:</p> <p>Contact information:</p>
--

Appendix 24: Summary of quantitative findings for participants

October 2012

Dear

The experiences of breast cancer in White, Black and South Asian women

I would like to thank you again for your time and participation in my research. The information you shared was very interesting and insightful, and has enhanced our understanding in this area.

Please find enclosed a summary of the findings. I hope you find this useful. Please feel free to get in touch if you have any comments or further questions about this research.

Thank you again.

Best Wishes

G. Patel

Geeta Patel

PhD Researcher
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Frenchay Campus
Bristol
BS16 1QY

Telephone: 0117 328 1895
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The experiences of breast cancer in White, Black and South Asian women

Funded by Breast Cancer Campaign

Feedback for participants

Background to the research

Breast cancer is the most common form of cancer in women of all ethnic groups. The diagnosis and treatment of the disease can be a challenging and distressing experience for any individual. Yet very little is known about Black and Minority Ethnic (BME) women's breast cancer experiences, especially in the UK. It is possible that their experiences may differ from White women's. In order to gain a better understanding of women's breast cancer experiences, it is important to explore the ways in which psychological, social and cultural factors affect quality of life. Quality of life is a complex concept that includes physical, emotional, social, psychological, spiritual and financial well-being.

Therefore, the aims of this study were to examine:

1. Factors that can impact breast cancer survivors' quality of life
2. Examine similarities and differences in breast cancer experiences amongst Black, South Asian and White breast cancer survivors.

The study

A questionnaire was designed to understand women's breast cancer experiences. Questionnaire packs were distributed to English-speaking women who were between 6 months and 5 years of their cancer diagnosis and had completed their main treatment(s). The questionnaire was sent to women living in England, mainly in cities such as Bristol, London, Birmingham and Coventry. 173 (80 White, 40 Black and 53 South Asian) breast cancer survivors took part in this study.

Findings

The findings from this study show

1. How the following factors contribute to breast cancer survivors' quality of life:
 - Demographic factors: Age at diagnosis, time since diagnosis, type of treatment and ethnicity.
 - Psychosocial factors: Psychological distress, beliefs pertaining to control of cancer, body image concerns, social support and healthcare experiences
2. That similarities and differences in breast cancer experiences exist between ethnic groups.

Impact of breast cancer on quality of life

- Older women reported having a better quality of life than younger women. It has been found that younger women report low levels of quality of life because they are at different stages (in terms of working, relationships, having young children or wanting children in the future) in their life than older women and therefore experience greater levels of distress.
- Women who had a lump removed (lumpectomy) reported a better quality of life compared to women who had their breast removed (mastectomy).
- Women who received chemotherapy treatment reported a poorer quality of life than women who did not undergo chemotherapy treatment.
- Women suffering with lymphoedema (swelling of the arm as a result of surgery) reported a poorer quality of life.
- Higher levels of anxiety, depression, body image concerns and holding a belief that God was in control of their breast cancer were associated with a poorer quality of life, while high levels of support and positive healthcare experience contributed to a better quality of life.

Depression, anxiety, receiving chemotherapy treatment and support played the biggest role in determining women's quality of life. Anxiety and depression have been reported to be the two most common psychological problems experienced by breast cancer patients. Levels of anxiety and depression can occur and vary at different time points of the breast cancer journey. For example, emotional distress can increase whilst awaiting treatment, it may decrease during treatment in a supportive environment with healthcare professionals (or increase due to the side effects of treatment which can affect one's body image, physical and cognitive abilities) and often increases at the end of treatment, when patients feel the most vulnerable (e.g. healthcare visits and support start to reduce, fears of recurrence are present). This study found that chemotherapy is an important factor in determining quality of life. This is not surprising considering the various negative short and long-term (including permanent) side effects that are associated with such an aggressive treatment.

Group differences

Differences in breast cancer experiences between the ethnic groups were also reported. In many cases, South Asian women's breast cancer experiences differ to White women's, while Black women displayed similar levels with both the White and South Asian women. Therefore, these findings show that while Black and South Asian women's breast cancer experiences are similar, there are aspects of Black and White women's breast cancer experiences that are more alike than different. Differences and similarities are described in detail below.

Psychological distress

- South Asian women reported higher levels of depression, anxiety and a poorer quality of life than White women.

Beliefs about the cancer in relation to control

- All the women believed that they were in control of their cancer; however, South Asian women reported higher levels of being in control of their cancer than White women.
- South Asian women (compared to White and Black women) also reported that their cancer was out of their control believing their cancer occurred due to chance and/or God (although both South Asian and Black women were more likely to believe that God was in control of their illness than White women).

Body image concerns

- The whole group reported high levels of body image concerns. Differences between the groups showed that South Asian and Black women reported higher levels of body image concerns than White women. Body image concerns were further examined according to treatment
 - *Surgical treatment:* Women who had a *mastectomy* reported high levels of body image concerns regardless of ethnicity. Increased body image concerns were also reported amongst those who had a *lumpectomy*. However, South Asian women reported greater levels of body image concerns than White women.
 - *Adjuvant treatment:* Greater levels of body image concerns were reported for those who received chemotherapy and/or radiotherapy treatment.
 - *Chemotherapy:* South Asian women reported greater body image concerns than White women.
 - *Radiotherapy:* South Asian and Black women reported greater body image concerns than white women.

Support

Sources of support

- All the women were satisfied with the support they received during their breast cancer experience. Family (95%), husband/partner (95%), friends (87%), healthcare professionals (86%) were reported to be the main sources of support. This did not differ by ethnicity.
- However, differences were found in support sought through religion, community groups and work colleagues.
 - A greater number of South Asian (64%) and Black (56%) women turned to religion/spirituality for support compared to the White women (21%).
 - More Black (36%) and South Asian (21%) women received support from their community groups than White women (14%).
 - White (84%) and Black (77%) women received support from work colleagues more than the South Asian women (44%).

Type of support

- Family and husbands/partners were reported to provide the majority of practical, emotional and moral support. Friends and healthcare professionals played a role in providing the women with emotional support.

- Support groups and healthcare professionals were reported to provide the most informational support.

Cosmetic products

Wigs

- Of the 108 women who underwent chemotherapy, 97 reported wearing wigs and on the whole, they were satisfied with them. However, White women reported greater levels of satisfaction than Black and South Asian women, who felt there was a limited choice and the wigs given to them were not natural looking (in relation to hair colour, style and texture).

Breast prosthesis

- Of the 57 women who had a mastectomy without breast reconstruction or delayed reconstruction, 50 reported wearing a breast prosthesis. The majority obtained this via the NHS (98%) and were satisfied with their product. However, Black and South Asian women felt there was a limited choice of skin colour matching prosthesis.

Lymphoedema sleeve

- Of the 39 women who reported suffering from lymphoedema, 23 used a lymphoedema sleeve. The majority of women got this from the NHS (91%) and were satisfied with the sleeve. Half the women felt the sleeves were uncomfortable to wear while the other half felt it served its purpose.

Healthcare experience

- All the women (regardless of ethnicity) reported high levels of satisfaction with their overall healthcare experience.
- 20 (12%) women reported a preference for wanting to be treated by female healthcare professionals.
- More South Asian (32%) women reported a preference of being treated by females than Black (5%) or White (1%) women.

Patient's language needs

- Of the 44 (83%) South Asian women who reported a language other than English as their mother tongue, 8 (19%) reported receiving breast cancer information in this language. This was found to be very useful in helping them to understand their illness.
- Of the 81% who did not receive the information in their own language, 41% stated that they would have liked to receive information or talk to someone about the cancer in their mother tongue language.

How have the results been used and what's next?

The findings from this study provided a lot of valuable and insightful information. This will be used to inform the development of recommendations for healthcare professionals and other relevant organisations, and inform the provision of culturally sensitive care and support to breast cancer patients that is tailored to their needs. The findings will also be disseminated at health related conferences and published in academic journals.

What do you think?

Thank you again for participating in this research. I hope this summary provides you with useful information about this research and the study you were involved in. If you have any comments or would like to know more about the research, please feel free to get in touch with me.

Best Wishes

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